

REPORTER'S RECORD
VOLUME 3 OF 3 VOLUMES
TRIAL COURT CAUSE NO. 048-112330-19

TINSLEE BREAN LEWIS, A) IN THE DISTRICT COURT
MINOR, ET AL)
)
 Plaintiffs,)
)
 VS.) TARRANT COUNTY, TEXAS
)
 COOK CHILDREN'S MEDICAL)
 CENTER)
)
 Defendant.) 48TH JUDICIAL DISTRICT

EXHIBITS TO
TEMPORARY INJUNCTION HEARING

On the 12th day of December, 2019, the following
proceedings came on to be heard in the above-entitled
and numbered cause before the Honorable Chief Justice
Sandee B. Marion, Judge presiding, held in Fort Worth,
Tarrant County, Texas:

Proceedings reported by machine shorthand.

1 A P P E A R A N C E S

2 Joe M. Nixon
3 THE NIXON LAW FIRM, P.C.
4 SBOT NO. 15244800
5 6363 Woodway, Suite 800
6 Houston, Texas 77056
7 PHONE: 713-550-7535
8 E-MAIL: joe@nixonlawtx.com
9 ATTORNEY FOR PLAINTIFFS

10 Emily Cook
11 THE LAW OFFICE OF EMILY KEBODEAUX COOK
12 SBOT NO. 24092613
13 4500 Bissonnet, Suite 305
14 Bellaire, Texas 77401
15 PHONE: 281-622-7268
16 E-MAIL: emily@emilycook.org
17 ATTORNEY FOR PLAINTIFFS

18 Kassi Dee Patrick Marks
19 THE LAW OFFICE OF KASSI DEE PATRICK MARKS
20 SBOT NO. 24034550
21 2101 Carnation Court
22 Garland, Texas 75040
23 PHONE: 469-443-3144
24 ATTORNEY FOR PLAINTIFFS

25 Geoffrey S. Harper
SBOT NO. 00795408
Thomas B. Walsh, IV
SBOT NO. 00785173
John Michael Gaddis
SBOT NO. 24069747
WINSTON & STRAWN LLP
2121 N. Pearl Street, Suite 900
Dallas, Texas 75201
PHONE: 214-453-6500
E-MAIL: gharper@winston.com
E-MAIL: twalsh@winston.com
E-MAIL: mgaddis@winston.com
ATTORNEYS FOR DEFENDANT

1 A P P E A R A N C E S (Continued)

2 Amy Warr
ALEXANDER DUBOSE & JEFFERSON LLP
3 SBOT NO. 00795708
515 Congress Avenue, Suite 2350
4 Austin, Texas 78701
PHONE: 512-482-9300
5 E-MAIL: awarr@adjtlaw.com
ATTORNEY FOR DEFENDANT

6
Cleve W. Doty
7 SBOT NO. 24069627
Charles K. Eldred
8 SBOT NO. 00793681
OFFICE OF THE ATTORNEY GENERAL
9 P. O. Box 12548
Austin, Texas 78711
10 PHONE: 512-936-1414
E-MAIL: cleve.doty@oag.texas.gov
11 E-MAIL: charles.eldred@oag.texas.gov
ATTORNEYS FOR AMICUS CURIAE

12

13

14

15

16

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19

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C E R T I F I C A T E

THE STATE OF TEXAS)

COUNTY OF TARRANT)

I, MONICA A. LINDSTROM, Official Court Reporter in and for the 67th District Court of Tarrant County, Texas, do hereby certify that the following exhibits constitute true and complete duplicates of the scanned original exhibits, excluding physical evidence, offered into evidence during the proceedings as set out herein before the Honorable Sandee B. Marion, Chief Justice of the Court of Appeals for the Fourth District of Bexar County, Texas, and a temporary injunction hearing beginning December 12, 2019.

I FURTHER CERTIFY that the total cost for the preparation of this expedited Reporter's Record is \$2,621.00 and was paid/will be paid by Defendant.

WITNESS MY OFFICIAL HAND on this, the 19th day of December, 2019.

/s/ Monica A. Lindstrom
MONICA A. LINDSTROM, CSR, RPR
Texas CSR 7910
Expiration: 10/31/2022
Official Court Reporter
67th District Court
Tarrant County, Texas
Tom Vandergriff Civil Courts Building
100 N. Calhoun Street, 4th Floor
Fort Worth, Texas 76196
(817) 884-1453 - Office
(817) 884-2384 - Fax
malindstrom@tarrantcounty.com

MONICA A. LINDSTROM, CSR, RPR
OFFICIAL COURT REPORTER
67TH DISTRICT COURT



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**PLAINTIFF'S
EXHIBIT**
1





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**PLAINTIFF'S
EXHIBIT**
2





PLAINTIFF'S
EXHIBIT

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**PLAINTIFF'S
EXHIBIT**
4





**PLAINTIFF'S
EXHIBIT**

5



CookChildren'sSM

Medical Center

October 23, 2019

Via Hand Delivery

Trinity Lewis
4212 Littlejohn Avenue
Fort Worth, TX 76105-4245

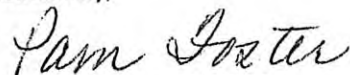
Dear Ms. Lewis:

I am writing to ask that you attend a meeting with members of Cook Children's ethics committee regarding Tinslee's future medical care, and to explain why an ethics committee review has been requested. This meeting is part of a formal review process available under a state law called the Texas Advance Directives Act. That law allows a physician to request a formal review by the hospital's ethics committee when the physician feels that continuing to honor a family's request to provide life-sustaining treatment to a patient with a terminal or irreversible condition is medically inappropriate. As you know, Tinslee is gravely ill, and in the professional opinion of the physicians caring for her, escalating care and continuing to provide life-sustaining treatment is medically futile and not in Tinslee's best interest.

Enclosed is a copy of a notice we are required by law to provide you, and which includes a detailed explanation of the review process and your rights related to that process. Also enclosed is a list maintained by the Texas Department of State Health Services that identifies health care providers and referral groups that have volunteered their readiness to consider accepting transfer or to assist in locating a provider willing to accept transfer. **The meeting is scheduled for Wednesday, October 30, 2019, at 12:00 p.m., and will be held in Room 1163 of the Medical Center's South Tower.**

It is very important that you attend the meeting next Wednesday so that the ethics committee can hear from you directly before making a determination regarding the appropriateness of continuing to sustain Tinslee's life through artificial means. The chaplain will meet you in Tinslee's room at 11:30 a.m., and will escort you to the meeting. You are welcome to invite any involved family members to support you at the meeting. In the meantime, please do not hesitate to call me with any questions you might have.

Sincerely,



Pam Foster, DMin, BCC
Chairman, Ethics Committee
Cook Children's Medical Center



801 Seventh Avenue
Fort Worth, TX 76104-2796
682-885-4000
www.cookchildrens.org

When There Is a Disagreement About Medical Treatment: The Physician
Recommends Against Certain Life-Sustaining Treatment That You Wish To Continue

You have been given this information because you have requested life-sustaining treatment¹ for yourself as the patient or on behalf of the patient, as applicable, which the attending physician believes is not medically appropriate. This information is being provided to help you understand state law, your rights, and the resources available to you in such circumstances. It outlines the process for resolving disagreements about treatment among patients, families, and physicians. It is based upon Section 166.046 of the Texas Advance Directives Act, codified in Chapter 166, Texas Health and Safety Code.

When an attending physician refuses to comply with an advance directive or other request for life-sustaining treatment because of the physician's judgment that the treatment would be medically inappropriate, the case will be reviewed by an ethics or medical committee. Life-sustaining treatment will be provided through the review.

You will receive notification of this review at least 48 hours before a meeting of the committee related to your case. You are entitled to attend the meeting. With your agreement, the meeting may be held sooner than 48 hours, if possible.

You are entitled to receive a written explanation of the decision reached during the review process.

If after this review process both the attending physician and the ethics or medical committee conclude that life-sustaining treatment is medically inappropriate and yet you continue to request such treatment, then the following procedure will occur:

1. The physician, with the help of the health care facility, will assist you in trying to find a physician and facility willing to provide the requested treatment.
2. You are being given a list of health care providers, licensed physicians, health care facilities, and referral groups that have volunteered their readiness to consider accepting transfer, or to assist in locating a provider willing to accept transfer, maintained by the Department of State Health Services. You may wish to contact providers, facilities, or referral groups on the list or others of your choice to get help in arranging a transfer.

¹ "Life-sustaining treatment" means treatment that, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificially administered nutrition and hydration. The term does not include the administration of pain management medication or the performance of a medical procedure considered to be necessary to provide comfort care, or any other medical care provided to alleviate a patient's pain.



3. The patient will continue to be given life-sustaining treatment until the patient can be transferred to a willing provider for up to 10 days from the time you were given both the committee's written decision that life-sustaining treatment is not appropriate and the patient's medical record. The patient will continue to be given after the 10-day period treatment to enhance pain management and reduce suffering, including artificially administered nutrition and hydration, unless, based on reasonable medical judgment, providing artificially administered nutrition and hydration would hasten the patient's death, be medically contraindicated such that the provision of the treatment seriously exacerbates life-threatening medical problems not outweighed by the benefit of the provision of the treatment, result in substantial irremediable physical pain not outweighed by the benefit of the provision of the treatment, be medically ineffective in prolonging life, or be contrary to the patient's or surrogate's clearly documented desires.
4. If a transfer can be arranged, the patient will be responsible for the costs of the transfer.
5. If a provider cannot be found willing to give the requested treatment within 10 days, life-sustaining treatment may be withdrawn unless a court of law has granted an extension.
6. You may ask the appropriate district or county court to extend the 10-day period if the court finds that there is a reasonable expectation that you may find a physician or health care facility willing to provide life-sustaining treatment if the extension is granted. Patient medical records will be provided to the patient or surrogate in accordance with Section 241.154, Texas Health and Safety Code.



Registry List of Health Care Providers and Referral Groups

Texas Health Care Information Collection

Center for Health Statistics

This registry lists providers and groups that have indicated to THCIC their interest in assisting the transfer of patients in the circumstances described, and is provided for information purposes only. Neither THCIC nor the State of Texas endorses or assumes any responsibility for any representation, claim, or act of the listed providers or groups.

Health Care Provider or Referral Group	Willing to Accept or Assist Transfer of Patients on Whose Behalf Life-sustaining Treatment Is Being Sought
C. T. Viers, LLC DBA Exceptional Home Health Care 1330 Church Street Sulphur Springs, TX 75482 Phone: 903-885-5566 Fax: 903-885-7766	
Cuidado Casero(CC) Home Health Care (Bilingual Staff) 6448 Hwy 290 E, Suite E-102 Austin, Texas 78723 Phone: 512-419-7738 www.cuidadocasero.com	Willing to provide bilingual professional nursing services, therapy services, and home health provider services.
Exquisite Queens In-Home Care 14211 Eventide Drive Cypress, Texas 77429 Phone: 281-653-2468 Fax: 832-213-2412	
The Floyd Law Firm 401 Congress, Suite 1540 Austin, Texas 78701 Phone: 512-687-3420	
Jacqueline H. Abernathy, Ph.D. Tarleton State University Assistant Professor, Master of Public Administration Program School of Criminology, Criminal Justice and Strategic Studies 6777 Camp Bowie Blvd., Suite 330-C Fort Worth, TX 76119 jabernathy@tarleton.edu Phone: 817-484-4394 Fax: 817- 732-7339	Willing to help patients and their families when healthcare providers no longer want to provide life-sustaining treatment.
Jerri Lynn Ward Garlo Ward, P.C. 505 E. Huntland Dr., Suite 335 Austin, Texas 78752 Phone: 512-302-1103, extension 115 www.garloward.com	Willing to receive requests for legal counsel from families that are going through a transfer.
Thaddeus Mason Pope, JD, PhD Mitchell Hamline School of Law 875 Summit Avenue	Willing to assist the transfer of patients in conflicts over life-sustaining medical treatment.



Health Care Provider or Referral Group	Willing to Accept or Assist Transfer of Patients on Whose Behalf Life-sustaining Treatment is Being Sought
Saint Paul, Minnesota 55105 Email: Thaddeus.Pope@mitchellhamline.edu www.thaddeuspope.com	
Newport Home Health Agency 1106 N Hwy 360 # 204, Grand Prairie, TX 75050 Phone: 972-602-3500 Fax: 972-602-3503 Email: Support@newporthomehealth.com Website: https://newporthomehealth.com	We are willing to provide non medical care such as caregivers, professional nursing services, therapy services, and home health provider services. English and Spanish translator available.
Robert Painter Painter Law Firm PLLC 12750 Champion Forest Drive Houston, Texas 77066 Phone: 281-580-8800 www.painterfirm.com	
Phong P. Phan, Esq. The Phan Law Firm, PC P.O. Box 50227 Austin, Texas 78753 Phone: 512-789-3890 www.phanlawaustin.com or Facebook	Willing to receive requests for legal counsel from families that are going through a transfer. Assistance available in Vietnamese.
Pro-Life Healthcare Alliance Program of Human Life Alliance 2900 Oak Shadow Circle Bedford, TX 76021 Phone: 817-576-3022 or 651-484-1040 www.prolifehealthcare.org	
Texas Right to Life 6776 Southwest Freeway, Suite 430 Houston, Texas 77074 Phone: 713-782-5433 www.TexasRightToLife.com	Willing to help transfer to a facility that provides treatment.
Woodrow W. Janese, MD, FACS BSME (G7246) 13303 Champion Forest Drive #4 Houston, Texas 77069 Phone: 281-537-6000	

Health Care Provider or Referral Group	Willing to accept or assist transfer of patients on whose behalf withholding or withdrawal of life- sustaining treatment is being sought
No health care providers or referral group registered.	
None of the facilities named above are withholding or withdrawing life sustaining treatment when it is being sought.	

CookChildren'sSM

Medical Center

October 31, 2019

Via Hand Delivery

Trinity Lewis
4212 Littlejohn Avenue
Fort Worth, Texas 76105-4245

Dear Ms. Lewis:

I am writing to notify you of the recommendation of Cook Children's ethics committee relating to the continuation of life-sustaining treatment for your daughter, Tinslee. After receiving the required notice from Cook Children's on October 25th, you, along with your mother and father, participated in the October 30th meeting of the ethics committee. Tinslee's attending physician, Dr. Jay Duncan, was also in attendance.

As previously discussed, Tinslee has been diagnosed with severe congenital heart disease, lung disease, and pulmonary hypertension. Tinslee's attending physicians have determined her condition is irreversible, meaning it may be treated but will never be cured or eliminated, and, without life-sustaining treatment provided in accordance with the prevailing standard of medical care, her condition is fatal. Tinslee's physicians feel that she is suffering. Dr. Duncan provided an overview of Tinslee's medical history and current condition to the committee, and explained that all of her physicians (including her pulmonologist, the cardiac surgeons, cardiac intensivists, and cardiologists) agree that continuing to provide life-sustaining treatment to Tinslee is futile. The committee members also heard you express your sincere belief that Tinslee is not suffering, and that her condition will improve.

The committee discussed the information that was presented and reviewed the benefits versus the burdens of continued treatment. After weighing all of the information presented, the committee concluded that the goal of restoring Tinslee's health is unattainable, that no other medical benefits can be accomplished by continuing treatment that artificially sustains her life, and that it is in Tinslee's best interest to allow her to die naturally. As a result, you have been informed that the committee concurs with the physicians' opinion that further treatment would be inappropriate, should not be continued, and that Tinslee should be allowed to die naturally. Despite this, it is my understanding that you do not agree with this decision and desire further treatment to be given to your daughter. We will continue to provide life-sustaining treatment to Tinslee for up to ten (10) days from the date you receive this letter, pending transfer to another facility. As you know, we have already made several unsuccessful attempts to locate a facility willing to accept Tinslee as a patient. We will continue to make reasonable efforts to find a facility that is acceptable to you that is willing to accept Tinslee as a patient and comply with your treatment directives. Please note that under state law, Cook Children's is not obligated to provide life-sustaining



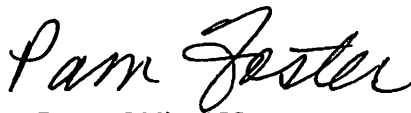
801 Seventh Avenue
Fort Worth, TX 76104-2796
682-885-4000
www.cookchildrens.org

treatment after the tenth day following your receipt of this letter. However, we will continue to provide artificial nutrition and hydration for as long as is medically appropriate.

Along with this letter, and as you requested, you are receiving paper copies of Tinslee's medical records for the last thirty (30) days, including all diagnostic reports. I understand you also recently requested an abstract of Tinslee's records for the entire admission, and that those records were provided to you on CD earlier this week.

We appreciate the difficulty of making decisions concerning the withdrawal of artificial life support. If you have any questions or if I can be of any further assistance, please do not hesitate to contact me.

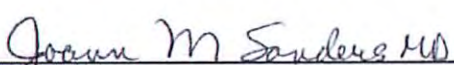
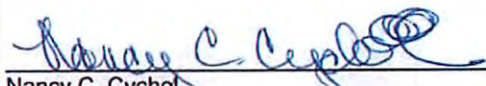
Sincerely,

A handwritten signature in cursive script that reads "Pam Foster".

Pam Foster, DMin, BCC
Chairman, Ethics Committee
Cook Children's Medical Center

CookChildren's

Medical Center

Subject: <div style="text-align: center; font-weight: bold; font-size: 1.2em;">ETHICS COMMITTEE FUNCTIONS</div> <div style="text-align: center; margin-top: 20px;"> Core General <u>X</u> </div>		<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 33%;">Section: QM/UM</td> <td style="width: 33%;">Policy Number: MC 285</td> <td style="width: 34%;">Page: 1 of 5</td> </tr> <tr> <td colspan="2">Application: Medical Center Wide</td> <td>Date of Issue: JUN 2019</td> </tr> <tr> <td colspan="2">Contact Person: Chairman, Ethics Committee</td> <td>Supersedes: JUN 2016</td> </tr> </table>		Section: QM/UM	Policy Number: MC 285	Page: 1 of 5	Application: Medical Center Wide		Date of Issue: JUN 2019	Contact Person: Chairman, Ethics Committee		Supersedes: JUN 2016
Section: QM/UM	Policy Number: MC 285	Page: 1 of 5										
Application: Medical Center Wide		Date of Issue: JUN 2019										
Contact Person: Chairman, Ethics Committee		Supersedes: JUN 2016										
Recommended: <div style="text-align: center;">  <hr/> Joann M. Sanders, M.D. Chief Quality Officer </div>		Approved: <div style="text-align: center;">  <hr/> Nancy C. Cychol Chief of Hospital Services and Affiliate Ventures </div>										
Review:												
Initial/Date												

PURPOSE:

To provide a mechanism for requesting and obtaining concurrent and retrospective review by, and/or assistance from, the Cook Children's Medical Center Ethics Committee.

POLICY:

Any person (including, but not limited to, a patient, a patient's family members, a patient's guardian or legal representative, professional staff members or employees) involved with a patient receiving care within Cook Children's Medical Center (CCMC) may consult the Ethics Committee.

The Ethics Committee is a diverse group of individuals who represent CCMC and the community-at-large. It is designed to create a regular forum to discuss and assist with complex clinical, social, and ethical issues and to help enhance the clear communication of information among those facing important treatment decisions. It is also designed to meet the statutory procedural requirements under the Texas Advance Directives Act (specifically, Texas Health and Safety Code Sections 166.039 and 166.046) for those situations that involve a disagreement between the attending physician and a patient or the person responsible for the patient's health care decisions regarding effectuating a directive or a health care or treatment decision for a patient.

The Ethics Committee has three main functions:

- A. Education - To provide education to all health care professionals, employees, administrative staff, families, and the community on ethical issues relating to patient care.
- B. Policy Review and Development - To act as a resource for review and analysis of the ethical aspects of existing and proposed policies, and to assist in the development of new policies.
- C. Case Review - To provide support and advice to those responsible for treatment decisions.

In case reviews, there are three categories of possible participation by the Ethics Committee:

1. Cases involving ethical uncertainty and perplexity in a clinical situation or the care of a patient. In these cases, the Ethics Committee may provide early intervention to facilitate discussion, ensure clear communication between all involved parties, and provide insight to help address the complex ethical issues.
2. Cases involving differences of opinion between or among the patient's care providers, and/or the patient's family members. In these cases, the Ethics Committee facilitates open discussion between the decision-makers with a goal of reaching a mutually-agreed upon plan of care.
3. Cases involving intractable differences of opinion between the physician and the patient or the person responsible for the patient's health care decisions regarding the patient's advance directive or a health care or treatment decision made by or on behalf of a patient. In these cases (called "Conflict Resolution Case Reviews"), the Ethics Committee acts as a "decision-making" body under the provisions of the Texas Advance Directives Act. (See section C of the Procedure section of this policy, below.)

PROCEDURE

A. Requesting an Ethics Committee Consultation

Ethics Committee consultations can be requested in several ways:

1. During normal business hours, the patient representative or chaplain may be contacted through the CCMC operator to arrange a consult.
2. During evenings and weekends, the chaplain or CCMC nursing supervisor will be contacted through the CCMC operator for assistance.
3. Patients/families may place a request for an ethics consult through the Patient Engagement Portal, or by contacting a staff member.
4. Physicians may place a request for an ethics consult through the computerized order entry system (CPOE) or by contacting the chairperson of the Committee.

B. Ethics Committee Consultative Reviews

Depending on the nature and urgency of the consult request, the matter may be reviewed:

1. At a regularly scheduled meeting of the Ethics Committee;
2. At a called meeting of the Ethics Committee; or
3. At a meeting of an ad-hoc smaller group of Ethics Committee members (called the "Ethics Committee Consultation Team") as determined to be appropriate by the chairperson of the Ethics Committee or his/her designee.
 - a. If an Ethics Committee Consultation Team is determined to be appropriate, it shall consist of at least one physician, one nurse, and one chaplain.
 - b. It is preferable, but not mandatory, that all three be members of the Ethics Committee to provide the necessary services.
 - c. The chairperson (or his/her designee) may appoint any other individual(s) as contributor(s) to the Ethics Committee Consultation Team.
 - d. The Ethics Committee Consultation Team may report its activities and the non-binding determinations that were made to the full Ethics Committee at its next regular

meeting, in accordance with Section A of the Documentation section of this policy.
(See below.)

C. Conflict Resolution Ethics Case Review

In cases where significant efforts have been made and documented to come to a consensus, but intractable differences of opinion continue to exist between the physician and the patient or the patient's parents/guardian regarding either 1) the **patient's advance directive**, or 2) a **health care or treatment decision made by or on behalf of the patient**, the full Ethics Committee will serve as a decision-making body. It will follow the procedures outlined in the Texas Advance Directives Act (specifically, Texas Health and Safety Code Section 166.046) as stated below. No physician with significant professional involvement in the case can be a member of the Ethics Committee during the review of the case.

Depending on the nature and urgency of the case, the full Ethics Committee may review the matter at its next regular meeting or at a called meeting. The following review process will be used:

1. The Ethics Committee will review the reasoning for the attending physician's refusal to honor a patient's advance directive or a health care or treatment decision.
2. Life-sustaining treatment must be given to the patient during the review process.
3. The patient or the person responsible for the patient's health care decisions:
 - a. May be given a written description of the Ethics Committee review process and any CCMC policies and procedures related to Section 166.046 of the Texas Advance Directives Act;
 - b. Shall be informed of the Ethics Committee review process not less than 48 hours before the meeting is called (unless the time period is waived by mutual agreement);
 - c. At the time of being informed about the review process, shall be provided with a copy of the appropriate statement required by Section 166.052 of the Texas Advance Directives Act (refer to Attachments 1 and 2);
 - d. Shall be provided a copy of the registry list of health care providers and external groups that have volunteered their readiness to consider accepting transfer or to assist in locating a provider willing to accept transfer, that is posted on the website maintained by the Department of State Health Services under Section 166.053 of the Texas Advance Directives Act; and
 - e. Is entitled to:
 - i. Attend the Ethics Committee meeting;
 - ii. Receive a written explanation of the decision reached during the review process;
 - iii. Receive a copy of the portion of the patient's medical record related to the treatment received by the patient at CCMC for the lesser of:
 1. The period of the patient's current admission to CCMC; or
 2. The preceding 30 calendar days; and
 - iv. Receive a copy of all of the patient's reasonably available diagnostic results and reports related to the medical record provided under Paragraph (C).
4. The Ethics Committee will issue a decision and identify, explain, monitor, and document recourse provisions for all parties. The written explanation of the decision reached by

the Ethics Committee must be included in the patient's medical record.

5. If the attending physician, patient, or person responsible for the patient's health care decisions does not agree with the decision reached during the review process, the attending physician (assisted by CCMC staff) shall make a reasonable effort to transfer the patient to a physician who is willing to comply with the directive.
6. If the patient or the person responsible for the patient's health care decisions is requesting life-sustaining treatment that the attending physician has decided, and the Ethics Committee has affirmed, is inappropriate treatment, the patient shall be given available life-sustaining treatment pending transfer.
 - a. Pain management medication, medical procedures necessary to provide comfort, or any other health care needed to alleviate a patient's pain may not be withheld or withdrawn pending transfer.
 - b. The patient is responsible for any costs incurred in transferring the patient to another facility.
7. The attending physician and CCMC are not obligated to provide the treatment after the tenth day after both the patient's medical record and the written decision of the Ethics Committee is provided to the patient or the person responsible for the health care decisions of the patient, unless ordered to do so by a court, except that artificially administered nutrition and hydration must be provided unless, based on reasonable medical judgment, providing artificially administered nutrition and hydration would:
 - a. hasten the patient's death;
 - b. be medically contraindicated such that the provision of the treatment seriously exacerbates life-threatening medical problems not outweighed by the benefit of the provision of the treatment;
 - c. result in substantial irremediable physical pain not outweighed by the benefit of the provision of the treatment;
 - d. be medically ineffective in prolonging life; or
 - e. be contrary to the patient's or surrogate's clearly documented desire to not receive artificially administered nutrition or hydration.
8. If the patient or the person responsible for the health care decisions of the patient seeks court intervention, a court may extend the time above if the court finds by "a preponderance of the evidence" there is a reasonable expectation that a physician or health care facility which will honor the directive or treatment decision will be found if the time extension is granted.
9. Life-sustaining treatment provided during the ten-day period, or period otherwise specified by the court, may not be entered in the patient's medical record as medically unnecessary treatment until the ten days or extension period has expired.
10. If during a previous admission to CCMC, a patient's attending physician and the Ethics Committee (in following the review process listed above) determined life-sustaining treatment is inappropriate, and the patient is subsequently re-admitted within six months from the date that decision was reached, the review process need not be followed again if the patient's attending physician and a consulting physician who is a member of the Ethics Committee document on the patient's re-admission that the patient's condition has either 1) not improved, or 2) has deteriorated since the review process was conducted.

DOCUMENTATION

- A. Documentation of Ethics Committee Consultation Team – A member of the Ethics Committee Consultation Team may summarize the ethical inquiry and the options reviewed in the medical record. A member of the team may also report on the matter to the full Ethics Committee at its next meeting. Ethics Committee Consultation Team determinations are non-binding. Documentation of the ad hoc Ethics Committee Consultation Team's report shall be reflected in the Ethics Committee's minutes.
- B. Documentation of Decisions Reached in Conflict Resolution Ethics Case Reviews - Texas Health and Safety Code Section 166.046 requires that the written explanation of the decision reached by the full Ethics Committee regarding whether or not to effectuate an advance directive or health care or treatment decision be included in the patient's medical record (the patient is also entitled to a copy of this explanation, as indicated in section C(3)(e) of the Procedure section of this policy, above).

REFERENCES

Texas Health and Safety Code Chapter 166 (also called the "Texas Advance Directives Act")
CMS 42.CFR489.24(b)

Attachment 1

In cases in which the attending physician refuses to honor an advance directive or health care or treatment decision requesting the provision of life-sustaining treatment, the statement required by Section 166.046(b)(3)(A) explaining the patient's right to transfer shall be in substantially the following form:

When There is a Disagreement About Medical Treatment: The Physician Recommends Against Certain Life-Sustaining Treatment that You Wish to Continue

You have been given this information because you have requested life-sustaining treatment for yourself as the patient or on behalf of the patient, as applicable,¹ which the attending physician believes is not appropriate. This information is being provided to help you understand state law, your rights, and the resources available to you in such circumstances. It outlines the process for resolving disagreements about treatment among patients, families, and physicians. It is based upon Section 166.046 of the Texas Advance Directives Act, codified in Chapter 166 of the Texas Health and Safety code.

When an attending physician refuses to comply with an advance directive or other request for life-sustaining treatment because of the physician's judgment that the treatment would be medically inappropriate, the case will be reviewed by an ethics or medical committee. Life-sustaining treatment will be provided through the review.

You will receive notification of this review at least 48 hours before a meeting of the committee related to your case. You are entitled to attend the meeting. With your agreement, the meeting may be held sooner than 48 hours, if possible.

You are entitled to receive a written explanation of the decision reached during the review process.

If after this review process both the attending physician and the ethics or medical committee conclude that life-sustaining treatment is medically inappropriate and yet you continue to request such treatment, then the following procedure will occur:

1. The physician, with the help of the health care facility, will assist you in trying to find a physician and facility willing to provide the requested treatment.
2. You are being given a list of health care providers, licensed physicians, health care facilities, and referral groups that have volunteered their readiness to consider accepting transfer, or to assist in locating a provider willing to accept transfer, maintained by the Department of State Health Services. You may wish to contact providers, facilities, or referral groups on the list or others of your choice to get help in arranging a transfer.
3. The patient will continue to be given life-sustaining treatment until the patient can be transferred to a willing provider for up to 10 days from the time you were given both the committee's written decision that life-sustaining treatment is not appropriate and the patient's medical record. The patient will continue to be given, after the 10-day period, treatment to enhance pain management and reduce suffering, including artificially administered nutrition and hydration, unless, based on reasonable medical judgment, providing artificially administered nutrition and hydration would hasten the patient's death, be medically contraindicated such that the provision of the treatment seriously exacerbates life-threatening medical problems not outweighed by the benefit of the provision of the treatment, be medically ineffective in prolonging life, or be contrary to the patient's or surrogate's clearly documented

¹ "Life-sustaining treatment" means treatment that, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificially administered nutrition and hydration. The term does not include the administration of pain management medication or the performance of a medical procedure considered to be necessary to provide comfort care, or any other medical care provided to alleviate a patient's pain.

desires.

4. If a transfer can be arranged, the patient will be responsible for the costs of the transfer.
5. If a provider cannot be found willing to give the requested treatment within 10 days, life-sustaining treatment may be withdrawn unless a court of law has granted an extension.
6. You may ask the appropriate district or county court to extend the 10-day period if the court finds there is a reasonable expectation that you may find a physician or health care facility willing to provide life-sustaining treatment if the extension is granted. Patient medical records will be provided to the patient or surrogate in accordance with Section 241.154, Texas Health & Safety Code.

Attachment 2

In cases in which the attending physician refuses to comply with an advance directive or treatment decision requesting the withholding or withdrawal of life-sustaining treatment, the statement required by Section 166.046(b)(3)(A) explaining the patient's right to transfer shall be in substantially the following form:

When There Is a Disagreement about Medical Treatment: The Physician Recommends Life-Sustaining Treatment That You Wish To Stop

You have been given this information because you have requested the withdrawal or withholding of life-sustaining treatment* for yourself as the patient or on behalf of the patient, as applicable, and the attending physician disagrees with and refuses to comply with that request. This information is being provided to help you understand state law, your rights, and the resources available to you in such circumstances. It outlines the process for resolving disagreements about treatment among patients, families, and physicians. It is based upon Section 166.046 of the Texas Advance Directives Act, codified in Chapter 166, Texas Health and Safety Code.

When an attending physician refuses to comply with an advance directive or other request for withdrawal or withholding of life-sustaining treatment for any reason, the case will be reviewed by an ethics or medical committee. Life-sustaining treatment will be provided through the review.

You will receive notification of this review at least 48 hours before a meeting of the committee related to your case. You are entitled to attend the meeting. With your agreement, the meeting may be held sooner than 48 hours, if possible.

You are entitled to receive a written explanation of the decision reached during the review process.

If you or the attending physician do not agree with the decision reached during the review process, and the attending physician still refuses to comply with your request to withhold or withdraw life-sustaining treatment, then the following procedure will occur:

1. The physician, with the help of the health care facility, will assist you in trying to find a physician and facility willing to withdraw or withhold the life-sustaining treatment.
2. You are being given a list of health care providers, licensed physicians, health care facilities, and referral groups that have volunteered their readiness to consider accepting transfer, or to assist in locating a provider willing to accept transfer, maintained by the Department of State Health Services. You may wish to contact providers, facilities, or referral groups on the list or others of your choice to get help in arranging a transfer.

* "Life-sustaining treatment" means treatment that, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificially administered nutrition and hydration. The term does not include the administration of pain management medication or the performance of a medical procedure considered to be necessary to provide comfort care, or any other medical care provided to alleviate a patient's pain.

Hospitals for Tinslee

JOV 2, 2017

- Riley Hospital for children at IU Health (Indianapolis, IN)
- Ø Le Bonheur children Hospital (Memphis, TN)
- Ø ~~St Louis children hospital~~
 - medical CTR
 - Children's Hospital of Philadelphia (Philly)
 - MCCC children's Heart Network of South Carolina (Charleston SC)
 - Ann and Robert H. Lurie Children's Hospital of Chicago
 - UPMC Children's Hospital of Pittsburgh (Pittsburgh)
- Ø ~~Dea children Hospital~~ (Austin)
- Arkansas children Hospital (Little Rock)
- Ø ~~Pediatric cardiology Oklahoma~~ (OU children's medical center)
- pediatric cardiology of Austin
- Children's Hospital Los Angeles
- Seattle Children's Hospital
- C.S. Mott children Hospital Michigan medicine
- Levine children's Hospital

Pr. We just
want you guys to
ask for a transfer



Hospital for Tinslee

NOV 2, 2019

- Riley Hospital for children at IU Health (Indianapolis, IN)
- Le Bonheur children Hospital (Memphis, TN)
- St Louis children Hospital
- medical Ctr
- Children's Hospital of Philadelphia (PHILLY)
- MURC children's Heart Network of South Carolina (Charleston SC)
- Ann and Robert H. Lurie Children's Hospital of Chicago
- UPMC Children's Hospital of Pittsburgh (Pittsburgh)
- Dell Children Hospital (Austin)
- Arkansas children Hospital (Little Rock)
- Pediatric Cardiology Oklahoma
- Pediatric Cardiology of Austin
- Children's Hospital Los Angeles
- Seattle Children's Hospital
- C. R. Mott Children Hospital Michigan Medicine
- Levine Children's Hospital

Pr. We just
want you guys to
ask for a transfer

X Trinity Davis

Date: NOV 4, 2019

X Mary Ann
Witness

X 11/4/19
Date

1015678564 M4123323 2/1/2019 f
Lewis, Tinslee Breana 02/01/2019

DUNCAN, JAY M



nutee Hwa

NOV 9, 2019

- New York Presbyterian Morgan Stanley-
Komanick Children Hospital
- St. Louis Children's Hospital Washington
University
- Nemours Alfred I. Dupont Hospital for
Children
- John Hopkins Children Center
- Children's Memorial Hermann Hospital
- Lucile Packard Children's Hospital Stanford
- Children Hospital of Wisconsin
- Rady Children's Hospital
- Maryland Children's Hospital
- Spectrum Health Helen DeVos Children's Hospital
- Children's Healthcare of Atlanta*
- Children's Hospital and Medical Center
- Monroe Children's Hospital
- Primary Children's Hospital
- Children's National Hospital
- Nationwide Children's Hospital
- Children's Hospital of Alabama
- Nicklaus Children's Hospital
- Rainbow Babies and Children's Hospital
- University Hospital - San Antonio
- Christus Hospital - San Antonio

X Trinity Keaton
Lewis via Telephone

11/5/19 0929

Date:

X

relationship to patient

11/5/19
X alh, RN 0929
Witness

X Behind RJ
Witness 11/5/19
0930

CookChildren's

Dear Patient and Family:

ing services after you. Your physician has recommended the following services after your child goes home:

Hospice Care		Medical Equipment	
Inpatient Rehabilitation		Home Health Care:	
		Infusion Therapy	
		Nursing Care	
		Occupational Therapy	
		Physical Therapy	
		Social Worker	
		Speech Therapy	
Other		Other	

You have the right to choose any of the providers, in your area, that can offer these services.

Please know:

- Your insurance company may only have contracts with certain providers.
- You may only have one provider in your area offering this service.

Selecting the provider that you use is your choice. Your RN Case Manager can tell you about the providers located close to your home, or give you a list of the providers that your insurance company uses.

I have chosen: <u>See attached list of facilities</u> Phone: _____		
I do not have a preference <input type="checkbox"/>		
Comments _____ _____		
I am already on service with _____ Phone _____		
<u>X</u> <u>Jamity dew</u>	<u>mom</u>	<u>NOV 4, 2019</u>
Signature	Relationship	Date
<u>H. Maton RN</u>		<u>11-4-19</u> <u>2015</u>
Hospital Witness	Date	Time

Place original on Medical Record and give copy to patient.

Attachment A

CookChildren's

Discharge Referral/Planning Form
(06/2011)

1015678564 M4123323 2/1/2019
Lewis, Tinslee Breun 02/01/2019



DUNCAN, JAY M



Patient Name: Tinslee Lewis

DOB: 2/1/2019

Conversations with Outside Facilities Regarding Patient Transfer

9/30 – Richard Chemelli Progress Note: There continues to be significant disagreement between the medical care team and the family regarding this child prognosis. Currently we are complying with the family's request for referral for a 2nd opinion to Boston Children's Hospital and Texas children's. In addition the ethics team is currently involved.

10/1 – Sarah Dye Social Work Note: Mom talked with SW about how she had reached out for a second and third opinion from Boston Children's and Houston.

10/1 – Susan Davis Progress Note: We are sending her data to Boston Children's as well as Texas Children's for a second opinion as requested.

10/2 – Jay Duncan Progress Note: There been multiple discussions with family members who are now seeking a 2nd opinion. This is being obtained from Texas children's Hospital as well as Boston Children's Hospital.

10/3 – Jay Duncan Progress Note: The family has begun to seek a 2nd opinion as we think there are no further options for surgical palliation.

10/3 – Matthew Dzurik Progress Note: Family has requested 2nd opinion send information has been sent to Boston Children's Hospital as well as Texas children's Hospital.

10/4 – Susan Davis Progress Note: Spoke with TCH/Houston yesterday; they have nothing more to offer Tinsley and will not accept on transfer. They stated they would communicate this to Tinsley's mother. Spoke with Boston children's yesterday as well. They have all information that they need but need time to review. They anticipate that they will be able to render opinion by Monday (10/6/19).

10/5 – Jay Duncan Progress Note: Texas children's Hospital has stated she would not be a candidate for any other intervention at their institution. We are awaiting input from Boston Children's Hospital.

10/6 – Susan Davis Progress Note: Mom has not been here today. By report, she was upset when informed Houston had not accepted Tinslee and wanted to talk to them personally. This was supposed to have happened per my phone conversation with Houston. Will ensure mother has phone number to call Houston and speak with their team re decision. Expect decision from Boston tomorrow.

10/7 – Susan Davis Progress Note: Tinslee's mother and grandmother were here last night. Discussed that Houston did not have any additional therapy to offer Tinsley. Mother has expressed frustration that Houston did not communicate directly with her. The physician, with whom I spoke, stated she would call her. There was also a plan made that if that call did not make connection, mother could call the transfer center there and they would put Trinity in contact with team so that any questions that she had could be answered. This was shared with mother at bedside. Boston Children's is expected to get decision back to us today. Reiterated to mother that while Tinsley is in a slightly better place than last week, she continues to require neuromuscular blockade and is nowhere near a point that she could be cared for out of an ICU setting. Mother expressed to me that she did not feel limitation was appropriate. I again reviewed that we had mechanically ventilated Tinsley for about 3 months and that most of that time had been spent at least



partially neuromuscularly blocked. We discussed that at this point I did not feel a tracheostomy would alter her course and that her cardiac anatomy was not amenable to further surgery in the setting of chronic lung disease as Tinsley has. I reiterated that the medical team feels increasingly that we are causing Tinsley to suffer rather than give her any real hope of survival. Mother stated that she did not feel this was the case.

10/8 – Richard Chemelli Progress Note: Referrals have been made to Boston Children's Hospital and Texas children's Hospital regarding any further interventions or options to be provided. Both institutions have said that everything has aggressively been done.

10/10 – Lane Lanier Progress Note: The patient's family has sought a 2nd opinion from two institutions who have both declined transfer. Parents have been here intermittently. We will continue to try to have conversations with them regarding patient's poor prognosis. We reached out to Boston Children's Hospital and Texas children's Hospital and have asked these institutions to evaluate for any other therapeutic surgeries or strategies to help this patient. Both of these institutions have contacted us and have stated that there is nothing more to do surgically for this patient and they agree the patient has a very poor prognosis. We have asked that these institutions contacted the mother directly to discuss this with her.

10/28 – letter from Children's Health (Dallas): Thank you for allowing us the opportunity to review the details of your patient. We came to the following conclusions: 1.) This patient is currently optimally managed from a cardiothoracic and cardiology perspective. The current situation with a palliation with a central shunt, Starnes procedure and clipped right ventricular outflow is the correct management. We would not advise any further procedures. 2.) It is regrettable and we agree that the current medical situation shows continuing decline without any reasonable prospect for recovery. For this reason we agreed that continuing escalation of treatment was futile.

10/29 – Jay Duncan Progress Note: The cardiac team from Children's Medical Center Dallas have evaluated all of her information and do not have any additional therapies to offer. They agree with our current assessment that further surgical care or intervention is futile.

10/29 – Susan Davis Progress Note: Mother has not had communication with Texas Children's Hospital regarding their denial of Tinslee earlier this month per CICU team. I was asked to follow up with TCH.

When they called me and denied the transfer (approximately October 3, 2019), they stated they would call Trinity. A plan was made if that fell through, that Tinslee's mother could call transfer center there, and they would put her in contact with the physician with whom I spoke. I conveyed that to mother earlier this month when she expressed frustration over them not calling her.

I called transfer center today and asked for something in writing to give to mother. The transfer director stated that they could not put anything in writing per their legal department regarding the denial. I asked that the cardiology team there put something in writing denying the transfer and they stated that they did not know if that could be done. They had mother's number in their records and it was re-confirmed. They state they will try to call her and they will get back to me regarding possibility of anything in writing.

11/1 – Ryan Meyer Progress Note: Despite reaching out to Boston Children's, Texas children's Hospital, and Children's Health Dallas no other Heart Center has agreed to transfer the patient as the Centers have communicated that they have no further intervention or additional support that would be meaningful to provide to this patient.

Mother has reached out to Boston Children's. Boston Children's has communicated directly with her and have tonight requests of transfer of Tinsley to their hospital as they have no further intervention or meaningful support to provide. Additionally we have reached out to Texas children's Hospital cardiac program. They have also verbally denied this child's transfer for the same reasons. We have reached out to Children's Health Dallas cardiac program which is also deny this child's transfer (which is also stated in a letter) again for not having any further intervention or meaningful support to provide based on her medical history and her current clinical status.

11/1 – Ashlee Skrhak Nursing Note: Mother at bedside requesting that we send Tinslee's patient information to Medical City Dallas. Trinity also requested that we send her information to Children's Medical Center of Plano, I informed her that they do not have a Cardiac ICU; that hospital is affiliated with Children's Medical Center of Dallas. Trinity also requested that we send her information to Texas Scottish Rite in Dallas, RN informed her that they do not have a Cardiac ICU either. Mother requested that information be sent to St. Louis Children's Hospital.

Mother then asked of other known Cardiac ICU's, I told her the only other ones in Texas are Texas Children's in Houston, Children's Medical Center of Dallas and Dell Children's in Austin.

Dr. Davis made aware of information discussed with RN and Trinity. Will evaluate sending paperwork over the weekend or Monday.

11/2 – Kacie Donelson Nursing Note: Mother gave this RN a list of hospitals that she wants this RN to give to Dr. Davis. Mother explained that this is a list of hospitals that she wants Dr. Davis to call to see if they will accept Tinslee to transfer there. This RN informed mother that Dr. Davis is not the doctor on call tonight and she is not sure when Dr. Davis will return. Mother stated that Dr. Davis has a list of other hospitals that she had given her and mother said Dr. Davis would be calling on Monday. Mother also stated "Do not give this list to Dr. Chemelli, I do not like him". She also stated "Make sure when they call they don't give their opinion on whether they think Tinslee should go there. That isn't fair because if it was their kid they would want her to be transferred too. They already did that on the other two hospitals and that is why they said no I bet". This RN informed mother that she would pass the list to the day shift nurse because this RN would not be seeing Dr. Davis. RN informed charge RN of list.

11/4 – Susan Davis Progress Note: Prior to the binding decision being rendered, Texas Children's, Dallas Children's and Boston Children's denied transfer with the assessment they had nothing more to offer.

Mom came in this evening. I shared with her that I had called St. Louis and they have requested more information. Their team will meet on Wednesday. We plan to get info to them tomorrow. Dr. Lanier spoke to Oklahoma Children's and they denied transfer today. She has a list with multiple hospitals that we are trying to call for possible transfer. Mother has requested that we just call centers and ask for transfer without giving information. I explained that this is not possible and that to accept Tinslee centers had to be given medical information. Encouraged Trinity to also think what would be most meaningful for her this week with Tinslee and reiterated to her that we were unable to secure an accepting hospital, the binding decision mandates withdrawal on 11/10/19.

11/4 – Susan Davis Progress Note: Spoke with team at St. Louis Children's Hospital via their Direct line 314-747-1986 regarding possible transfer as requested by mother. They assembled a conference call with cardiology/CVICU. Reviewed basics of Tinslee's course and status. They have requested additional information be sent to them by tomorrow so that case could be reviewed in their team conference on

Wednesday. Contact person: Dr. Orr (cardiology); fax # 314-454-2561. Packet being put together. Will send in AM.

Tried to reach Medical City, Dallas. On hold for > 20 minutes with their transfer line. Will attempt to make contact with their CVICU tomorrow if unable to go through transfer system.

Will continue to work through list provided by patient's mother.

11/4 – Hannah Morton Nursing Note: Approximately 1830: Mother arrived to the unit and requested to speak to patient advocate. House Supervisor paged at this time. Dr. Davis notified of mother's arrival and came bedside. Dr. Davis spoke with mother for approximately 20 minutes regarding the status of the hospital transfer list as well as asked mother goals for the week as removal of care on Sunday is the current plan if no hospital will accept Tinslee. Mother stated she will think about her goals and get back to us. Mother kept stating throughout the conversation she just doesn't understand and believe that Tinslee is not suffering. She stated she is not brain dead so she doesn't know why Ethics had to get involved. Dr. Davis continued to provide education. Mother was on the phone multiple times during the conversation.

Nursing Supervisor arrived at the end of the conversation with Dr. Davis. Mother requested to go get her cousin from the waiting room and asked to speak in private somewhere. P. Armstrong, Nursing Supervisor lead family to Conference room in the CICU. Mother was asking questions regarding legal matters. Nursing supervisor stated that will need to be discussed with Patient Advocate and Ethics in the morning as she did not have specific answers to that. Mother then presented this RN with a second list of hospitals she would like to be contacted regarding transfer. Mother also stated that Dr. Davis told her today some of the hospitals on her list did not have CICUs, and therefore mother asked us to identify hospitals that do not have CICUs. P. Armstrong stated that we would try our best. P. Armstrong discussed the time constraint we are under and that mother should look at making a list with her top priority hospitals at the top. Mother stated understanding. Many of mother's questions were regarding ethics/patient advocate so it was suggested she try to be at the hospital tomorrow to meet with them. Mother stated she will call in the morning and see when she could meet with them. All questions addressed at this time. Encouraged mother to write down additional questions we could not answer and bring them tomorrow. Mother stated understanding.

11/5 – Lane Lanier Progress Note: Over the last 24 hr, I have spoken to two institutions regarding transfer of the patient. On 11/4/2019, I spoke to Dr. Andy Gormley who is the head of the cardiac ICU at OU Children's Medical Center and Oklahoma City, Oklahoma. I described the patient's congenital heart disease and course in the cardiac ICU. I outlined the patient's surgical course and challenges. I communicated the patient's most recent echocardiogram and catheterization data. After discussing the patient's current state, Dr. Gormley stated that he has institution would not have anything more to offer the patient surgically or medically.

In addition, I contacted Dell Children's Hospital in Austin Texas on 11/5/2019. I spoke with Dr. Michael Auth who is the attending on service in the cardiac ICU. I described the patient's clinical course and surgeries. After discussion of the patient's current medical regimen and condition, Dr. Auth stated that he would have nothing more medically to offer this patient.

11/5 – Hollie Schreiber CM Discharge Plan:

11/5/19

0930 COMPLETED VERBAL CONSENT VIA PHONE WITH TRINITY LEWIS REGARDING THE SECOND LIST OF FACILITIES SHE PROVIDED FOR COOK TO CONTACT FOR POSSIBLE TRANSFER. BEDSIDE NURSE ANNA WITNESSED.

1030 MESSAGED MELISSA WILLIAMS IN HIM REGARDING ELECTRONICALLY SENDING IMAGES (ECHO/CATH/XR) TO OTHER FACILITIES.

1046 RECEIVED VM MESSAGE FROM MELISSA IN HIM REQUESTING A CALL BACK.

1049 SPOKE TO MELISSA WILLIAMS IN HIM REGARDING ELECTRONICALLY SENDING IMAGES (ECHO/CATH/XR) TO OUTSIDE FACILITY. SHE STATED IF THEY HAVE Epic THEY CAN JUST LOOK AT THE IMAGES BUT IF NOT A DISC CAN BE MAILED TO THE FACILITY.

1150 SPOKE TO BECKY DAVIS IN ECHO LAB WITH SHELBY KEENER. ASKED ABOUT LIFE IMAGE AND SHE STATED IF OTHER FACILITIES HAD LIFE IMAGE WE COULD ONLY SEND ECHOS/CATHS TO THOSE FACILITIES ELECTRONICALLY.

1145 SPOKE TO DEB IN THE ECHO LAB AT ST. LOUIS CHILDREN'S REGARDING LIFE IMAGE SOFTWARE TO ACCEPT ECHO/CATH IMAGES. SHE STATED SHE WOULD HAVE THE IT PERSON CALL ME BACK.

1200 SENT EMAIL REQUESTING DISC WITH ECHO/CATH/CXR BE SENT TO ST. LOUIS CHILDREN'S OVERNIGHT.

1217 MELISSA WILLIAMS IN HIM REC'D EMAIL REQUEST FOR DISC OF IMAGES. SHE REPORTS THAT FED EX PICKS UP AT 1400 FOR DELIVERY TOMORROW. SHE STATES THAT DEPENDING ON HOW FAST ECHO LAB GETS THE DISC TO HER WILL DETERMINE IF IT GOES OUT TODAY. CM WILL CALL ECHO LAB AND REQUEST THAT THEY EXPEDITE REQUEST.

1230 SPOKE TO BECKY DAVIS IN ECHO LAB REGARDING REQUEST TO EXPEDITE ECHO IMAGES ON DISC TO HIM SO THEY CAN BE SENT FED EX OVERNIGHT TODAY. BECKY STATED SHE WOULD LIKE TO CALL ST. LOUIS CHILDREN'S HERSELF TO INVESTIGATE SENDING RECORDS ELECTRONICALLY VS. MAIL. CM PROVIDED BECKY WITH NUMBER 314-747-1986.

1301 MELISSA IN HIM PROVIDED FED EX TRACKING NUMBER FOR CXR DISC fedex tracking # 8149.5620.7337

1320 SENT EMAIL TO BECKY DAVIS IN ECHO LAB REQUESTING ASSISTANCE WITH ELECTRONICALLY SENDING ECHO/CATH IMAGES TO CHILDREN'S HOSPITAL LOS ANGELES AND ARKANSAS CHILDREN'S HOSPITAL.

NOTIFIED MELISSA IN HIM THAT 2 MORE CXR IMAGE DISKS ARE NEEDED FOR CHILDREN'S HOSPITAL LOS ANGELES AND ARKANSAS CHILDREN'S.

1537 NOTIFIED BY AMY FENN, UNIT SECRETARY IN CICU, THAT ST. LOUIS CHILDREN'S HOSPITAL FAXED A DENIAL OF TRANSFER.

1623 NOTIFIED BY MELISSA IN HIM THAT IMAGE DISKS ARE READY TO BE PICKED UP BY THIS CM.

1628 SPOKE TO LAURA COPELAND AND SHE STATES SHE WILL PICK UP THE DISKS FROM HIM AND TAKE THEM TO FED EX TONIGHT.

1637 SPOKE TO CARLOS AT THE HIM WINDOW AND NOTIFIED HIM THAT LAURA COPELAND WILL BE PICKING UP THE DISKS.

11/6/19

1148 SENT EMAIL REQUEST TO BECKY DAVIS IN CATH LAB TO SEND ECHO/CATH IMAGES TO CS MOTT CHILDREN'S IN MICHIGAN.

1335 SENT EMAIL REQUEST TO BECKY DAVIS IN CATH LAB TO SEND ECHO/CATH IMAGES TO LEBONHEUR CHILDREN'S IN MEMPHIS TENNESSEE.

1345 SENT EMAIL TO HIM REQUESTING CXR IMAGE ON DISK WITH FED EX OVERNIGHT LABEL FOR LEBONHEUR CHILDREN'S IN MEMPHIS TENNESSEE.

1402 SENT EMAIL TO HIM REQUESTING CXR IMAGE ON DISK WITH FED EX OVERNIGHT LABEL FOR CS MOTT CHILDREN'S IN MICHIGAN.

1509 SENT EMAIL TO HIM REQUESTING CXR IMAGE ON DISK WITH FED EX OVERNIGHT LABEL FOR RADY CHILDREN'S IN SAN DIEGO.

1517 SENT EMAIL REQUEST TO BECKY DAVIS IN CATH LAB TO SEND ECHO/CATH IMAGES TO RADY CHILDREN'S IN SAN DIEGO.

1620 LAURA COPELAND SENT EMAIL REQUESTING THIS CM TEXT HER CELL PHONE WHEN THE IMAGE DISKS ARE READY TO BE PICKED UP FROM HIM.

1622 SENT TEXT MESSAGE TO LAURA COPELAND TO NOTIFY HER THAT DISKS ARE READY FOR PICK UP.

1623 REC'D TEXT RESPONSE.

11/7/19

1250 RECEIVED EMAIL NOTIFICATION FROM DR. DAVIS THAT UNIVERSITY MEDICAL CENTER IN SAN ANTONIO REQUESTED CLINICAL AND IMAGES ON DISK. THE FACILITY DOES NOT HAVE LIFE IMAGE.

1354 SENT EMAIL TO HIM REQUESTING ECHO/CATH/CXR IMAGES ON DISK TO BE SHIPPED VIA FED EX OVERNIGHT TO:

Dr. Elaine Maldonado

Department of Cardiothoracic Surgery UT Health San Antonio

7703 Floyd Curl Drive Room 211-L

San Antonio, Texas 78229

1519 RECEIVED EMAIL NOTIFICATION FROM MELISSA WILLIAMS IN HIM THAT IMAGE DISK IS READY FOR PICK UP AT HIM WINDOW.

11/5 – Shanda Campbell CM Discharge Plan:

11/5/19

1105 spoke with Danielle (404-785-7778) in the transfer center at Children's Healthcare atlanta - they have a CICU - provider would need to call transfer center line to be connected to their physician to discuss possible transfer. Information emailed to Dr Davis

1115 Spoke with patricia (317-963-3330) in the transfer center at Riley Hospital for Children at IU Helath - they have CICU- provider has to call transfer center and they will conferece call the appropriate provider to discuss possible transfer. Information emailed to Dr Davis

1120 Clinical faxed to St Louis children's hospital (314-454-2561) and confirmation received - spoke with Terry (314-747-1986) address to mail images is 1 Children's place St Louis Missiour 63110. Information emailed to Dr Davis and Hollie, RN CM.

1130 Spoke with Brett (901-287-4408) in the transfer center at Le Bonheur Children's Hospital - they have CVICU- physican will need to call transfer center to be connected to the approparite provider to discuss possible transfer. Information emailed to Dr Davis

1134 Spoke with Shonda (800-590-2160) in transport at Children's Hospital of Philadelphia - they have CICU - direct line is 215-590-2160 for physician to call in to start process of possible transfer. Information emailed to Dr Davis

1144 Spoke with Susan at MUSC children's heart network of south carolina (musc children's health medical university of south carolina) (843-792-2200) - they have CICU-their transfer center is 843-792-3306 for physician to physician referral for possible transfer. Information emailed to Dr Davis

1148 Spoke with Liz (800-540-4131) in transport at Ann & Robert H. Lurie Children's Hospital of Chicago- they have CICU- transport direct line is 312-227-3700 - they will conference physician to CICU provider to discuss possible transfer. Information emailed to Dr Davis

1152 spoke with Josh (800-544-2500) in transport at UPMC Children's Hospital of Pittsburgh- they have CICU - physician can call 412-647-7000 to start the process for possible transfer. Information emailed to Dr Davis

1158 spoke with Ann (512-324-3515) in transport at Dell Children's Medical Center - they have CICU- physician will need to call to be connected to appropriate physician to discuss possible transfer. Information emailed to Dr Davis

1200 Spoke with Autum (800-224-4357) in transport at Arkansas Children's - they have CICU- physician will need to call in to start the process for possible transfer. Information emailed to Dr Davis

1205 Spoke with Tim (888-631-2452) in the access center at Children's Hospital Los Angeles - they have CICU- provided diagnosis information and CICU phone number - he requested Facesheet be faxed over - he stated he will contact their CICU physician to call our CICU to speak to Dr Davis. Spoke with CICU to let them know of the incoming call. Face sheet faxed to 323-361-1351.

1312 Clinical faxed to Children's Hospital Los Angeles per information from Hollie, RN CM and Dr Davis attn: Dr Jessica Ascencio at 323-361-4018. Received VM from Tim requesting call back after 1330

1316 Spoke with Katie (206-987-5437) in transport at Seattle Children's - they have CICU- physician would need to call and they would put them into contact with CICU physician to discuss possible transfer. Information emailed to Dr Davis

1330 Received email from Dr Davis stating Children's Hospital Los Angeles would like Images, but they did not provide her with a way to get them there. Responded that will look into getting them images.

1339 Spoke with Tim at Children's Hospital Los Angeles - he stated they are requesting clinical information. Cardio meets on Thursday to discuss cases. Asked where images could be sent, and he stated he would check and call back. Spoke with Hollie, RN CM - she is going to check with echo/cath lab to see if they can send their images electronically.

1320 Spoke with Mary Ann (800-962-3555) in transfer center at C.S. Mott Children's Hospital - they have CICU- transfer center direct line is 734-764-3289 - transfer center will connect provider to their physician to discuss possible transfer. Information emailed to Dr Davis.

1325 Spoke with Kendall (800-421-9195) in transport at Levine Children's Hospital - they have CICU - physician will need to call physician line at 704-512-7878 to speak with the transfer center. Information emailed to Dr Davis.

1430 Received email from Dr Davis requesting clinical info be sent to Dr Michelle Moss, Arkansas Children's, one Children's way, Little Rock, AR 72202

for their review. Dr Moss suggested images be sent overnight delivery. Dr Davis requested to include our contact information for Dr Moss. Replied to email asking if fax number had been provided to send over information.

1438 Spoke with Tracy (800-224-4357) at Arkansas Children's in transport - she stated clinical can be faxed to 501-364-1205 and they will get the information to Dr Michelle Moss. Clinical information faxed.

1445 Spoke with Hollie, RN CM - she is working on imaging for LA and Arkansas.

1455 - Spoke with Johnnie (212-305-6591) at NewYork-Presbyterian Morgan Stanley Children's Hospital - he provided number for transfer center 800-697-7828 - spoke with Karen in the transfer center - they have CICU- provider will need to call to be connected with a physician to discuss possible transfer. Information emailed to Dr Davis.

1510 Spoke to Raquel (302-651-4199) in admissions at Nemours Alfred I. duPont Hospital for Children - referred to Nursing supervisor Lisa - they have CICU - transport team is 302-651-5461 - physician will need to call to discuss possible transfer. Information emailed to Dr Davis

1525 Spoke to Brittney (410-955-9444) in transport at Johns Hopkins Children's Center - she stated they have a CICU - provided patient's name, date of birth, and diagnosis along with contact number to CICU for Dr Davis - she stated she would give Dr Davis a call in the CICU. Spoke with the CICU to let them know the call would be coming in. Information emailed to Dr Davis.

1536 Spoke with Vanessa At Children's Hospital Los Angeles - they do not use Epic - transferred to Tim - he stated the ICU staff is discussing case and they will call him back when they decide how they would like the images sent.

1540 Spoke with Autum- At Arkansas Children's - they use Epic - asked if they are able to see imaging in Epic for this patient - it would need to be in care everywhere so they can see it - she requested a call back once we have shared it.

1550 Spoke with Hollie, RN CM - she provided Care Everywhere ID CCZ-237-8856 provided by HIM that will allow Arkansas Children's to see the patient's information.

1557 Spoke with Tim At Arkansas Children's - provided him with the CCZ-237-8856. He stated he will pass the information to the correct person and call back if there are any issues.

11/6/19

0820 Received Email from Dr Davis requesting cath images/reports, cxr, echo images/reports and surgical reports be sent over to Arkansas. Faxed cath report, echo report, and OP notes to Arkansas. CXR was overnight mailed on 11/5/19. Will follow up with Hollie, RN CM to see if cath/echo was able to send the images electronically to Arkansas. Replied to Email with update.

0837 Spoke with Sally (713-704-2500) in the Transfer Center for Children's Memorial Hermann Hospital - she stated they have a PICU and the heart center for complex cardiac patients. For potential transfers, physician can call the transfer center to start the process. Information emailed to Dr Davis

0849 Spoke with Amy (650- 723-7342) in the transfer center at Lucile Packard Children's Hospital at Stanford - they have CICU- physician can call the transfer center to be connected to a physician to discuss possible transfer. Information emailed to Dr Davis

0857 Spoke with Kat (800-266-0366) in transport at Children's Hospital of Wisconsin - they do have CICU - physician can call transport to be connected with a physician to discuss possible transfer. Information emailed to Dr Davis

0915 Spoke with Maria (858-576-1700) at Rady Children's Hospital - they have CICU - provided CICU phone number - she stated their physician will call to speak with Dr Davis. Spoke with CICU to let them know of incoming call. Emailed Dr Davis to let her know

0928 Spoke with Christine (800-373-4111) at University of Maryland Children's Hospital- they do not have a CICU. Information emailed to Dr Davis

0938 Spoke with Kara (616-391-3800) In the Transfer center at Helen DeVos Children's Hospital - they have CICU - physician can call transfer center to get in contact with physician to discuss possible transfer. Information emailed to Dr Davis

0948 Spoke with Jay (855-850-5437) at the physician's line at Children's Hospital & Medical Center (Omaha) - they have CICU - physician can call the line and they will connect them with the appropriate provider about a possible transfer. Information emailed to Dr Davis

1002- Spoke with Judith (866-936-7811) in the access center at Monroe Carell Jr. Children's Hospital at Vanderbilt - they have CICU - physician can call the access center to be connected to the appropriate provider to discuss possible transfer. Information emailed to Dr Davis

1011 Spoke with Jordan (844-662-1662) in the physician access line at Primary Children's Hospital - they have CICU - physician can call the access line to be connected with appropriate provider to discuss possible transfer - provided name, date of birth, and diagnosis - Information emailed to Dr Davis.

1027 Spoke with Derek (202-476-4880) in the physician access line at Children's National Hospital - they have CICU - physician can call the access line to be connected with appropriate provider to discuss possible transfer. Information emailed to Dr Davis.

1033 Spoke with Shelia (614-335-0221) in the physician access line at Nationwide Children's Hospital - they have CICU - physician can call the access line to be connected with appropriate provider to discuss possible transfer. Information emailed to Dr Davis.

1058 Spoke with Dennis At Children's Hospital Los Angeles - discussed sending cath/echo images - asked if they can be sent to the Tele box in Life Image - he took contact number and will call this CM back after speaking with the provider

1109 Spoke with Kristy (205-212-7200) in the placement center at Children's hospital of Alabama- they have CVICU - physician can call the placement center to be connected with appropriate provider to discuss possible transfer. Information emailed to Dr Davis

1119 Spoke with Liz (888-543-3358) in the transfer center at Nicklaus Children's Hospital - they have CICU - physician can call the transfer center to be connected with appropriate provider to discuss possible transfer. Information emailed to Dr Davis

1126 Spoke with Tracey At Arkansas Children's - they received the images for echo/cath and they were sent to Dr Moss this morning. Information emailed to Dr Davis.

1132 Spoke with Mike (216-844-1111) In the transfer center at Rainbow babies and children's hospital - they do not have a CICU. Information Emailed to Dr Davis

1137 Spoke with Josie (855-484-7733) In the Patient placement center at University Hospital San Antonio- they have CICU - physician can call the placement center to be connected with appropriate provider to discuss possible transfer. Information emailed to Dr Davis

1146 Received call back from Dennis at LA - he stated he spoke with Dr Ascencio and requested images be sent via LifeImage to the Hospitalist box. Sent Email to dr davis and echo/cath lab with information.

1156 Spoke with Veronica (877-255-5439) in the command center at Children's Hospital San Antonio Christus - they do not have CICU. Information emailed to Dr Davis

1211 Clinical faxed to 734-232-7395 for Dr. Nate sznycer-Taub at CS Mott Childrens Hospital. Dr Davis emailed that clinical has been sent

1215 Spoke with Jackie (858-966-8113) at Rady Children's Hospital - clinical can be sent to 858-966-7903 attn Jackie

1230 Clinical Faxed to 858-966-7903 for Jackie at Rady Children's Hospital - Dr Davis emailed that clinical has been sent

1321 Spoke with Malia at LeBonheur Children's Hospital transfer center - she stated clinical can be faxed to the CVICU at 901-287-7222 attention Michelle Grandberry - she stated they use life image and images can be sent to the referral box and they will be directed to the appropriate physician Spoke with Hollie, RN CM and updated her on the Life Image referral box.

Clinical faxed. Emailed dr davis to up date that clinical was faxed and images can be sent via Life image.

1412 Left VM for Jackie at Rady Children's requesting call back to see if they are needing imaging and if so how can it be sent to them

1432 Spoke with Michelle at children's hospital Los angeles - asked how to gain access to Life Image to send requested information- she stated she would call this CM back

1420 Received call from Jackie at Rady Children's Hospital -she is receiving the clinical- she provided mailing address of 3020 Children's Way Mail Code 5004 San Diego Ca 92123 attn Jacqueline Rodriquez. Transferred to HIM to see how to get access to LifeImage. Spoke with Corey - she stated Scott could assist with getting images his contact number is 858-966-1021.

Sent information to Hollie, RN CM

1528 Spoke with Jackie at Rady Children's - they are still receiving the fax. She will call if they do not receive all pages. She stated Scott's phone number for images is 858-966-5967. Sent updated information to Hollie and echo/cath lab

1539 Spoke with Tim at los angeles - asked who gives access to LifeImage - transferred to CVICU - spoke with Brittany she spoke with the film room and radiology - they are on the phone with a physician from Cook to sort out the issue. Sent email update to cath/echo and dr davis

1607 Called 858-966-5967 -Scott at Rady Children's - no answer

Spoke with Jackie at Rady Children's - asked if she had a different way to reach Scott - placed on hold - she spoke with scott - provided email of shows@rchsd.org to email a link to the images

Emailed information to cath/echo lab and hollie

11/7/19

0820 Received call from Dr Daniel Fieour calling on behalf of Dr Moss at Arkansas' children's he requested echo report, OP report, and cath reports be faxed to 501-364-2117 attn Dr Moss. He is checking with his cath lab to obtain the images that were sent on 11/6/19 via Life Image.

Requested clinical faxed.

0840 Entire fax did not go through to LeBonheur Children's Hospital- refaxed last pages

1310 Spoke with Damon at University Hospital San Antonio - he cannot verify the fax number or address provided to Dr Davis by Dr Maldonado

1325 Spoke with Rita (210-562-5378) in the Cardiology Clinic for Dr Maldonado- the fax number 210-562-5380 is the clinic fax. The address 7703 Floyd Curl Drive Room 211-L

San Antonio, Texas 78229 is correct. She requested to add Department of Cardiothoracic Surgery at UT Health San Antonio.

Clinical faxed.

Address provided to Hollie, RN CM

1347 Spoke with Damon at University Hospital San Antonio - asked if they use LifeImage for cath/echo - he stated they do not this and would need the images on a disk. Updated Hollie, RN CM and cath/echo lab

1356 Spoke with Liz in the Cardiology Clinic for Dr Maldonado - asked if the cath/echo images could sent electronically or via email and she stated they typically receive them via disk. She did not have an email to send them to. Updated cath/echo lab

1515 Received phone call from Dr Maldonado at University Hospital San Antonio - she stated after speaking with Dr Davis and looking over the clinical information she agrees that the patient is not a candidate for glenn or single ventricle. She agrees with the current treatment, plan of care, and the ethics committee decision. She does not feel they would be able to provide anything further and declines transfer.

Notified Dr Davis via phone of the decline of transfer.

11/5 – Susan Davis Progress Note: We are continuing to reach out to hospitals with regarding transfer as requested by family. I have had the following communication today.

1) Heard back from St. Louis; Dr. Orr. After review of documentation and imaging, the cardiology, CV surgery, and CICU teams do not feel they have anything to offer Tinslee and have denied transfer.

2) Children's Hospital of Atlanta; Dr. Kevin Maher; Reviewed Tinslee's course and current status by phone. They did not feel that they had additional therapy that would alter course. Transfer denied.

3) Children's Hospital of Arkansas; Dr. Michele Moss and other physicians. Data reviewed by phone. They have asked for additional data to review. Case management to send packet.

4) Johns Hopkins: Case briefly presented as per their request to CICU staff. They have asked for progress note and current status to be sent in writing. Have faxed progress note from yesterday which includes a significant amount of Tinslee's history. This will be reviewed by their MD's and they will let us know any additional questions/data that they feel will be helpful in their decision.

5) Children's Hospital of LA; Dr. Jessica Ascencio; Reviewed case in detail. They have requested additional information and imaging. Case management is sending packet.

11/6 – Ryan Meyer Progress Note: Cardiac ICU attending addendum pertaining to transfer request regarding Tinslee Lewis.

I spoke at length with the cardiac ICU doctor at medical city Dallas Children's Hospital, Dr. Tejas Shah, regarding possible transfer of Tinslee Lewis. We spoke at length regarding this patient's current medical status, her past medical history, her current medications and drips, previous surgical interventions, echocardiogram data, current mechanical vent support, and desires of the mother. Throughout our phone conversation Dr. Shah asked multiple appropriate questions regarding this patient's medical history to help delineate the full medical picture. At the conclusion of the conversation he felt strongly that their cardiac center (Medical City Dallas Children's Hospital) had no further or additional surgical intervention or medical therapy to offer that would be meaningful and therefore declined transfer of this patient.

11/6 – Ryan Meyer Progress Note: Cardiac intensive care unit addendum pertaining to mother's request for transfer of this patient.

I contacted and spoke at length today (late this morning) with the cardiac ICU (Dr. Sachin Tadphale) at LeBonheur Children's Hospital in Memphis Tennessee. They requested her packet of information (medical records and studies) be sent to them via FedEx overnight. I have sent this request for overnight information to our administrative support personnel. Once the information is received they will review her case and call us back with her decision.

11/6 – Susan Davis Progress Note: Spoke with LA Childrens again today (Dr. Ascencio). Additional information given as requested. They are reviewing. They needed ECHO/CXR images. I have communicated to case management/Echo lab working on sending).

Spoke with Children's Hospital of Philadelphia (CICU MD). Initial information given. They will review and get back to me regarding any additional information needed.

Spoke with Herman Children's Hospital, Houston. Denied based on insurance, lack of bed availability.

11/6 – Susan Davis Progress Note: Mother visiting in the evening. Mr. Reed here early this morning briefly. No other family here during day today. Ongoing calls being made to centers as requested by family for transfer. At present, the following centers have denied: Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia and Boston Children's Hospital. The following centers have been called and are reviewing data with their teams: Rady Children's San Diego, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott Children's in Michigan, LeBonheur Children's in Memphis, and Johns Hopkins.

11/6 – Hannah Morton Nursing Note: Mother arrived at approximately 2240. She stated she was unable to find the name of the hospice that she contacted today. She stated "all the ones in the area are for old people and I don't think they will take her." She then presented an additional list of hospitals for possible transfer, and then stated she was tired and didn't want to hold Tinslee tonight. RN stated understanding. Mother then stated she will be back after her dentist appointment and will hold then. Mother again asked for a copy of the physician notes which contain the transfer responses from outside hospitals. RN again stated she would have to contact medical records for that information. Mother was upset and said "I will deal with it tomorrow."

11/7 – Jay Duncan Progress Note: CICU update regarding patient transfer; 11/7/2019: Methodist Children's Hospital, San Antonio, TX; Today I spoke at length with Dr. Punkaj Gupta regarding possible transfer of this patient to their Medical Center. We spoke at length reviewing her entire history, surgical history, current level of support, echocardiogram data, cardiac catheterization data and current clinical status. There were appropriate questions asked regarding the medical history. At the conclusion of the conversation he felt strongly that there Cardiac Center had no further recommendations or surgical interventions for this patient's care and agreed with current management as well as conclusions regarding medical futility. They will not accept the patient in transfer.

11/7 – Susan Davis Progress Note: Spoke with Dr. Stacie Peddy from Children's Hospital of Philadelphia last evening; after review of the data, they have denied transfer stating they do not have any additional treatment for Tinslee that has not been done.

Spoke with Dr. Jamie Schwartz from Johns Hopkins this morning. They have denied transfer and stated they do not have additional treatment options.

Spoke with Dr. Elaine Maldonado, cardiologist from University Hospital in San Antonio regarding parent's wish for transfer. They will review data and let us know. Case management will send CXR images, cata data, echo images and packet today.

11/7 – Susan Davis Progress Note: Mother visited just now briefly. I reviewed with her that we have received denials from Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia, Johns Hopkins, Methodist Hospital San Antonio and Boston Children's Hospital. We are waiting to hear back from Rady Children's San Diego, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott Children's in Michigan, LeBonheur Children's in Memphis, and University Hospital in San Antonio. I also told mother that the hospital would not initiate additional calls to other institutions to try to arrange transfer as discussed with legal this morning (Laura Copeland). Mother is aware that she or her family can continue to try to find an accepting facility and that we will provide any information needed to facilitate a transfer in that scenario. Mother has explored hospice and asked if we would transfer her to hospice. I have told her that my knowledge of transfers to hospice centers would involve extubating Tinslee on arrival to such facility with subsequent comfort care but that mother could ask any hospice center that she was interested in to call us for more information. Mother stated that she might want to extubate her to high flow prior to Sunday and asked if that would be possible. I told mother that she and her family could decide to remove the ventilator before Sunday and that care directed at Tinslee's comfort which could include high flow and medications to alleviate suffering would be appropriate. I asked mother if they waited until Sunday (11/10) if she had a preferred time for withdrawal. She stated that she and her family would be here and they will let me know what time. Mother stated that she would return later tonight. I did provide the aforementioned institutions to mother in writing.

11/7 – Susan Davis Progress Note: University Hospital, San Antonio called and spoke to Shanda Campbell in case management. They have denied transfer stating that they have reviewed documentation and do not have additional therapies to offer Tinslee.

11/7 – Jay Duncan Progress Note: I have spoken with Dr. Michele Moss from Arkansas Children's Hospital this evening. Today they reviewed all of Tinslee's medical not a including echocardiograms and cardiac catheterization at their multi disciplinary cardiac catheterization conference attended by cardiac surgeons, Cardiology, and intensive care unit physicians. After a detailed review they do not feel that any further surgical intervention is warranted given her severe chronic lung disease, pulmonary hypertension, and single ventricle physiology. They have no additional therapies or procedures to offer this patient. They have denied transfer.

11/7 – Jay Duncan Progress Note: I have smoke good with multiple cardiac ICU physicians from CS Mott Children's Hospital at the University of Michigan. After careful review of the complete clinical data as well as consultation with our cardiac team they are in agreement with our judgment on the clinical care of this child. They would not accept transfer as they do not think that they could offer any more or better care than what is already being provided.

There have also been multiple discussions with the cardiac team from Children's Hospital Los Angeles. After review of the data that they have they cannot accept this patient in transfer with the current data. They did state that if we were to perform another cardiac catheterization or echocardiogram they would be willing to review that data but understood that these studies could not be clinically indicated.

11/8 – Susan Davis Progress Note: I called Rady Children's in San Diego this evening. They have asked the cardiac intensivist to call me back. This is the only institution that has not officially denied her

transfer that we called/sent information to. Transfer has been denied by: Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia, Johns Hopkins, Methodist Hospital San Antonio, Boston Children's Hospital, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott Children's in Michigan, LeBonheur Children's in Memphis, and University Hospital in San Antonio. I have asked Trinity this week and her mother today if there was a time that they would like to withdraw on Sunday. They have stated that they will be here but have not given me a time. We will continue to work with family as possible.

11/8 – Susan Davis Progress Note: Dr. Sachin Tadphale at LeBonheur Children's Hospital called this morning regarding possible transfer of Tinslee. They have reviewed her course and cardiac data. They feel they have nothing more to offer and have denied her transfer. Letter has been faxed stating same.

11/9 – Richard Chemelli Progress Note: Dr. Stringer at Rady Children's Hospital in San Diego called last evening regarding possible transfer of Tinslee. They have reviewed her course and cardiac data and felt our management was heroic. They feel we have already done everything they would and therefore they have nothing more to offer and have denied her transfer. They agree with our assessment of Medical Futility.

11/9 – Lane Lanier Progress Note: Elaine Maldonado MD from University Hospital in San Antonio, TX reviewed the packet sent from us regarding Tinslee Lewis and stated that she concurs with the treatment plan by our team and she believes the patient is receiving appropriate care at Cook Children's Medical Center. She states that there is no need to transfer to University Hospital at San Antonio.

On 11/7/2019, case management spoke with Dr. Maldonado and left a note specifically declaring that University Hospital declined transfer. Dr. Davis was also on call.

11/10 – Susan Davis Progress Note: Multiple institutions called during 10 day period. The following institutions denied transfer after review of her records: Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia, Johns Hopkins, Methodist Hospital San Antonio, Boston Children's Hospital, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott Children's in Michigan, LeBonheur Children's in Memphis, University Hospital in San Antonio, and Rady Children's Hospital in San Diego. Family attorney secured temporary restraining order mandating ongoing care today. Administration and legal involved. Medical team continues to provide ongoing aggressive treatment for Tinslee accordingly. DNR rescinded today by mother. She has a full code order now in place.

11/14 – Letter from Cleveland Clinic: It is with heavy heart to inform you that Cleveland Clinic Children's is not able to offer any further treatment options to improve the quality of life for Tinslee. EPIC access gave me the opportunity to review Tinslee's past medical history and her current status. I reviewed the notes with Hani Najm, MD Chair Pediatric and Congenital Cardiac Surgery, Gerard Boyle, MD Head Pediatric Heart Failure and Samir Latifi, MD Chair Pediatric Critical Care Medicine. Our decision was unanimous.

11/18 - Ryan Meyer Progress Note: She will undergo repeat echocardiogram today for which results will be sent to more outside institutions to be reviewed.

11/19 – Jay Duncan Progress Note: 11/19/2019: Patient's prognosis remains quite poor. We continue to provide aggressive CICU support. We are communicating with other institutions regarding their opinion and potential transfer. The mother has been kept up-to-date when she is at the bedside.

11/23 – Lane Lanier Progress Note: I spoke with a CICU physician at Dell Children's Hospital over the last 24 hr. They reiterated that they would not be accepting the patient and that she was not a candidate for transfer to their center. We will continue to discuss her with Cardiology and cardiothoracic surgery daily.

12/6 – Jasmine Cobb Nursing Note: Mother called this am at 0735 for update on patient status. This RN obtained patient name and DOB for verification. This RN informed mother that patient is stable and resting at the moment. This RN told mother changes made overnight and mother verbalized that she was updated by the RN on the previous shift. This RN asked mother what time she will be returning to the unit today to obtain consents for cardiac catheterization procedure. Mother stated "she's getting a cath?" This RN stated "per the request of Boston's Children's, a cath procedure was requested to consider transfer. Were you not informed?" Mother stated, "No, I was never told she was getting a cath. What time is she going to cath?" This RN stated that the patient was not on the official schedule yet but it was scheduled to happen today. Mother stated that her father had surgery earlier this week so she is at a doctor appointment with him, and she will be returning to the unit by noon. This RN asked if mother had any other questions and mother stated no.

12/6 – Jasmine Cobb Nursing Note: Jay Duncan, MD informed of mother's unawareness of patient's potential cardiac catheterization. MD to call mother later this AM to explain rationale.

12/6 – Jay Duncan Progress Note: There has been a request from Boston Children's Hospital for both CT of the chest which has been accomplished as well as cardiac catheterization to further define her hemodynamics. They state that they will be unable to make a decision regarding suitability for transport to their institution without these studies. There was some confusion this morning with the patient's mother stating she had no awareness of the cardiac catheterization. I had a telephone conversation with her this morning where she did state she knew of the possibility of cardiac catheterization. I described in detail the rationale for cardiac catheterization for the purposes of achieving more clinical information so that Boston Children's Hospital could make a decision regarding transfer. I discussed with her that the objective findings of cardiac catheterization once reviewed by Boston Children's Hospital could have them come to the conclusion that she was not a suitable candidate for transfer. The mother expressed concerns that she may not consent to a cardiac catheterization unless there is assurance that Boston Children's Hospital would take her daughter. I reiterated to the mother that if she refused cardiac catheterization she would not be a candidate for transfer to Boston Children's Hospital as they would not be able to render a decision without that clinical information. She will come back to the hospital before noon this morning for further discussions. Currently the patient is scheduled for potential cardiac catheterization later this afternoon.

12/6 – Jasmine Cobb Nursing Note: This RN called Trinity (mother) at 1153 to get a time that she would be here. This RN explained to mother that if the consents/waivers were not signed now, Dr. Kuo will not perform the cardiac cath procedure today (per Lindsay Howell, RN). Mother stated "I'll try to be there maybe around 1 o'clock. And it's whatever. I didn't want her to have a cath today anyway." This RN confirmed what mother stated and told her we will see her at 1300. This RN notified charge RN (D. Thompson, RN) and J. Duncan, MD.

12/6 – Jasmine Cobb Nursing Note: Jay Duncan, MD spoke with Trinity (mother) this morning at 0840 via phone to discuss cath procedure. This RN present during conversation to hear MD, but mother was

not on speaker phone. MD discussed that Boston Children's initially denied transfer of Tinslee to their care but recently reconsidered. Per Boston Children's, they would reconsider transfer if a chest CT and a cardiac cath was obtained. MD explained the purpose for the cardiac cath procedure and the risks involved. MD continued to explain that this does not guarantee that Boston Children's will accept her as a patient, but that they will not make a decision on whether they will accept or deny her without the cardiac cath data. Mother stated to physician that she would to the unit around noon or a little before.

12/7 – Jay Duncan Progress Note: Both myself and Dr. Tam had a lengthy discussion with the cardiac surgeon from Children's Hospital of Omaha. At his request another echocardiogram was performed. We also measured her CVP from her PICC line which was 30. After careful review of her clinical data in the studies he communicated to Dr. Tam that this patient would not be accepted in transfer his institution. He had stated to me that this would be communicated by him with the mother however I do not know of this occurred. We had also discussed cardiac catheterization which had been requested by the team a Boston Children's Hospital with the mother. We had made arrangements to perform this test yesterday however the mother refused to consent to the procedure and stated later to multiple nurses that she did not want the procedure. It was explained to her that the patient would not be a candidate for transfer to Boston Children's Hospital without cardiac catheterization. She vocalized understanding of this.

Multiple institutions have been contacted regarding transfer care. All have declined stating that they did not feel anything to offer to alleviate this patient is suffering. This most recently the Children's Hospital of Omaha was contacted who has declined the patient in transfer. Boston Children's Hospital has reconsidered after there were initial denial. They had requested a CT of the chest and cardiac catheterization. CT of the chest has been performed and been reviewed by the team in Boston. Mother has declined cardiac catheterization. She has been made aware that the patient would not be considered for transfer to Boston if cardiac catheterization was not performed. She vocalized understanding of these instructions.

12/7 – Kara Berg Nursing Note: 1858 - 1926 Trinity at bedside with Maternal Grandmother and Maternal Grandfather. At this time Dr. Duncan, A. Sills RN, and K Berg RN are present.

Dr. Duncan explained that Omaha declined to accept Tinslee as a patient after re-evaluation. Dr. Duncan reiterated the implications of not having the cardiac catheterization. Dr. Duncan explained that if we perform the cath Tinslee will be able to be evaluated by Boston Children's but if we do not perform the cath then there is no possibility that they will accept her. He also explained that if we perform the cath there is still the possibility that Boston may not take her on as a patient. After having this discussion Trinity verbalized understanding and stated that she would consent for cath on Monday.

Dr. Duncan encouraged Trinity to stay the night on Sunday 12/8/2019 in order to expedite signing consents for cath on Monday morning. Trinity verbalized understanding and agreement.

12/8 – Jay Duncan Progress Note: After lengthy discussion with the mother overnight she now once a cardiac catheterization so the Boston Children's Hospital can complete their evaluation. This will be done tomorrow. I expressed to her how she needs to either spend the night here tonight or be here by 07:00 tomorrow morning so that appropriate consents can be signed and the procedure will not be delayed. She stated she would be here overnight.

12/9 – Susan Davis Progress Note: We continue to provide supportive care at this time. She will undergo catheterization today as requested by Boston Children's prior to reconsideration for possible transfer (initially denied).

12/10 – Susan Davis Progress Note: There have been extensive discussions with Tinslee's family regarding futility of ongoing heroic care with continued suffering. Her mother has not felt limitation was appropriate. The case was presented to the Ethics Committee and a binding decision was given to withdraw care. Multiple facilities were contacted following this decision to try to find an accepting facility in accordance with mother's wishes without success. Family sought legal counsel and her case is being reviewed within the court system. We continue to provide supportive care at this time. She underwent cath yesterday as requested by Boston Children's to reconsider for possible transfer (initially denied).

Mother requested cath be done and this was completed yesterday. Data will be sent to Boston as requested.

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM

Author: Susan Lynn Davis, MD
Filed: 12/11/2019 12:39 AM

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Author Type: Physician
Creation Time: 12/10/2019 5:29 PM

Status: Signed

Editor: Susan Lynn Davis, MD (Physician)

CICU PROGRESS NOTE

Tinslee is a critically ill 10 month old with severe Ebstein's anomaly, requiring Starnes patch and placement of a 3.0 BT shunt as a neonate. She has had significant lung disease from heart failure and prematurity, requiring HFNC or ventilation since birth. She has been hospitalized all of her life, most of which has been in the CICU. Beginning in late June, her respiratory status became more tenuous, requiring more oxygen and flow. She acutely decompensated on 7/9/19 with profound hypoxemia, requiring emergent intubation and ECMO support. Shunt was upsized to a 5.0 shunt on 7/14/19, and she was able to separate from ECMO in the OR. Despite this, saturations remained marginal and repeat cath showed stenosis of the right innominate artery. She was taken back to the OR for shunt revision 8/16/19. Unfortunately she has been unable to wean from vent support since July. She has required at least partial neuromuscular blockade for the majority of this time. Given single ventricle physiology and chronic vent dependence with marked aberration in lung function, her prognosis is dismal. There have been extensive discussions with Tinslee's family regarding futility of ongoing heroic care with continued suffering. Her mother has not felt limitation was appropriate. The case was presented to the Ethics Committee and a binding decision was given to withdraw care. Multiple facilities were contacted following this decision to try to find an accepting facility in accordance with mother's wishes without success. Family sought legal counsel and her case is being reviewed within the court system. We continue to provide supportive care at this time. She underwent cath yesterday as requested by Boston Children's to reconsider for possible transfer (initially denied).

Surgeon: Tam, Vincent K.H, MD

Operations:

- 2/13/19. Starnes operation with fenestrated closure of the tricuspid valve, open atrial septectomy with cardiopulmonary bypass, placement of a 3 mm modified BT shunt, reduction right atrial plasty, and pulmonary valvotomy, Dr. Vincent Tam, Chest left open.
- 2/14/19: Mediastinal exploration, to assess recurrent bleeding/effusion posterior to heart, clip placed to isolate MPA from RV to prevent blood from flowing back to RV, Dr. Vincent Tam, Chest left open.
- 2/22/19: Chest closed
- 5/17/19: Diagnostic cardiac catheterization, with balloon angioplasty of the right pulmonary artery
- 7/9/19: Emergent cannulation (neck) for VA ECMO
- 7/14/19: Decannulated from VA ECMO, placement of a 5.0 mm BT shunt, patch augmentation of the RVOT with opening of the RVOT, reduction right atrioplasty, repair of right common carotid artery, repair of right internal jugular vein. Clip placed on the RVOT after noted desaturations coming off bypass with improvement of saturations, Dr. Vincent Tam, chest left open.
- 7/19/19: Chest closed
- 8/16/19: Shunt revision, taking the proximal takeoff from the innominate artery and placing it in a central position off the aorta

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

Hospital Day: 312

SUBJECTIVE:

Interval History: Tinslee has not had new problems. Ventilatory requirements are unchanged; PIP's generally remain in the low 30's. Norepinephrine was decreased to 0.01 mcg/kg/min without change in blood pressure. Epinephrine infusion remains at 0.04 mcg/kg/min. She continues to require significant sedation and partial neuromuscular blockade. She did diurese with a negative fluid balance on q 6 hour lasix and diuril.

OBJECTIVE:

Current Support:

Cardiovascular:

Antiarrhythmic Support: Amiodarone 42.5 daily; flecainide 11 mg q 8 hours

Pacemaker: None

Other Cardiac Medications: Epinephrine 0.04 mg/kg/min; norepinephrine 0.01 mcg/kg/min; lasix 10 mg q6h; diuril 44.44 mg (5.23 mg/kg) q 12h; bosentan 17.5 mg BID; sildenafil 3 mg q 6 hours.

Anticoagulation: Aspirin 40.5 mg daily

Respiratory

Respiratory Support:

SpO2: 81%

FiO2: 40%

Vent Rate: 35

PEEP: 8 cm H2O

Pressure Support: 12 cm H2O

Vt (mL): 60 mL

Insp Time: 0.6 sec

ABG: 7.35/59/40/5.4

Pulmonary program: Albuterol 5 mg q 3 hours; atrovent 250 mcg q6h; vest CPT q 3 hours; 3% hypertonic saline nebs q6h; pulmozyme 2.5 mg daily and budesonide 0.5 mg BID

Ins and Outs:

Intake: 912.3 ml, for 107.3 ml/kg/day

Output: 1043 ml, for a net -130.7 ml fluid balance

Urine: 1008 ml, for 4.9 ml/kg/hr

Lines

Active :

Name:	Placement date:	Placement time:	Site:	Days:
Peripheral IV 12/09/19	12/09/19	2132	—	less than 1
Anterior;Right Foot				
Arterial Line 08/16/19 Left	08/16/19	1700	Ulnar	116
Ulnar				

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

DL PICC RED/WHT 07/29/19	07/29/19	1032	Other (Comment)	134
Left Other (Comment)				

Physical Assessment:

Temp: [36.2 °C (97.2 °F)-37.2 °C (99 °F)] 36.5 °C (97.7 °F)

Pulse: [100-122] 111

Resp: [34-40] 35

BP: (85-99)/(33-43) 85/35

SpO2: [75 %-85 %] 81 %

Arterial Line BP: (65-95)/(34-47) 68/35

FiO2: [40 %-45 %] 40 %

GENERAL: Sedated, partially neuromuscularly blocked, nasotracheally intubated, on full ventilatory support. She appears well perfused.

HEENT: Baseline facial features. MM are dusky pink and moist. Small amount of dried blood at nares (following reintubation/replacement of feeding/ng tubes yesterday.)

NECK: Without new findings.

CHEST: Breath sounds are generally quite coarse. She does clear at times after vest treatments. Breathing in phase with ventilator.

HEART: RRR. Sinus. Shunt murmur is present. Perfusion is good. Pulses are easily palpable. Extremities are warm. Capillary refill is brisk.

ABDOMEN: Full but soft in general. Massive hepatomegaly persists with liver felt at the umbilicus. Bowel sounds are present. Spleen tip is noted.

EXTREMITIES: Without new findings.

NEURO: Sedated, partially neuromuscularly blocked. Does open eyes briefly and moves extremities when more awake.

SKIN: No new issues.

Labs Reviewed: Yes

Labs:

Results from last 7 days

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

Lab	Units	12/10/19 1614	12/10/19 0405
WBC	x10e3/uL	--	10.05
HGB	g/dL	--	12.2
HCT	%	--	39.4*
HEMATOCRIT	%	37	--
PLATELETS	x10e3/uL	--	83*

Results from last 7 days

Lab	Units	12/10/19 1614	12/10/19 0405
SODIUM	mmol/L	--	145*
SODIUM GEM	mmol/L	146*	--
POTASSIUM	mmol/L	--	3.7
POTASSIUM GEM	mmol/L	3.5*	--
CHLORIDE	mmol/L	--	105
CARBON DIOXIDE LEVEL	mmol/L	--	28*
BUN	mg/dL	--	26*
CREATININE	mg/dL	--	0.54*
GLUCOSE	mg/dL	--	99
CALCIUM	mg/dL	--	10.3

CHEST XRAY: ETT is in good position. CXR suggests some mild improvement in left greater than right diffuse airspace opacities; however, she continues to have persistent confluent bibasilar opacities. Film has been personally reviewed by me and radiologist's interpretation read.

MAR Reviewed: Yes

ASSESSMENT/PLAN by SYSTEM

A/B: Ongoing need for full ventilatory support. Gas exchange adequate for physiology. Pulmonary toilet regimen intensified given thick tracheal secretions --will give trial of 3% hypertonic nebs QID and add pulmozyme to thin secretions.

CVS: Norepinephrine decreased slightly. No real change thus far in blood pressure. Will follow carefully. Other support without change and listed above. Cath yesterday remarkable for significant pulmonary vein desaturation in LUPV, LLPV and RLPV (70's). LVEDP 18. LA mean pressure 16. Qp:Qs calculated to 3-3.6; PVR calculated to <1. Branch PA's were 6.5 mm on the right and 7.2 mm on the left. There was an abnormal appearance of the distal arborization. Will review with team.

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

Neuro: Sedation is unchanged. She continues on methadone 2.5 mg q 6 hours; ativan 2.6 mg q 6 hours; seroquel 4.3 mg q 8 hours; gabapentin 45 mg q 8 hours, precedex at 1 mcg/kg/hr; and vecuronium at 0.05 mg/kg/hr. PRN doses of ativan/morphine/benadryl/ketamine available if needed.

FEN/GI: Negative fluid balance past 24 hours. Renal indices are unchanged. Will continue increased lasix (q6h) with diuril (q12h). TPN support continues. On bethanechol. Will add milk of magnesia to increase gut motility. Most recent attempt to enterally feed failed last week with increasing abdominal distension. Calories decreased today per nutritionist to 65 cal/kg/day. Sodium in mid 140's; stable, but needing ongoing observation with increased diuretics, 3% saline nebs etc. On prevacid.

HEME: CBC noted. Transfused platelets yesterday. On aspirin.

ID: No new issues. Off antibiotics. No significant fever.

Renal: As noted.

Endo: No active issues.

Lines: As noted above;
Reason for Central Venous Line: Difficult Access
Reason for Foley: Not Applicable (No Foley)

Parents: Mom here. Spoke to her and discussed plans. She voiced no questions.

Communication: Plan discussed with multidisciplinary team, including cardiology and CV surgery, as well as nutrition, rehab therapists, and nursing.

VTE Screen performed:

No, not applicable

ACTIVE PROBLEMS with BRIEF HISTORY, COURSE, ASSESSMENT and PLAN:*** Ebstein's anomaly of tricuspid valve***Assessment & Plan*

Severe anomaly with inadequate pulmonary blood flow, marked RA and RV dilatation compromising LV filling and encompassing much of chest. Now s/p modified Starnes operation with fenestrated closure of the tricuspid valve, open atrial septectomy with cardiopulmonary bypass, placement of a 3 mm modified BT shunt, reduction right atrial plasty, and pulmonary valvotomy, Dr. Vincent Tam, 2/13/19. Chest left open. 2/14/19: Mediastinal exploration, to assess recurrent bleeding/effusion posterior to heart, clip placed to isolate MPA from RV to prevent blood from flowing back to RV.

Patient underwent delayed sternal closure 2/22/2019

May 17, 2019: Cardiac catheterization showed decreased diameter of the pulmonary arteries with subsequent balloon dilatation of both pulmonary arteries.

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

7/14/2019: Patient taken OR by Dr. Tam where she was decannulated from ECMO support, had her BT shunt replaced with a 5.0 mm BT shunt, patch augmentation of right ventricular outflow tract, reduction right atrioplasty, repair of the right common carotid artery and right internal jugular vein. While in the OR the patient had significant desaturations coming off bypass requiring a clip to be placed over the right ventricular outflow tract. With this maneuver saturations and pulmonary blood flow increased.

7/19/2019: Patient underwent delayed sternal closure

8/17/2019: Due to inadequate pulmonary blood flow in significant gradient from the innominate artery to the BT shunt the patient was taken back to the operating room where the BT shunt was taken off the innominate artery at its proximal takeoff and reconnected to the aorta with formation of a central shunt.

10/8/2019: Referrals have been made to Boston Children's Hospital and Texas children's Hospital regarding any further interventions or options to be provided. Both institutions have said that everything has aggressively been done.

11/4/19: Patient has also been denied at Dallas Childrens.

Staphylococcus aureus infection*Assessment & Plan*

Patient had fever prompting cultures on 11/13/2019. There is abundant growth of Staph aureus from the endotracheal tube. There are not significant elevation of inflammatory markers. We will plan on seven days of treatment with oxacillin.

11/27/19: Completed course of oxacillin/bactrim for staphylococcus LRI. Problem resolved.

11/29/19: Again with growth of abundant Staphylococcus aureus from ETT in setting of chronic lung disease, secretions and high fever. Vancomycin started 11/28-->oxacillin 11/29. Probable 10 days course.

12/9/19: Completed 10 day course. Now off antibiotics. Ongoing surveillance.

Infection due to Stenotrophomonas maltophilia*Assessment & Plan*

Growth of abundant Stenotrophomonas from tracheal aspirate 9/26/19. Bactrim initiated 9/28 once culture grew. Plan 14 day course.

10/22/19: Has had fever with discontinuation of bactrim prompting new cultures and starting of bactrim. Ongoing surveillance for response. Typically has had less fever when treated.

11/4/19: Course of bactrim was complete 10/31/19

11/17/19: Again with abundant stenotrophomonas in tracheal aspirate associated with increased secretions. Bactrim initiated overnight.

11/27/19: Completed course of bactrim. Ongoing surveillance.

Personal history of ECMO*Assessment & Plan*

Patient with profound hypoxemic respiratory failure with worsening pulmonary hypertension requiring ECMO rescue 7/9/2019

7/12/2019: Patient remains on VA ECMO support with excellent perfusion and low lactate levels.

7/14/2019: Patient transitioned off of VA ECMO support with decannulation in the OR.

Pulmonary hypertension (CMS/HCC)

Assessment & Plan

Pulmonary hypertension associated with chronic lung disease. On June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO2 was weaned as well as the flow on the nasal cannula. The patient was started on sildenafil. On June 10, 2019 the nitric oxide has been weaned off. BNP was elevated over 500.

6/19/19: Improved bnp (308), continues on sildenafil 1.1 mg q 8 hours.

6/24/19: Sildenafil increased yesterday to 2.3 mg q 8 hours for higher oxygen needs

6/25/19: Worsening aeration, tight breath sounds. Sildenafil decreased back to previous dose.

7/1/19: Weaning sildenafil to off, tolerating thus far.

7/2/2018: Sildenafil is off.

7/9/2019: Patient with worsening hypoxemia and work of breathing and desaturation over the last several days. High-flow a been escalated. Patient placed back on nitric oxide 7/8/2019: Patient with severe hypoxemic decompensation with likely worsening pulmonary hypertension this morning. Patient transitioned on to VA ECMO support.

7/12/2019: Patient remains on VA ECMO support and inhaled nitric oxide.

7/14/2018: Patient decannulated from VA ECMO support in the OR. Patient underwent replacement of her BT shunt with a 5.0 mm BT shunt. Patient was unable to wean off nitric oxide in OR and remains on inhaled nitric oxide at 20 parts per million and 100% FiO2 from the ventilator.

7/18/2019: Patient has had intolerance of sildenafil. Bosentan and will be started today. The patient remains on nitric oxide

7/21/2019: The patient remains on inhaled nitric oxide. There has been improvement in saturations with Bosentan.

7/27/2019: The patient remains on nitric oxide and bosentan

8/2/2019: The patient remains on nitric oxide, Bosentan, mechanical ventilation with high inspired oxygen. She continues to require at high driving pressure to maintain adequate pulmonary blood flow

8/8/19: Nitric oxide increased back from 5 to 10 ppm in past 24 hours for worsening oxygenation especially with agitation.

8/11/2019: Inhaled nitric oxide increased back to 20 parts per million.

8/13/2019: Marginally better but still labile on paralysis, are giving a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentin. Child has very small pulmonary arteries attached to her 5 mm shunt likely representing significant anatomic resistance to pulmonary blood flow, cardiac catheterization evaluation today.

8/15/2019: Cardiac catheterization on the 14th revealed a stenosis with a likely 60-80 mm gradient in the innominate artery between the ascending aorta and the takeoff of the BT shunt, this could explain the need for hypertensive blood pressures to maintain adequate oxygen saturations and amenable to surgical correction. Dr. Tam is performing a central shunt today.

8/16/2019: Central shunt delayed until today.

8/18/2019: Bosentan discontinued

8/20/2018: Patient remains on inhaled nitric oxide and Bosentan. It should be noted that cardiac catheterization data demonstrating approximately 1/3 to 1/2 systemic pulmonary artery pressures performed in the setting of deep sedation and paralysis, inhaled nitric oxide, and Bosentan. If the patient

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

demonstrates evidence of pulmonary overcirculation we will begin weaning nitric oxide.

8/22/2019: Patient remains on full mechanical ventilatory support, inspired oxygen, nitric oxide, and Bosentan. We will attempt to start sildenafil today.

8/25/2019: The patient remains on full mechanical ventilatory support, nitric oxide at 20 parts per million, bosentan, and now sildenafil has been escalated to 1 milligram/kilogram every 6 hr.

9/2/19: Patient weaned off nitric oxide this morning. Continues on bosentan and sildenafil.

10/4/19: Sildenafil reduced to 2 mg/kg/day given vasodilation, evidence of pulmonary overcirculation, and hypotension.

11/9/2019: Patient remains on sildenafil and bosentan therapy with reasonable saturations off of vecuronium.

11/16/19: Has required reinstitution of vecuronium for ventilatory dyssynchrony/agitation.

11/17/19: Sildenafil dose has been decreased by 25% given issues with hypotension with adequate PaO₂ on blood gas on 45% oxygen.

11/19/2019: Patient remains on both Bosentan sildenafil. PaO₂ is a are in the high 30s.

12/1/2019: The patient continues on aggressive treatment of pulmonary hypertension with Bosentan, sildenafil, mechanical ventilation, and inspired oxygen.

Chronic lung disease in neonate

Assessment & Plan

Patient with history of prematurity, complex congenital heart disease, and gross anatomic emphysema seen at the time of initial cardiac surgery. Pulmonary veins are desaturated on cardiac catheterization

7/12/2019: Patient remains on Pulmicort and albuterol therapy and is followed by pulmonology.

7/27/2019: Patient continues to struggle with issues related to underlying chronic lung disease. She will likely require long-term mechanical ventilation.

8/20/2019: Patient with severe chronic lung disease. She has required systemic steroids approximately once a month over the last 3-4 months. She continues on Pulmicort with aggressive beta agonist therapy.

9/11/2019: Patient continues to exhibit evidence of severe chronic lung disease with poor pulmonary compliance with oxygen and diuretic requirements. Has a very poor overall pulmonary prognosis.

12/1/2019: This continues to be a significant problem given poor pulmonary compliance and appearance of chest radiograph.

12/6/2019: Chest CT confirms evidence of chronic lung disease by radiograph appearance. There is also the presence of bronchiectasis.

Acute systolic heart failure (CMS/HCC)

Assessment & Plan

Infant initially with cardiogenic shock in the immediate postoperative period. While shock has resolved, infant continues to have heart failure, requiring epinephrine support. Has variably been on milrinone, currently off.

2/24/2019: Patient continues on aggressive heart failure management. The patient is currently on epinephrine infusion as well as diuretics.

2/26/2019: Patient remains on diuretics. We have discontinued epinephrine in an effort to see if this would help with the dysrhythmia. We will also be more liberal on fluid administration.

2/27/2019; Blood pressure and NIRS lower off epinephrine. Restarted at 0.02 mcg/kg/min with milrinone at

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

0.3 mcg/kg/min. Gradual improvement noted in perfusion and blood pressure. Ongoing need for titration of vasoactive medications.

3/4/2019: Off epinephrine. Improved perfusion on milrinone. Still with rhythm issues, intermittent atrial bigeminy with some compromise of cardiac output; NIRS remain marginal.

3/10/2019: Patient remains on Milrinone and diuretics. Patient's hemodynamics have been more stable when in a sinus rhythm.

3/28/2019: Milrinone weaned off. Patient remains on Lasix only.

4/19/2019: Patient transitioned to IV Lasix earlier in the week. We will transition back to p.o. Lasix twice daily.

4/22/19: Continues to struggle with fluid balance. Significantly positive balance on twice daily Lasix, increased to q.8 hours today.

4/28/2019: Continues to do better on increased diuretics (q 8 hours)

5/1/19: Continues on increased diuretics, now q 6 hours.

5/7/19: Continues on diuretics, now q.8 hours Lasix.

5/15/2019: Patient has been transitioned to twice daily Lasix.

5/21/19: Now on increased diuretics s/p cath with respiratory failure. Perfusion remains good without other cardiac medications.

6/19/19: Continued need for meticulous attention to fluid status and diuretic therapy. Siladenafil has been added to regimen. BNP down to 308 6/19/19 from 560.1 several days ago.

6/25/19: BNP 351 yesterday. Diuretics increased past 24 hours for tighter breath sounds. Given lack of improvement, team again considering cath

7/1/19: Reasonable week. Support unchanged other than weaning sildenafil to off. Remains on increased diuretics with stable renal indices.

7/7/2019: Worsening hypoxemia resulted in increase in high-flow nasal cannula 20 liters/minute with 80-90% FiO₂.

7/9/2019: Patient with clinical decompensation. Placed on epinephrine and Milrinone infusions to augment cardiac output. Patient ultimately transitioned on to veno arterial ECMO support.

7/14/2019: Patient now on epinephrine and Milrinone therapy after upsizing of her shunt in the OR today. Patient decannulated from ECMO support.

7/18/2019: Patient remains on epinephrine. Milrinone will be initiated today due to poor peripheral perfusion. She remains on aggressive pulmonary hypertensive and respiratory support.

7/21/2019: The patient remains on epinephrine infusion as well as pulmonary hypertensive therapies. She is warm and well perfused. We will attempt to wean epinephrine as tolerated. She is on diuretics.

7/27/2019: Patient remains on epinephrine and Milrinone infusions. She remains on diuretics. Given her normal LV function on echocardiogram and the vaso dilated appearance of her exam we will attempt to wean her Milrinone. My hope would be that with better vascular tone we will be able to improve pulmonary blood flow and wean epinephrine.

8/2/2019: Patient remains on a low-dose epinephrine infusion. She has required higher driving pressures to facilitate pulmonary blood flow. She continues on aggressive pulmonary hypertensive support

8/3/2019: Epinephrine infusion has been discontinued. She continues on aggressive pulmonary hypertensive measures. She continues on aggressive diuretics.

8/12/2019: Patient with increasing BNP, intolerance of feeds, fever and desaturations. Patient started on Milrinone at 0.5 micrograms/kilogram per minute. Patient remains on Bumex and Diuril.

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

8/13/2019: Continues to struggle from lability of oxygen saturations. Milrinone increased to 1 microgram/kilogram per minute and diuretics held for now.

8/14/2019: Despite hyperdynamic appearance of heart on echocardiogram the child did respond with less labile oxygen saturations after starting epinephrine, currently at 0.08 micrograms/kilogram per minute.

8/17/2019: Epinephrine has been discontinued in the operating room. The patient remains on Milrinone and aggressive pulmonary hypertensive therapies.

8/18/2019: Restarted on epinephrine due to poor oxygen saturations, however this was likely due to underlying poor pulmonary function and not pulmonary blood flow as echo showed good flow and pulmonary arteries and shunt.

8/20/2019: Patient remains on Milrinone. We are weaning epinephrine as tolerated.

8/21/2019: Patient remains on Milrinone and aggressive diuretic support. Epinephrine is been discontinued. Milrinone will be weaned as tolerated

8/25/2019: Milrinone will be discontinued today. Patient continues on aggressive diuretics. She is quite vasodilated in the setting of sildenafil therapy.

9/8/2019: Patient remains off vasoactive infusions on aggressive diuretics. She continues to have hepatomegaly on exam.

9/17/2019: Diuretics with the exception of Aldactone a been discontinued in the setting of elevated creatinine and persistent fevers felt to be either drug related or secondary to intravascular volume depletion. We will assess BUN and creatinine in need for diuretics over the coming days.

09/18/2019: Patient restarted on Milrinone in hopes of improving cardiac output and improved diuresis.

09/19/2019: Patient started on metolazone IV every 12 hr. Remains on Milrinone now being weaned.

9/20/2019: Milrinone weaned off.

10/2/2019: The patient remains on metolazone, Diuril, and a Bumex infusion has been added. Tolvaptam has been discontinued. An epinephrine infusion is also been added due to hypotension.

10/5/2019: The patient remains on epinephrine infusion, Bosentan, sildenafil which has reduced dosage, Bumex, Diuril. Metolazone is been discontinued.

10/13/2019: Bumex increased to 0.01 milligram/kilogram per hour. Low-dose epinephrine drip discontinued.

10/16/2019: We have had to back off on diuretics considerably given worsening of renal insufficiency. Low-dose epinephrine infusion has been re-initiated. She continues on aggressive pulmonary hypertension measures.

10/22/19: Ongoing titration of diuretics as possible to improve edema; continues to require epinephrine support. On sildenafil 2 mg/kg/day and bosentan.

10/28/2019: The patient remains on epinephrine as well as aggressive pulmonary hypertension measures. Diuretics were reduced significantly through the course of last week due to worsening renal insufficiency. BUN and creatinine have improved and diuretics will be again escalated. This has been an ongoing issue.

11/9/2019: Patient continues on epinephrine and multiple pulmonary hypertensive medications.

11/12/2019: The patient remains on epinephrine to provide adequate driving pressure to promote pulmonary blood flow. She continues on aggressive support for pulmonary hypertension. Diuretics continue however she has not achieved in negative fluid balance and is becoming more edematous.

11/16/2019: Has required increase in epinephrine to 0.04 mcg/kg/min. Marginal blood pressures. Titrating diuretics accordingly.

11/19/2019: Over the course of the last several days hypotension has been a problem. Norepinephrine was

Progress Notes by Susan Lynn Davis, MD at 12/10/2019 5:29 PM (continued)

added on 11/17/2019 with improvement. Unfortunately diuretics had to be held due to the need for volume expansion. Bumex has been restarted at a low dose and will be advanced today to 0.01 milligrams/kilogram per hour. We will give a single dose of Diuril today.

11/25/2019: The patient remains on epinephrine and norepinephrine. She has responded to diuretics however BUN and creatinine are increasing. We will titrate diuretic support appropriately.

12/1/2019: The patient remains on epinephrine at 0.04 micrograms/kilogram per minute, norepinephrine at 0.02 micrograms/kilogram per minute. There is ongoing titration of diuretic support given renal insufficiency. Currently the patient is on Lasix every 8 hr. Diuril has been discontinued

12/3/2019: Patient transitioned back to Lasix and Diuril every 12 hr.

Electrolyte and fluid disorder*Assessment & Plan*

Requiring ongoing boluses of calcium chloride and bicarbonate first postoperative night. Ongoing need for volume replacement to maintain adequate filling pressures for cardiac output. Will require ongoing meticulous supportive care and once stabilized, diuretics to resolve edema.

2/20/2019: Persistent truncal edema, on diuretic therapy.

3/6/2019: Significant improvement in edema. Now on intermittent lasix. Ongoing need for surveillance of electrolytes.

4/12/19: The patient has had issues with hypoglycemia associated with bolus feeds. This appears to be improving.

6/19/19: Has tolerated bolus feeds without hypoglycemia in interim since last update. Fasting study planned before discharge by endocrine. Ongoing need for diuretics, electrolyte monitoring and sodium chloride supplementation for hyponatremia.

7/16/19: Acute deterioration on 7/9/19, ongoing TPN support given cardiorespiratory status. Diuretics have been given as appropriate. Requiring manipulation of electrolytes in TPN.

7/27/2019: Continue ongoing surveillance and replacement of electrolytes

8/8/19: Increased edema in past 24 hours, now back on bumex infusion with diuril. Addressing hypochloremic alkalosis with diamox, normal saline IVF.

8/17/2019: Patient with ionized hypocalcemia, hypokalemia, hyperglycemia, metabolic acidosis all as would be expected following cardiac surgery. There will be ongoing surveillance replacement

9/2/19: Metolazone started 8/30 for persistent edema despite bumex and diuril. Good response. Marked electrolyte derangements as is common with use of this diuretic. Requiring aldactone, supplemental potassium, and sodium. Scheduled metolazone q 24 hours 9/1/19. Ongoing close surveillance of fluid status and electrolytes needed.

9/4/2019: Held metolazone and diuril today for elevated BUN/Cr. Electrolyte supplementation decreased.

9/9/2019: In interim, diuril and metolazone restarted. Titrating to effect.

9/10/19: Ongoing titration of diuretics targeting optimal fluid balance. Trial of bumex to lasix today. Diuril unchanged. Metolazone will be given on an as needed basis rather than scheduled.

9/15/19: Increased lasix to 1.5 mg/kg q 6 hours with ongoing diuril q 12h. Still requiring occasional dose of metolazone. Positive fluid balance and edema on exam.

9/17/2019: Continue ongoing surveillance and replacement of electrolytes in the setting of changing diuretic therapy

09/23/2019: Child received tolvaptan with increase in serum sodium as expected.

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10/1/19: Reintroduction of loop diuretics. If recurrent fever in absence of infection will stop. Electrolytes requiring close surveillance.

10/22/19: Has not had sustained fever on loop diuretics although still with some intermittent fevers. Edema persistent but improved. Ongoing therapy.

11/17/19: Has continued on diuretic therapy. Ongoing titration based on fluid balance. Ongoing surveillance of electrolytes required.

12/1/2019: There continues to be ongoing electrolyte surveillance and replacement with daily adjustments made in TPN.

Acute respiratory failure with hypoxia and hypercarbia (CMS/HCC)**Assessment & Plan**

Multifactorial including prematurity, marked cardiomegaly and ongoing issues with pulmonary blood flow. Ventilated preoperatively with difficulty, requiring JET ventilation and marginal saturations despite iNO. Early pulmonary interstitial emphysema noted prior to surgery. Postoperatively, requiring significant support, with ongoing use of iNO, FiO2 1.0, and significant pressures to offset abnormal respiratory system compliance. Titrating support as possible, to minimize ongoing barotrauma.

2/14/19: Some improvement in gas exchange, able to wean FiO2. Lungs with emphysematous appearance at time of chest exploration.

2/20/19: Continues to require full ventilatory support. Chest remains open.

2/24/2019: Remains on full mechanical ventilatory support. We will wean as tolerated

2/26/2019: Patient with evidence of poor gas exchange yesterday. This is likely multifactorial due to not only intrinsic lung disease but issues with pulmonary blood flow. The patient remains on nitric oxide and full mechanical ventilatory support

3/4/19: Improving gas exchange appropriate for physiology; not yet ready ready for significant weaning.

3/6/19: Making slow gains. Has tolerated some decrease in rate.

3/10/19: Difficult to wean ventilation. She has good gas exchange when cardiac output is good. We will attempt to wean as tolerated.

3/13/2019: With improvement of cardiac output over the last several days we have begun weaning mechanical ventilation. Gas exchange remains good

3/21/2019: Patient is tolerating weaning of mechanical ventilation. She will likely be extubated soon.

3/22/2019: Plans are for extubation to high-flow nasal cannula today

3/23/2019: The patient has been extubated to high-flow nasal cannula 12 L. Patient exhibits evidence of reasonable gas exchange despite a paralyzed right hemidiaphragm

3/27/2019: Weaning HFNC, down to 10 L

3/29/2019: Improving gradually, now on 8 LPM

4/6/2019: Continues to require high-flow nasal cannula. This is multifactorial given chronic lung disease, chronic heart failure, as well as enlarged cardiac size.

4/12/2019: High-flow nasal cannula is being weaned slowly. This appears to be tolerated

4/16/2018: The patient has had episodic increased work breathing. This may be secondary to aspiration or chest difficulty secretions.

4/19/2019: Earlier in the week the patient had high-flow nasal cannula increased. We have begun weaning this again. Currently now at 6 liters/minute.

4/23/19: Tolerating 6 lpm with 4lpm with feeds.

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4/25/19: Tolerating 4 lpm with some intermittent increase in breathing.

4/27/2019: Worsening difficulty maintaining oxygen saturations, decreased aeration and intermittently increased work of breathing caused increase of high-flow back to 15 L with addition of med nebs and albuterol every 3 hr. Diffuse atelectasis noted on chest x-ray.

4/28/19: Stabilizing in past 24 hours with improved respiratory status; able to wean to 10 lpm this morning.

4/29/2019: Continue to have episodes of desaturation and poor aeration, necessary to increase high-flow back up to 15 L and restart med neb treatments. Low-dose Ativan added for tolerance of IPV treatments. Good response overnight to aggressive pulmonary recruitment.

5/1/19: Prelone started 4/29 x 5 days. Weaning flow gradually. IPV ongoing. Not needing as much sedation.

05/02/2019. High-flow nasal cannula went 8 liters/minute.

5/4/2019: Patient has been transitioned to a standard nasal cannula.

5/6/2019: The patient was transiently on a regular nasal cannula but escalated back to a high-flow nasal cannula on 5/4/2019 in the afternoon. She remains on 6 liters/minute.

5/15/2019: The patient remains on 6 liters/minute of high-flow nasal cannula. She continues to have intermittent episodic airway obstruction and wheezing. She has responded to albuterol. She continues on Pulmicort.

May 17, 2019: Patient returned from the cardiac catheterization lab intubated. A bronchoscopy showed otherwise normal upper airway with slight inflammation on the left main bronchus. Significant hypoxemia and V/Q mismatch that improved with inhaled nitric oxide. Significant amount of secretions and the baby was started on broad-spectrum antibiotics.

5/19/2019: Has remained on full ventilatory support, nitric oxide and aggressive chest physiotherapy in last 24 hr. Overall pulmonary function appears to be improving especially with improvement in saturations after transfusion. She should be ready to start weaning on her aggressive treatment of her hypoxemia.

5/20/2019: The patient remains on mechanical ventilatory support. This is being aggressively weaned over the last 24 hr. This is being well tolerated. We will work towards extubation.

5/21/2019: Patient extubated last night to HFNC. Reasonable gas exchange, but continued increased work of breathing/marginal respiratory status.

05/25/2019: Placed on isolation. Respiratory pathogen panel sent and revealed rhino virus. Patient remains on high-flow nasal cannula that went from 10 L up to 15 L due to increased work of breathing and secretions.

5/26/2019: IPV treatments every 3 hr added again due to increasing oxygen requirement tachypnea, improved overnight with improved chest x-ray.

5/29/2019: IPV treatments decreased every 6 hr, high-flow currently at 12 liters/minute and overall the child appears to be making some slow steady progress.

5/30/2019: Patient has been increased to 15 liters/minute of high-flow nasal cannula. She has episodic increased work of breathing. She continues to recover from her rhino virus infection.

6/5/2019: Child had increasing oxygen requirement with decreasing saturations with worsening cough overnight. High-flow nasal cannula oxygen increased to 20 liters/minute and started back on IPV treatments every 6 hr with some improvement.

June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO2 was weaned as well as the flow on the nasal cannula.

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The patient was started on sildenafil

6/17/19: Patient has had interval improvement of respiratory status. Currently on 6 liters/minute with an FiO2 of 0.35.

6/19/19: Requiring increased flow today for work of breathing and FiO2 requirements.

6/25/19: Continues on 15 lpm flow. Breath sounds tighter past 24 hours, diuretics increased and now on q 2 hour albuterol.

6/26/2019: The patient continues on high-flow nasal cannula. Subjectively she has been improved since continuous feeds were started. She continues to have variable oxygen requirement.

6/28/19: Interval improvement. Trial of decreased flow to 12 lpm. Albuterol back to q 3 hours

6/30/19: The patient has had gradual interval improvement through the week. The patient has been weaned to 10 liters/minute of high-flow nasal cannula.

7/1/19: Tolerated 8 lpm of flow in past 24 hours. Clinically with good aeration. Weaning sildenafil to off.

7/8/2018: High-flow nasal cannula oxygen has slowly been escalated 15 liters/minute as a child wean off of sildenafil in order to maintain good oxygen saturations and maintain a reasonable work of breathing.

7/9/2019: Patient with acute respiratory arrest in the early morning hours of 7/9/2019. Patient had acute loss of air movement and was difficult to bag mask ventilate. Apparent cause was some mucus plugging.

Patient was emergently intubated and despite aggressive pulmonary toilet measures it was very difficult oxygen and ventilated. This also likely lead to a pulmonary hypertensive crisis. Despite aggressive pulmonary toilet measures, sedation, neuromuscular blockade, systemic alkalinization, and transfusion there was not much improvement. Patient emergently placed on VA ECMO.

7/14/2018: Patient transitioned off of ECMO in OR. After return from OR patient needing 100% FiO2 and 20 parts per million of nitric with high ventilatory settings to keep appropriate oxygen saturations.

July 15, 2019: The child had profound hypoxemia with saturations around 30%, after bagging ventilation and suctioning with 100% oxygen and inhaled nitric oxide at 20 parts per million, the baby is oxygen saturations did not improved. After increasing the the nitric oxide to 80 parts per million, epinephrine 0.1 micrograms/kilos per minute and a fluid bolus, the oxygen saturations started to improve. Echocardiogram showed an open shunt with concerns for increased pulmonary vascular resistance.

7/16/19: Right pneumothorax present on morning CXR which was evacuated. Improving saturations/NIRS through day, requiring volume and vasoactive medications to drive shunt flow. Still requiring FiO2 upwards of 0.6.

7/18/2019: Patient has had some improvement. Continues with significant hypoxemia. Currently on full mechanical ventilatory support. The patient has not tolerated sildenafil for pulmonary hypertension. We will likely start bosentan

7/21/2019: The patient remains on full mechanical ventilatory support continuing ongoing titration. Her saturations appear to be more stable in the setting of Bosentan therapy. She continues to require aggressive pulmonary toilet measures.

7/22/2019: Trial of IPV therapy to see whether this improves saturations.

7/27/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension measures. She will likely need tracheostomy for long-term ventilation as a no other means of therapy and support for her chronic lung disease and pulmonary hypertension

8/2/2019: Patient has had clinical improvement over the last 1-2 days. Continues to require high driving pressure to overcome pulmonary hypertension with epinephrine. Continues on Bosentan. Continues on nitric oxide and full mechanical ventilatory support. The patient has been started on a five day course of

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Solu-Medrol. This has transiently improved her in the past. She will likely continue to require chronic mechanical ventilation and tracheostomy.

8/4/19: Off epinephrine. Maintaining adequate saturations on < 0.5 FiO₂.

8/8/19: More wet in past 24 hours. Increased distress and less ability to be awake and tolerate ventilatory support. No room for weaning of support.

8/10/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension of measures.

8/13/2019: Continues to struggle from labile oxygen saturations despite paralysis and aggressive respiratory support. Will start a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentin.

8/17/2019: Patient is on full mechanical ventilatory support following surgery. This will be titrated appropriately. She remains on inhaled nitric oxide.

8/18/2019: Child decompensated with extremely poor pulmonary compliance and persistent oxygen saturations in the high 50s to low 60s despite paralysis, aggressive analgesia and sedation, suctioning and other interventions on conventional mechanical ventilatory support. Ultimately transition to the oscillator with slow pulmonary recruitment and stability overnight.

8/20/2019: Patient with severe chronic lung disease superimposed with likely acute lung injury in the setting of a recent cardiac surgery. There is been no infectious etiology for her decompensation. After some time on high-frequency mechanical ventilation she has been transition to conventional ventilation. She is on systemic steroids for a five day course the and aggressive beta agonist therapy. Overall her prognosis from a chronic lung disease standpoint remains quite guarded

8/25/2019: Patient continues to struggle with underlying chronic lung disease, acute lung injury, single ventricle physiology, profound hypoxemia, airway reactivity. She remains on pressure control ventilation that was started on 08/23 due to high peak inspiratory pressures. Her gas exchange is been reasonable. She remains on a relatively high inspired oxygen not being able to be wean lower than 0.5. She remains on nitric oxide, Bosentan, in sildenafil at escalating doses. She remains on systemic steroids have been weaned to q.12 as well as albuterol at 5 mg an hour.\

8/29/2019: Off of continuous albuterol, steroids weaned to once daily. She continues to have rhonchi, wheezes and poor pulmonary compliance and does not appear to have had a significant response to steroids nor albuterol. She has been reasonably tolerant of cares lately on decreased vecuronium however.

8/31/2019: The patient continues on full mechanical ventilatory support. Unfortunately with discontinuation of her vecuronium she had profound desaturation hypoxemia and neuromuscular blockade is been restarted. She remains on inhaled nitric oxide in deep sedation. She continues to required aggressive pulmonary toilet measures

9/6/2019: The patient remains on full mechanical ventilatory support. She remains on deep sedation. Neuromuscular blockade is being reduced. She continues aggressive pulmonary toilet.

9/9/19: Off neuromuscular blockade infusion. Tolerating much better than in the past.

9/11/2019: The patient remains on full mechanical ventilatory support. Continues to have evidence of poor pulmonary compliance. Continues to have a persistent oxygen requirement with an FiO₂ of 0.5-0.6.

9/17/2019: The patient remains on full mechanical ventilatory support. The patient has been on 65-70% oxygen for most of the last 24 hr. Pulmonary compliance continues to be an issue. Prognosis remains quite

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poor to guarded

9/21/2019: Patient remains on full mechanical ventilatory support and 100% FiO₂. Her fluid overload has been compromising her oxygenation and ventilation. Prognosis remains poor.

10/2/2019: The patient remains on full mechanical ventilatory support. There have been some difficulties in ventilation. IMV is been increased. FiO₂ is been weaned to 0.75. Gas exchange is somewhat suboptimal

10/5/2019: Patient remains on full mechanical ventilatory support. We have been able to wean the FiO₂ somewhat, IMV is been increased due to mild respiratory acidosis

10/10/2019: Patient with complete atelectasis of the left lung requiring aggressive recruitment maneuvers with IPV and bag suctioning.

10/14/2019: The patient has had some improvement over the last several days with aggressive pulmonary toilet measures. She remains on quite stout mechanical ventilatory support. We have been able to wean her FiO₂ which is mostly between 40 and 50%. She continues to require deep sedation and neuromuscular blockade. Her prognosis remains quite poor.

10/19/2019: Patient has required increasing FiO₂ over the last 48-72 hours. She continues to require relatively deep sedation with intermittent neuromuscular blockade. Prognosis remains poor

10/20/2019: Restarted on low-dose vecuronium due to persistent agitation and need for excessive p.r.n. Medications, child was also given a trial of ketamine without significant improvement.

10/25/2019: The patient remains on full mechanical ventilatory support requiring between 40 and 70% oxygen deep sedation, neuromuscular blockade, and aggressive pulmonary toilet interventions to maintain reasonable gas exchange

11/7/2019: Vecuronium infusion stopped today given discussion of withdrawal by family. Vecuronium will be given on prn basis for issues with ventilating or excessive movement.

11/10/2019: Continues to require full ventilatory support. Intermittent increase in PIP's with agitation/airway secretions. Requiring increased oxygen off vecuronium. Vecuronium will be used on PRN basis for excessive movement threatening safety of ETT and ventilatory dyssynchrony with desaturation.

11/17/19: Interval worsening of secretions with tracheal aspirate growing abundant Staph aureus as well as stenotrophomonas maltophilia. Febrile at time culture was drawn. Antibiotics ongoing. Plan 7-10 day course. Vest therapy used in place of IPV given issues with hypotension.

11/19/2019: Patient has had worsening pulmonary compliance with increasing edema as diuretics were held in the setting of hypotension. Peak inspiratory pressures are now in the low to mid 40s. My hope is this will improve with reinstitution of diuretics now that hemodynamics are more stable.

11/25/2019: The patient remains on full mechanical ventilatory support. There has been some improvement in pulmonary compliance with aggressive diuresis however peak pressures remained in the mid 30s.

12/1/2019: Patient remains on full mechanical ventilatory support. She continues on aggressive pulmonary toilet measures.

12/4/2019: CT scan of the chest demonstrates in chronic lung disease changes with ground-glass appearance opacities, bronchiectasis, and multiple areas of atelectasis.

SVT (supraventricular tachycardia) (CMS/HCC)

Assessment & Plan

Began preoperatively, initially treated with esmolol, and later transitioned to amiodarone after developing atrial flutter. Heart irritable at time of surgery, better after atrial reduction. Ongoing support with amiodarone 5 mg/kg/day at time of admission to CICU. Ongoing surveillance planned.

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2/21/19: Increased frequency of runs of SVT yesterday morning in the setting of epinephrine at 0.05 mcg/kg/min. Epinephrine decreased (0.03) and amiodarone increased to 10 mg/kg/day with better control.

2/24/2019: Amiodarone reduced to 5 milligrams/kilogram per day yesterday.

3/4/19: Ongoing issues with premature beats/atrial bigeminy, requiring pacing to try to suppress ectopic beats. On esmolol for same. Titrating to minimum dose.

March 7, 2019: The baby was started on oral flecainide with conversion to sinus rhythm.

3/10/2019: The patient remains on flecainide. Patient will be changed to oral amiodarone today.

3/11/2019: The patient remains on flecainide and amiodarone. There was a breakthrough event of SVT yesterday requiring rapid atrial pacing.

3/12/2019: In addition to atrial flutter yesterday the patient also had breakthrough SVT. Flecainide has been increased. It IV amiodarone infusion is been restarted. Patient is in a sinus rhythm this morning. It is slow so we are using temporary pacemaker support augment cardiac output

3/13/2019: Patient has been in a sinus rhythm for the last 24 hr. Temporary pacing is been discontinued.

3/14/2019: Esmolol d/c

03/16/2019: Remains on amiodarone 5 milligram/kilogram per day and flecainide 4 mg enteral every 8 hr.

3/19/2019: Flecainide increased to 5 mg every 8 hr.

3/23/2019: Patient remains on amiodarone of 5 milligrams/kilogram per day. The patient is also on flecainide. We are awaiting a flecainide level. Once that level has returned we will continue to maximize flecainide therapy prior to reducing amiodarone.

3/29/2019: Ongoing titration of antiarrhythmics per EP service. Flecainide increased in response to low level, amiodarone has been decreased to 2.5 mg/kg/day IV. Plan to eventually transition to oral amiodarone, 5 mg/kg/day. Rhythm has been well controlled.

4/1/2019: Amiodarone transitioned to enteral route today (5 mg/kg/day). Flecainide unchanged, level still low, rhythm remains well controlled.

4/5/2019: Patient remains on amiodarone. Flecainide dose increased yesterday

6/19/19: No breakthrough, continues on amiodarone and flecainide, with dose adjusted for weight.

7/6/2019: No SVT noted. Patient remains on amiodarone and flecainide.

7/9/2019: Flecainide discontinued as patient transition on to VA ECMO support.

7/10/2019: Patient has been transitioned to amiodarone infusion

7/27/2019: We will transition to oral amiodarone at 5 milligrams/kilogram per day

8/3/2019: Patient with multiple PACs and dysrhythmia yesterday. Flecainide has been restarted

9/4/19: Flecainide level slightly subtherapeutic 8/27. No breakthrough tachydysrhythmia on amiodarone and flecainide.

9/20/2018: Patient remains on flecainide and amiodarone. No breakthrough dysrhythmias.

11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic

12/1/2019: Patient continues on flecainide and amiodarone. We continue with ongoing thyroid function surveillance in the setting of amiodarone therapy

Atrial flutter (CMS/HCC)*Assessment & Plan*

Occurred preoperatively, required synchronized cardioversion, followed by amiodarone. In sinus rhythm since 2/4/19. Continued on amiodarone 5 mg/kg/day at time of surgery 2/13/19.

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2/24/2019: The patient remains on amiodarone
2/26/2019: Patient had recurrence of atrial flutter this morning. Was rapid atrial paced out of it. Continues on amiodarone.
3/10/2019: Patient transitioned to oral amiodarone
3/12/2019: Patient with worsening atrial flutter in the last 24 hr. Ultimately requiring cardioversion and rapid atrial pacing several times. IV amiodarone is been reinstituted. Flecainide was found to be subtherapeutic. Dosing has been increased.
3/13/2019: Came off pacemaker support with underlying sinus rhythm
3/14/2019: Esmolol was d/c
3/30/2019: Patient remains on flecainide and continuous amiodarone at this time.
4/4/2019: Good control, on enteral amiodarone and flecainide.
4/9/2019: Flecainide level remains subtherapeutic but patient without ectopy. Will remain on current dose.
5/9/19: Flecainide level back from 4/29/19 and is now therapeutic at 0.4. Dose continues as previously. No breakthrough dysrhythmias noted.
6/19/19: Flecainide has been adjusted for weight gain; therapeutic level 6/11/19. Amiodarone ongoing. No breakthrough dysrhythmias noted.
7/6/2019: No breakthrough of abnormal rhythms. Patient remains on amiodarone flecainide. Flecainide levels being drawn intermittently.
7/9/2019: Flecainide discontinued. Patient has been transition to IV amiodarone while on VA ECMO support.
7/14/2019: Patient has returned from the OR. We will continue IV amiodarone at this time. Patient off of VA ECMO support.
7/27/2019: We will transition to oral amiodarone
8/4/2019: Developed short runs of SVT. Flecainine restarted 8/2/19.
8/9/2019: Flecainide level suboptimal. Flecainide dose increased.
9/4/19: Most recent level of flecainide checked on 08/27 and was slightly low at 0.18. She has not had breakthrough tachydysrhythmias despite this slightly subtherapeutic level.
9/20/2019: Patient remains on flecainide and amiodarone therapy. No breakthrough dysrhythmias.
11/9/2019: Patient remains on amiodarone and flecainide without breakthrough dysrhythmias.
11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic
12/1/2019: Patient continues on flecainide and amiodarone. We continue with ongoing thyroid function surveillance in the setting of amiodarone therapy

End of life care*Assessment & Plan*

Over the last weeks all of the services (Cardiac Intensive Care, Cardiology and CV surgery) involved in the care of Tinslee have come to the same conclusion that her ongoing care has reached the level of medical futility. And furthermore that we have no additional interventions or treatments to offer her and that she has failed aggressive escalation of her pulmonary shunt to a central shunt due to her underlying chronic lung disease and pulmonary hypertension. Overall this has left her fluid overloaded with marginal pulmonary status, with marked agitation requiring aggressive sedation analgesia and paralysis which we have been unable to wean. In addition, she has been febrile and toxic on her diuretics although we have

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restarted them on a compassionate basis., she remains on an epinephrine infusion just to facilitate a more neutral fluid balance although she continues to get progressively fluid overloaded. We are also unable to feed her despite multiple attempts to do so.

While the extended family has expressed their concerns that the child is suffering. The child's parents do not recognize this nor do they want to deal with this situation despite all of the physicians expressing their concerns regarding the child's ongoing suffering. Due to this impasse, we have engaged the ethics committee. An Ethics committee meeting was scheduled for yesterday morning with the family invited, and having previously confirmed that they would attend, failed to show up for the meeting. The meeting was held without them unfortunately, the medical case was presented to the Ethics committee members. The committee members suggested possible deescalation of our aggressive support measures including diuretics, epinephrine, paralysis and sedation as well as additional medications. However, while the child has been made a DNR, the family has expressed no interest in deescalating any of her care putting us in a very precarious situation. While we have tried to wean things in the past we have needed to reinstitute these therapies, including a recent trial off of paralysis this weekend. This leaves the poor child suffering and in limbo without a clear pathway forward.

10/26/2019: A lengthy discussion was held with the patient's mother last night. A letter had been delivered by the nursing supervisor in regards to the upcoming ethics committee and potential binding decisions regarding the patient's care. The mother express significant anger and a lengthy discussion was held regarding the purpose of the meeting, as well as a review of Tinslee's hospital course, current medical problems, and prognosis. The mother reiterated that she does not feel that there is any undue suffering from her daughter. She stated that she still feels like that her daughter will "get better." I encouraged her to take the upcoming meeting seriously and to be present to express her concerns, desires for care, and to explain her thought process in decision making for her daughter.

11/4/19: Ethics committee met 10/30/19 and rendered binding decision to withdraw. Family informed with written letter given to them 10/31/19. In 10 day grace period contacting other centers as per family wishes.

11/10/19: Multiple institutions called during 10 day period. The following institutions denied transfer after review of her records: Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia, Johns Hopkins, Methodist Hospital San Antonio, Boston Children's Hospital, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott Children's in Michigan, LeBonheur Children's in Memphis, University Hospital in San Antonio, and Rady Children's Hospital in San Diego. Family attorney secured temporary restraining order mandating ongoing care today. Administration and legal involved. Medical team continues to provide ongoing aggressive treatment for Tinslee accordingly. DNR rescinded today by mother. She has a full code order now in place.

11/19/2019: Patient's prognosis remains quite poor. We continue to provide aggressive CICU support. We are communicating with other institutions regarding their opinion and potential transfer. The mother has been kept up-to-date when she is at the bedside.

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12/7/2019: Multiple institutions have been contacted regarding transfer care. All have declined stating that they did not feel anything to offer to alleviate this patient is suffering. This most recently the Children's Hospital of Omaha was contacted who has declined the patient in transfer. Boston Children's Hospital has reconsidered after their initial denial. They had requested a CT of the chest and cardiac catheterization. CT of the chest has been performed and been reviewed by the team in Boston. Mother has declined cardiac catheterization. She has been made aware that the patient would not be considered for transfer to Boston if cardiac catheterization was not performed. She vocalized understanding of these instructions.

12/10/19: Mother requested cath be done and this was completed yesterday. Data will be sent to Boston as requested.

Fever*Assessment & Plan*

Previously we have proven that she developed a toxic reaction to loop diuretics with high fever and has been off of these for several days.

9/26/2019: Developed fever again, cultures sent and started on cefepime. Infectious Disease indices do not did appear impressive, it is possible that she is having an adverse reaction to her metolazone or her Diuril.

10/1/19: Cultures positive for *Stenotrophomonas* from lung as well as *Klebsiella* in urine. Antibiotics changed to bactrim 9/28/19 as both are sensitive.

11/6/19: No significant fever since 10/24/19. Off antibiotics since 10/31/19. Ongoing surveillance.

11/8/19: Febrile overnight. Cultures sent.

11/14/19: Febrile overnight. Cultures sent.

11/27/19: Completed course of antibiotics for *Stenotrophomonas* and *S. Aureus* LRI in past 24 hours. Again febrile overnight without other finding other than thick tracheal secretions. Ongoing close surveillance culturing as indicated.

11/30/19: Grew abundant *Staph aureus* 11/27. Ongoing treatment with oxacillin with improved secretions. Febrile 11/28. Hypernatremic at time. Correcting with manipulation of diuretics/free water in TPN. Ongoing surveillance.

12/9/19: Afebrile currently; S/p course of oxacillin for *S. Aureus*. Sodium has stabilized.

Fluid overload*Assessment & Plan*

9/22/2019: This child was proven to be toxic on loop diuretics with high fever and increasing diuretic resistant. A multi disciplinary discussion determined that she is not a candidate for renal replacement therapy and that this would likely just increase her suffering. We have however started Zaroxolyn twice daily with minimal effect. Will add scheduled Diuril twice daily to this regimen but it is unlikely to be very effective. During a care conference earlier in the week the family was informed regarding this unfortunate development and that the recommendation of the care team is that further escalation of care should not happen.

09/23/2019: Child on Diuril IV every 12 hr and given tolvaptan with good response.

10/1/19: Despite aggressive non loop diuretics, Tinslee remains markedly swollen. Mother has not been able to limit care. Loop diuretics reintroduced. If fever recurs, will stop.

10/6/19: Has responded to bumex infusion favorably with ongoing diuril. Other diuretics serially held/stopped. Edema is improved, but persistent. Renal indices have increased slightly, and dose limited

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accordingly to 0.005 mg/kg/hr. She has one one temp elevation to 38.5 transiently during the week. There have not been persistent fevers as previously. Ongoing surveillance planned.

10/16/2019: We have had to back off on her diuretics significantly. We will follow BUN and creatinine closely.

10/28/2019: With reduction of diuretic burden BUN and creatinine have improved. Bumex will again be increased to 0.01 milligrams/kilogram per hour today.

11/12/2019: Over the last two weeks there has been significant titration of her diuretics. They are titrated in accordance with fluid balance while weighing underlying renal insufficiency. Currently on Bumex 0.01 milligrams/kilogram per hour and Diuril twice daily.

11/17/19: Diuril decreased to once daily given issues with lower blood pressure.

11/19/2019: Patient with worsening edema with a positive 1.5 L fluid balance over the last 72 hr. Bumex will be escalated to 0.01 milligrams/kilogram per hour today and we will give her a single dose of Diuril. We will need to assess her hemodynamics closely with this diuresis.

11/27/19: Continued need for aggressive diuretics. Fluid status currently improved, but BUN/Cr have increased somewhat. Ongoing requirement to titrate diuretics accordingly.

12/1/2019: Patient continues to show evidence of volume overload. We have had to reduce diuretics in the setting of worsening renal insufficiency.

12/6/2019: Significant renal insufficiency persists with BUN in the mid 30s and creatinine 0.5-0.6. She continues on twice daily Lasix and Diuril.

Difficult intravenous access

Assessment & Plan

Requiring interventional radiology to place a PICC line on July 29, 2019

Billing Time: I have personally seen and examined this patient and spent 60 minutes of critical care time on this patients behalf.

Coding Queries

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Lori Lee Nessler, MD		Procedure Note	02/01/2019 2110	Response Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nessler, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Lori Lee Nessler, MD : 02/04/2019 - 10:19 AM



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Coding Queries (continued)

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background d	Lori Lee Nesslein, MD		Procedure Note	02/01/20 19 2111	Response Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background d	Rekha Balla Hamilton, MD		Procedure Note	02/09/20 19 1745	Response Received			

Query Message

--- Doc Query Message ---

From: Rekha Balla Hamilton, MD
Sent: 2/9/2019 9:46 PM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Rekha Balla Hamilton, MD : 02/09/2019 - 09:46 PM

END OF REPORT

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM

Author: Jay M Duncan, MD
Filed: 12/8/2019 8:38 AM
Status: Signed

Service: Critical Care
Date of Service: 12/8/2019 8:34 AM
Editor: Jay M Duncan, MD (Physician)

Author Type: Physician
Creation Time: 12/8/2019 8:34 AM

CICU PROGRESS NOTE

Tinslee Breau Lewis is a 10 m.o. female admitted for Ebstein's anomaly of tricuspid valve. The patient was initially admitted the cardiac intensive care unit in the early neonatal. Following initial palliative surgery. She has continued to struggle in the ICU with issues related to her underlying single ventricle physiology, chronic lung disease and pulmonary hypertension. We continue to provide what the team perceives as futile care in this patient with an extremely poor prognosis.

Chief Complaint: The patient remains critically ill in the CICU.

Operation Date: 2/13/2019, Operation-starts procedure with 3 mm BT shunt and reduction right atrialplasty, surgeon-Tam, Vincent K.H, MD

5/17/2019: Diagnostic cardiac catheterization. Patient also underwent balloon angioplasty of the right pulmonary

7/9/2019: Neck cannulation for VA ECMO

7/19/2019: Delayed sternal closure

8/16/2019: The 5 mm BT shunt was removed from its proximal takeoff of the innominate artery and placed in a central position off the aorta. The innominate artery was repaired. This was done utilizing cardiopulmonary bypass

Hospital Day: 310

Allergies: Patient has no known allergies.

SUBJECTIVE:

Interval History: Patient remains critically ill in the cardiac intensive care unit. There been no significant untoward events in the last 24 hr. She remains on full mechanical ventilatory support as well as her I inotropic support to maintain adequate blood pressure and diuresis. She remains NPO on TPN lipids. There has been improvement of her abdominal exam over the last 24-48 hours with discontinuation of feeds. She continues on aggressive diuretics with underlying renal insufficiency. She has had no bleeding issues with her thrombocytopenia. After lengthy discussion with the mother overnight she now once a cardiac catheterization so the Boston Children's Hospital can complete their evaluation. This will be done tomorrow. I expressed to her how she needs to either spend the night here tonight or be here by 07:00 tomorrow morning so that appropriate consents can be signed and the procedure will not be delayed. She stated she would be here overnight.

Current Support:



Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

Cardiovascular:

Antiarrhythmic Support Amiodarone, flecainide

Pacemaker: No

Other Cardiac Medications: Bosentan, diuretics, sildenafil, epinephrine, norepinephrine

Anticoagulation: Aspirin

Ins and Outs:

Admission Weight: 1.81 kg

Weight change:

I/O Last 2 Shifts

12/07 0700 - 12/08 0659

In: 1025.1 [I.V.:157.3]

Out: 862 [Urine:862]

Net: 163.1

I/O Last Shift

12/07 1900 - 12/08 0659

In: 521.1 [I.V.:76.6]

Out: 497 [Urine:497]

Net: 24.1

OBJECTIVE:**Physical Assessment:****Visit Vitals**

BP	(!) 93/39 (BP Location: Right leg)
Pulse	(!) 108
Temp	36.8 °C (98.2 °F) (Rectal)
Resp	35
Ht	67.5 cm
Wt	10.9 kg
HC	44 cm (17.32")
SpO2	(!) 82%
BMI	23.48 kg/m ²
BSA	0.45 m ²

NIRS - Left Cerebral: 54
NIRS - Right Cerebral: 37
NIRS - Renal: 52
FiO2: 30 %
Vent Rate: 35
PEEP: 8 cm H2O
Pressure Support: 12 cm H2O
Vt (mL): 60 mL
Insp Time: 0.6 sec

GENERAL: Edematous female infant who is sedated, intubated, mechanically ventilated. She is under the influence of neuromuscular blockade

HEENT: Facial and periorbital edema remain present. She remains nasally intubated. Enteric tubes are in place. Pupils equally round reactive to light. Gaze conjugate

NECK: Neck is supple, trachea is midline.

CHEST: Well there is reasonable aeration of both lung fields are coarse rhonchi heard throughout.

HEART: Normal sinus rhythm with audible shunt murmur. Pulses are 2+ in all four extremities. Capillary refill is less than 2 sec

ABDOMEN: Abdomen remains quite full and round. I would say that her abdominal exam is somewhat better over the last 48 hr. Bowel sounds remain hypoactive. Liver and spleen remains enlarged

EXTREMITIES: Warm and well perfused. Pulses are 2+.

NEURO: Patient remains sedated and under the influence of some neuromuscular blockade. She does appear to arouse to my examination. Pupils are reactive to light. Gaze is conjugate. There is trace movement of all four extremities

SKIN: Surgical wounds are well healed. Her support tube and lines sites look good.

Gu: Normal female with some dependent edema

Labs Reviewed: Yes

Labs:

Recent Results (from the past 12 hour(s))

Basic Metabolic Panel

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

Collection Time: 12/08/19 4:05 AM

Result	Value	Ref Range
Sodium Level	140	136 - 142 mmol/L
Potassium Level	4.4	3.7 - 5.6 mmol/L
Chloride Level	102	98 - 110 mmol/L
Carbon Dioxide Level	26 (H)	14 - 24 mmol/L
Anion Gap	12	10 - 16 mmol/L
Blood Urea Nitrogen	31 (H)	3 - 17 mg/dL
Creatinine	0.55 (H)	0.32 - 0.53 mg/dL
Glucose Level	97	60 - 108 mg/dL
Calcium Level	10.4	9.0 - 11.0 mg/dL
Calculated Osmolality	286	265 - 300 mOsm/kg

CBC with Differential

Collection Time: 12/08/19 4:05 AM

Result	Value	Ref Range
White Blood Cell Count	9.90	6.00 - 17.00 x10e3/uL
Red Blood Cell Count	3.84	3.70 - 4.90 x10e6/uL
Hemoglobin	11.3	10.5 - 12.8 g/dL
Hematocrit	36.0	33.0 - 38.0 %
Mean Corpuscular Volume	93.8 (H)	70.0 - 84.0 fL
Mean Corpuscular Hemoglobin	29.4	23.0 - 30.0 pg
Mean Corpuscular Hemoglobin Content	31.4	31.0 - 37.0 g/dL
Red Cell Distribution Width	14.3	12.0 - 16.0 %
Platelet Count	71 (L)	150 - 450 x10e3/uL
Mean Platelet Volume	14.2 (H)	6.2 - 12.8 fL

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

% Immature Granulocytes	0.8	%
% Neutrophils	52.1	%
% Lymphocytes	30.4	%
% Monocytes	14.2	%
% Eosinophils	2.1	%
% Basophils	0.4	%
Absolute Immature Granulocytes	80	/uL
Absolute Total Neutrophils	5,150	1,000-6,000 /uL
Absolute Lymphocytes	3,010	3,000-7,000 /uL
Absolute Monocytes	1,410 (H)	250-1,200 /uL
Absolute Eosinophils	210	30 - 800 /uL
Absolute Basophils	40	0 - 200 /uL

Albumin (Q: 223, L: 1081)

Collection Time: 12/08/19 4:05 AM

Result	Value	Ref Range
Albumin	3.3	2.5 - 4.6 g/dL

Blood Gas, Arterial

Collection Time: 12/08/19 4:05 AM

Result	Value	Ref Range
Patient Temperature	37.0	DEG C
Arterial Blood pH	7.37	7.35 - 7.45
Arterial Blood PCO2	53 (H)	35 - 48 mmHg
Arterial Blood PO2	43 (LL)	83 - 108 mmHg
Arterial Blood HCO3	30.6 (H)	16.0 - 24.0 mmol/L
Arterial Blood Total CO2	32.2 (H)	10.0 - 24.0 mmol/L
Arterial Blood Base Excess	4.3 (H)	-2.0 - 2.0 mmol/L
Arterial Bld O2 Saturation (Calc)	77.0 (L)	95 - 100 %
Blood Gas Inspired Oxygen	30.0	%
Blood Gas Vent Rate	35	bpm
Bld Gas Peak Inspiratory Pressure	35	cm H20

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

Blood Gas PEEP	8	cm H2O
Blood Gas Tidal Volume	60.0	mL
Blood Gas Pressure Support	12	cm H2O
Oxygen Saturation (Pulse Oximetry)	85	%
Blood Gas Modality	SIMV/PCVG	
Operator:	J DELBOSQUE RT	
Notified:	K BERG RN	
Notified Time:	409	

Ionized Calcium, GEM

Collection Time: 12/08/19 4:05 AM

Result	Value	Ref Range
Ionized Calcium GEM	1.05 (L)	1.12 - 1.32 mmol/L

Lactic Acid, GEM (Lactate)

Collection Time: 12/08/19 4:05 AM

Result	Value	Ref Range
Lactic Acid GEM	0.5	0.5 - 2.2 mmol/L

Smear Review

Collection Time: 12/08/19 4:05 AM

Result	Value	Ref Range
RBC Morphology		
Tear Drop Cells	Few	
WBC Morphology		
PLT Morphology		

CHEST XRAY: No chest radiograph to report

MAR Reviewed: Yes

ASSESSMENT/PLAN

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

A/B: Patient remains on aggressive full mechanical ventilatory support with ongoing pulmonary toilet measures. Blood gas as above. Hypertonic saline is ongoing to improve with airway clearance. Chest radiograph as above. Continue current Support

CVS: The patient has reasonable hemodynamics in the setting of epinephrine and norepinephrine therapy. She continues on aggressive therapy for her pulmonary hypertension. Unfortunately with her severe chronic lung disease and pulmonary hypertension single ventricle physiology there is no further surgical palliation that would be beneficial in the setting. She is on Lasix every 12 hr and Diuril every 12 hr. Continue current management. Cardiac catheterization will be performed tomorrow.

Neuro: The patient remains on high-dose methadone, Ativan, Seroquel, gabapentin, as well as a Precedex infusion. She continues on a vecuronium infusion to mitigate pulmonary hypertensive crisis. We will continue titration of medications appropriately. Continue ongoing rehabilitation efforts.

FEN/GI: Patient has been made NPO and is on TPN lipids. Feedings were stopped due to abdominal distension and poor pulmonary compliance. Continue ongoing electrolyte surveillance and replacement.

HEME: No significant bleeding. Labs as above. We will transfuse her today to optimize oxygen delivery in the setting of single ventricle physiology.

ID: Afebrile. Currently on no antibiotics.

Endo: We will continue ongoing surveillance for thyroid disease in the setting of amiodarone therapy.

Lines:

Reason for Central Venous Line: Central Strength Medications

Reason for Foley: Not Applicable (No Foley)

Parents: Plan is been discussed in detail with the mother.

Communication: Plan discussed with multidisciplinary team.

VTE Screen performed:

No, not applicable

Hospital Problem List

	Noted
* (Principal)Ebstein's anomaly of tricuspid valve	2/8/2019
Junctional cardiac arrhythmia	2/15/2019
Acute respiratory failure with hypoxia and hypercarbia	2/15/2019
Electrolyte and fluid disorder	2/15/2019
Cholestasis in newborn	2/15/2019

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

	Noted
Nutritional deficiency	2/15/2019
Abnormal findings on neonatal screening	2/8/2019
Atrial flutter	2/2/2019
SVT (supraventricular tachycardia)	2/8/2019
Prematurity, 1,750-1,999 grams, 33-34 completed weeks	2/15/2019
Pulmonary hypertension secondary to increased PVR	2/16/2019
Acute systolic heart failure	2/20/2019

Staphylococcus aureus infection

Assessment & Plan

Patient had fever prompting cultures on 11/13/2019. There is abundant growth of Staph aureus from the endotracheal tube. There are not significant elevation of inflammatory markers. We will plan on seven days of treatment with oxacillin.

11/27/19: Completed course of oxacillin/bactrim for staphylococcus LRI. Problem resolved.

11/29/19: Again with growth of abundant Staphylococcus aureus from ETT in setting of chronic lung disease, secretions and high fever. Vancomycin started 11/28-->oxacillin 11/29. Probable 10 days course.

Personal history of ECMO

Assessment & Plan

Patient with profound hypoxemic respiratory failure with worsening pulmonary hypertension requiring ECMO rescue 7/9/2019

7/12/2019: Patient remains on VA ECMO support with excellent perfusion and low lactate levels.

7/14/2019: Patient transitioned off of VA ECMO support with decannulation in the OR.

Chronic lung disease in neonate

Assessment & Plan

Patient with history of prematurity, complex congenital heart disease, and gross anatomic emphysema seen at the time of initial cardiac surgery. Pulmonary veins are desaturated on cardiac catheterization

7/12/2019: Patient remains on Pulmicort and albuterol therapy and is followed by pulmonology.

7/27/2019: Patient continues to struggle with issues related to underlying chronic lung disease. She will likely require long-term mechanical ventilation.

8/20/2019: Patient with severe chronic lung disease. She has required systemic steroids approximately once a month over the last 3-4 months. She continues on Pulmicort with aggressive beta agonist therapy.

9/11/2019: Patient continues to exhibit evidence of severe chronic lung disease with poor pulmonary compliance with oxygen and diuretic requirements. Has a very poor overall pulmonary prognosis.

12/1/2019: This continues to be a significant problem given poor pulmonary compliance and appearance of chest radiograph.

12/6/2019: Chest CT confirms evidence of chronic lung disease by radiograph appearance. There is also the presence of bronchiectasis.

End of life care*Assessment & Plan*

Over the last weeks all of the services (Cardiac Intensive Care, Cardiology and CV surgery) involved in the care of Tinslee have come to the same conclusion that her ongoing care has reached the level of medical futility. And furthermore that we have no additional interventions or treatments to offer her and that she has failed aggressive escalation of her pulmonary shunt to a central shunt due to her underlying chronic lung disease and pulmonary hypertension. Overall this has left her fluid overloaded with marginal pulmonary status, with marked agitation requiring aggressive sedation analgesia and paralysis which we have been unable to wean. In addition, she has been febrile and toxic on her diuretics although we have restarted them on a compassionate basis., she remains on an epinephrine infusion just to facilitate a more neutral fluid balance although she continues to get progressively fluid overloaded. We are also unable to feed her despite multiple attempts to do so.

While the extended family has expressed their concerns that the child is suffering. The child's parents do not recognize this nor do they want to deal with this situation despite all of the physicians expressing their concerns regarding the child's ongoing suffering. Due to this impasse, we have engaged the ethics committee. An Ethics committee meeting was scheduled for yesterday morning with the family invited, and having previously confirmed that they would attend, failed to show up for the meeting. The meeting was held without them unfortunately, the medical case was presented to the Ethics committee members. The committee members suggested possible descalation of our aggressive support measures including diuretics, epinephrine, paralysis and sedation as well as additional medications. However, while the child has been made a DNR, the family has expressed no interest in descalating any of her care putting us in a very precarious situation. While we have tried to wean things in the past we have needed to reinstitute these therapies, including a recent trial off of paralysis this weekend. This leaves the poor child suffering and in limbo without a clear pathway forward.

10/26/2019: A lengthy discussion was held with the patient's mother last night. A letter had been delivered by the nursing supervisor in regards to the upcoming ethics committee and potential binding decisions regarding the patient's care. The mother express significant anger and a lengthy discussion was held regarding the purpose of the meeting, as well as a review of Tinslee's hospital course, current medical problems, and prognosis. The mother reiterated that she does not feel that there is any undue suffering from her daughter. She stated that she still feels like that her daughter will "get better." I encouraged her to take the upcoming meeting seriously and to be present to express her concerns, desires for care, and to explain her thought process in decision making for her daughter.

11/4/19: Ethics committee met 10/30/19 and rendered binding decision to withdraw. Family informed with written letter given to them 10/31/19. In 10 day grace period contacting other centers as per family wishes.

11/10/19: Multiple institutions called during 10 day period. The following institutions denied transfer after review of her records: Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia, Johns Hopkins, Methodist Hospital San Antonio, Boston Children's Hospital, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

Children's in Michigan, LeBonheur Children's in Memphis, University Hospital in San Antonio, and Rady Children's Hospital in San Diego. Family attorney secured temporary restraining order mandating ongoing care today. Administration and legal involved. Medical team continues to provide ongoing aggressive treatment for Tinslee accordingly. DNR rescinded today by mother. She has a full code order now in place.

11/19/2019: Patient's prognosis remains quite poor. We continue to provide aggressive CICU support. We are communicating with other institutions regarding their opinion and potential transfer. The mother has been kept up-to-date when she is at the bedside.

12/7/2019: Multiple institutions have been contacted regarding transfer care. All have declined stating that they did not feel anything to offer to alleviate this patient is suffering. This most recently the Children's Hospital of Omaha was contacted who has declined the patient in transfer. Boston Children's Hospital has reconsidered after there were initial denial. They had requested a CT of the chest and cardiac catheterization. CT of the chest has been performed and been reviewed by the team in Boston. Mother has declined cardiac catheterization. She has been made aware that the patient would not be considered for transfer to Boston if cardiac catheterization was not performed. She vocalized understanding of these instructions.

Infection due to *Stenotrophomonas maltophilia**Assessment & Plan*

Growth of abundant *Stenotrophomonas* from tracheal aspirate 9/26/19. Bactrim initiated 9/28 once culture grew. Plan 14 day course.

10/22/19: Has had fever with discontinuation of bactrim prompting new cultures and starting of bactrim. Ongoing surveillance for response. Typically has had less fever when treated.

11/4/19: Course of bactrim was complete 10/31/19

11/17/19: Again with abundant *stenotrophomonas* in tracheal aspirate associated with increased secretions. Bactrim initiated overnight.

11/27/19: Completed course of bactrim. Ongoing surveillance.

Fever*Assessment & Plan*

Previously we have proven that she developed a toxic reaction to loop diuretics with high fever and has been off of these for several days.

9/26/2019: Developed fever again, cultures sent and started on cefepime. Infectious Disease indices do not did appear impressive, it is possible that she is having an adverse reaction to her metolazone or her Diuril.

10/1/19: Cultures positive for *Stenotrophomonas* from lung as well as *Klebsiella* in urine. Antibiotics changed to bactrim 9/28/19 as both are sensitive.

11/6/19: No significant fever since 10/24/19. Off antibiotics since 10/31/19. Ongoing surveillance.

11/8/19: Febrile overnight. Cultures sent.

11/14/19: Febrile overnight. Cultures sent.

11/27/19: Completed course of antibiotics for *Stenotrophomonas* and *S. Aureus* LRI in past 24 hours. Again febrile overnight without other finding other than thick tracheal secretions. Ongoing close surveillance culturing as indicated.

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

11/30/19: Grew abundant Staph aureus 11/27. Ongoing treatment with oxacillin with improved secretions. Febrile 11/28. Hypernatremic at time. Correcting with manipulation of diuretics/free water in TPN. Ongoing surveillance.

Fluid overload*Assessment & Plan*

9/22/2019: This child was proven to be toxic on loop diuretics with high fever and increasing diuretic resistant. A multi disciplinary discussion determined that she is not a candidate for renal replacement therapy and that this would likely just increase her suffering. We have however started Zaroxolyn twice daily with minimal effect. Will add scheduled Diuril twice daily to this regimen but it is unlikely to be very effective. During a care conference earlier in the week the family was informed regarding this unfortunate development and that the recommendation of the care team is that further escalation of care should not happen.

09/23/2019: Child on Diuril IV every 12 hr and given tolvaptan with good response.

10/1/19: Despite aggressive non loop diuretics, Tinslee remains markedly swollen. Mother has not been able to limit care. Loop diuretics reintroduced. If fever recurs, will stop.

10/6/19: Has responded to bumex infusion favorably with ongoing diuril. Other diuretics serially held/stopped. Edema is improved, but persistent. Renal indices have increased slightly, and dose limited accordingly to 0.005 mg/kg/hr. She has one temp elevation to 38.5 transiently during the week. There have not been persistent fevers as previously. Ongoing surveillance planned.

10/16/2019: We have had to back off on her diuretics significantly. We will follow BUN and creatinine closely.

10/28/2019: With reduction of diuretic burden BUN and creatinine have improved. Bumex will again be increased to 0.01 milligrams/kilogram per hour today.

11/12/2019: Over the last two weeks there has been significant titration of her diuretics. They are titrated in accordance with fluid balance while weighing underlying renal insufficiency. Currently on Bumex 0.01 milligrams/kilogram per hour and Diuril twice daily.

11/17/19: Diuril decreased to once daily given issues with lower blood pressure.

11/19/2019: Patient with worsening edema with a positive 1.5 L fluid balance over the last 72 hr. Bumex will be escalated to 0.01 milligrams/kilogram per hour today and we will give her a single dose of Diuril. We will need to assess her hemodynamics closely with this diuresis.

11/27/19: Continued need for aggressive diuretics. Fluid status currently improved, but BUN/Cr have increased somewhat. Ongoing requirement to titrate diuretics accordingly.

12/1/2019: Patient continues to show evidence of volume overload. We have had to reduce diuretics in the setting of worsening renal insufficiency.

12/6/2019: Significant renal insufficiency persists with BUN in the mid 30s and creatinine 0.5-0.6. She continues on twice daily Lasix and Diuril.

Difficult intravenous access*Assessment & Plan*

Requiring interventional radiology to place a PICC line on July 29, 2019

Pulmonary hypertension (CMS/HCC)

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

Assessment & Plan

Pulmonary hypertension associated with chronic lung disease. On June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO2 was weaned as well as the flow on the nasal cannula. The patient was started on sildenafil. On June 10, 2019 the nitric oxide has been weaned off. BNP was elevated over 500.

6/19/19: Improved bnp (308), continues on sildenafil 1.1 mg q 8 hours.

6/24/19: Sildenafil increased yesterday to 2.3 mg q 8 hours for higher oxygen needs

6/25/19: Worsening aeration, tight breath sounds. Sildenafil decreased back to previous dose.

7/1/19: Weaning sildenafil to off, tolerating thus far.

7/2/2018: Sildenafil is off.

7/9/2019: Patient with worsening hypoxemia and work of breathing and desaturation over the last several days. High-flow a been escalated. Patient placed back on nitric oxide 7/8/2019: Patient with severe hypoxemic decompensation with likely worsening pulmonary hypertension this morning. Patient transitioned on to VA ECMO support.

7/12/2019: Patient remains on VA ECMO support and inhaled nitric oxide.

7/14/2018: Patient decannulated from VA ECMO support in the OR. Patient underwent replacement of her BT shunt with a 5.0 mm BT shunt. Patient was unable to wean off nitric oxide in OR and remains on inhaled nitric oxide at 20 parts per million and 100% FiO2 from the ventilator.

7/18/2019: Patient has had intolerance of sildenafil. Bosentan and will be started today. The patient remains on nitric oxide

7/21/2019: The patient remains on inhaled nitric oxide. There has been improvement in saturations with Bosentan.

7/27/2019: The patient remains on nitric oxide and bosentan

8/2/2019: The patient remains on nitric oxide, Bosentan, mechanical ventilation with high inspired oxygen. She continues to require at high driving pressure to maintain adequate pulmonary blood flow

8/8/19: Nitric oxide increased back from 5 to 10 ppm in past 24 hours for worsening oxygenation especially with agitation.

8/11/2019: Inhaled nitric oxide increased back to 20 parts per million.

8/13/2019: Marginally better but still labile on paralysis, are giving a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentin. Child has very small pulmonary arteries attached to her 5 mm shunt likely representing significant anatomic resistance to pulmonary blood flow, cardiac catheterization evaluation today.

8/15/2019: Cardiac catheterization on the 14th revealed a stenosis with a likely 60-80 mm gradient in the innominate artery between the ascending aorta and the takeoff of the BT shunt, this could explain the need for hypertensive blood pressures to maintain adequate oxygen saturations and amenable to surgical correction. Dr. Tam is performing a central shunt today.

8/16/2019: Central shunt delayed until today.

8/18/2019: Bosentan discontinued

8/20/2018: Patient remains on inhaled nitric oxide and Bosentan. It should be noted that cardiac catheterization data demonstrating approximately 1/3 to 1/2 systemic pulmonary artery pressures performed in the setting of deep sedation and paralysis, inhaled nitric oxide, and Bosentan. If the patient

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

demonstrates evidence of pulmonary overcirculation we will begin weaning nitric oxide.

8/22/2019: Patient remains on full mechanical ventilatory support, inspired oxygen, nitric oxide, and Bosentan. We will attempt to start sildenafil today.

8/25/2019: The patient remains on full mechanical ventilatory support, nitric oxide at 20 parts per million, bosentan, and now sildenafil has been escalated to 1 milligram/kilogram every 6 hr.

9/2/19: Patient weaned off nitric oxide this morning. Continues on bosentan and sildenafil.

10/4/19: Sildenafil reduced to 2 mg/kg/day given vasodilation, evidence of pulmonary overcirculation, and hypotension.

11/9/2019: Patient remains on sildenafil and bosentan therapy with reasonable saturations off of vecuronium.

11/16/19: Has required reinstitution of vecuronium for ventilatory dyssynchrony/agitation.

11/17/19: Sildenafil dose has been decreased by 25% given issues with hypotension with adequate PaO₂ on blood gas on 45% oxygen.

11/19/2019: Patient remains on both Bosentan sildenafil. PaO₂ is a are in the high 30s.

12/1/2019: The patient continues on aggressive treatment of pulmonary hypertension with Bosentan, sildenafil, mechanical ventilation, and inspired oxygen.

Acute systolic heart failure (CMS/HCC)

Assessment & Plan

Infant initially with cardiogenic shock in the immediate postoperative period. While shock has resolved, infant continues to have heart failure, requiring epinephrine support. Has variably been on milrinone, currently off.

2/24/2019: Patient continues on aggressive heart failure management. The patient is currently on epinephrine infusion as well as diuretics.

2/26/2019: Patient remains on diuretics. We have discontinued epinephrine in an effort to see if this would help with the dysrhythmia. We will also be more liberal on fluid administration.

2/27/2019: Blood pressure and NIRS lower off epinephrine. Restarted at 0.02 mcg/kg/min with milrinone at 0.3 mcg/kg/min. Gradual improvement noted in perfusion and blood pressure. Ongoing need for titration of vasoactive medications.

3/4/2019: Off epinephrine. Improved perfusion on milrinone. Still with rhythm issues, intermittent atrial bigeminy with some compromise of cardiac output; NIRS remain marginal.

3/10/2019: Patient remains on Milrinone and diuretics. Patient's hemodynamics have been more stable when in a sinus rhythm.

3/28/2019: Milrinone weaned off. Patient remains on Lasix only.

4/19/2019: Patient transitioned to IV Lasix earlier in the week. We will transition back to p.o. Lasix twice daily.

4/22/19: Continues to struggle with fluid balance. Significantly positive balance on twice daily Lasix, increased to q.8 hours today.

4/28/2019: Continues to do better on increased diuretics (q 8 hours)

5/1/19: Continues on increased diuretics, now q 6 hours.

5/7/19: Continues on diuretics, now q.8 hours Lasix.

5/15/2019: Patient has been transitioned to twice daily Lasix.

5/21/19: Now on increased diuretics s/p cath with respiratory failure. Perfusion remains good without other

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cardiac medications.

6/19/19: Continued need for meticulous attention to fluid status and diuretic therapy. Siladenafil has been added to regimen. BNP down to 308 6/19/19 from 560.1 several days ago.

6/25/19: BNP 351 yesterday. Diuretics increased past 24 hours for tighter breath sounds. Given lack of improvement, team again considering cath

7/1/19: Reasonable week. Support unchanged other than weaning sildenafil to off. Remains on increased diuretics with stable renal indices.

7/7/2019: Worsening hypoxemia resulted in increase in high-flow nasal cannula 20 liters/minute with 80-90% FiO₂.

7/9/2019: Patient with clinical decompensation. Placed on epinephrine and Milrinone infusions to augment cardiac output. Patient ultimately transitioned on to veno arterial ECMO support.

7/14/2019: Patient now on epinephrine and Milrinone therapy after upsizing of her shunt in the OR today. Patient decannulated from ECMO support.

7/18/2019: Patient remains on epinephrine. Milrinone will be initiated today due to poor peripheral perfusion. She remains on aggressive pulmonary hypertensive and respiratory support.

7/21/2019: The patient remains on epinephrine infusion as well as pulmonary hypertensive therapies. She is warm and well perfused. We will attempt to wean epinephrine as tolerated. She is on diuretics.

7/27/2019: Patient remains on epinephrine and Milrinone infusions. She remains on diuretics. Given her normal LV function on echocardiogram and the vaso dilated appearance of her exam we will attempt to wean her Milrinone. My hope would be that with better vascular tone we will be able to improve pulmonary blood flow and wean epinephrine.

8/2/2019: Patient remains on a low-dose epinephrine infusion. She has required higher driving pressures to facilitate pulmonary blood flow. She continues on aggressive pulmonary hypertensive support

8/3/2019: Epinephrine infusion has been discontinued. She continues on aggressive pulmonary hypertensive measures. She continues on aggressive diuretics.

8/12/2019: Patient with increasing BNP, intolerance of feeds, fever and desaturations. Patient started on Milrinone at 0.5 micrograms/kilogram per minute. Patient remains on Bumex and Diuril.

8/13/2019: Continues to struggle from lability of oxygen saturations. Milrinone increased to 1 microgram/kilogram per minute and diuretics held for now.

8/14/2019: Despite hyperdynamic appearance of heart on echocardiogram the child did respond with less labile oxygen saturations after starting epinephrine, currently at 0.08 micrograms/kilogram per minute.

8/17/2019: Epinephrine has been discontinued in the operating room. The patient remains on Milrinone and aggressive pulmonary hypertensive therapies.

8/18/2019: Restarted on epinephrine due to poor oxygen saturations, however this was likely due to underlying poor pulmonary function and not pulmonary blood flow as echo showed good flow and pulmonary arteries and shunt.

8/20/2019: Patient remains on Milrinone. We are weaning epinephrine as tolerated.

8/21/2019: Patient remains on Milrinone and aggressive diuretic support. Epinephrine is been discontinued. Milrinone will be weaned as tolerated

8/25/2019: Milrinone will be discontinued today. Patient continues on aggressive diuretics. She is quite vasodilated in the setting of sildenafil therapy.

9/8/2019: Patient remains off vasoactive infusions on aggressive diuretics. She continues to have hepatomegaly on exam.

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9/17/2019: Diuretics with the exception of Aldactone have been discontinued in the setting of elevated creatinine and persistent fevers felt to be either drug related or secondary to intravascular volume depletion. We will assess BUN and creatinine in need for diuretics over the coming days.

09/18/2019: Patient restarted on Milrinone in hopes of improving cardiac output and improved diuresis.

09/19/2019: Patient started on metolazone IV every 12 hr. Remains on Milrinone now being weaned.

9/20/2019: Milrinone weaned off.

10/2/2019: The patient remains on metolazone, Diuril, and a Bumex infusion has been added. Tolvaptan has been discontinued. An epinephrine infusion is also been added due to hypotension.

10/5/2019: The patient remains on epinephrine infusion, Bosentan, sildenafil which has reduced dosage, Bumex, Diuril. Metolazone is been discontinued.

10/13/2019: Bumex increased to 0.01 milligram/kilogram per hour. Low-dose epinephrine drip discontinued.

10/16/2019: We have had to back off on diuretics considerably given worsening of renal insufficiency. Low-dose epinephrine infusion has been re-initiated. She continues on aggressive pulmonary hypertension measures.

10/22/19: Ongoing titration of diuretics as possible to improve edema; continues to require epinephrine support. On sildenafil 2 mg/kg/day and bosentan.

10/28/2019: The patient remains on epinephrine as well as aggressive pulmonary hypertension measures. Diuretics were reduced significantly through the course of last week due to worsening renal insufficiency. BUN and creatinine have improved and diuretics will be again escalated. This has been an ongoing issue.

11/9/2019: Patient continues on epinephrine and multiple pulmonary hypertensive medications.

11/12/2019: The patient remains on epinephrine to provide adequate driving pressure to promote pulmonary blood flow. She continues on aggressive support for pulmonary hypertension. Diuretics continue however she has not achieved in negative fluid balance and is becoming more edematous.

11/16/2019: Has required increase in epinephrine to 0.04 mcg/kg/min. Marginal blood pressures. Titrating diuretics accordingly.

11/19/2019: Over the course of the last several days hypotension has been a problem. Norepinephrine was added on 11/17/2019 with improvement. Unfortunately diuretics had to be held due to the need for volume expansion. Bumex has been restarted at a low dose and will be advanced today to 0.01 milligrams/kilogram per hour. We will give a single dose of Diuril today.

11/25/2019: The patient remains on epinephrine and norepinephrine. She has responded to diuretics however BUN and creatinine are increasing. We will titrate diuretic support appropriately.

12/1/2019: The patient remains on epinephrine at 0.04 micrograms/kilogram per minute, norepinephrine at 0.02 micrograms/kilogram per minute. There is ongoing titration of diuretic support given renal insufficiency. Currently the patient is on Lasix every 8 hr. Diuril has been discontinued

12/3/2019: Patient transitioned back to Lasix and Diuril every 12 hr.

Electrolyte and fluid disorder

Assessment & Plan

Requiring ongoing boluses of calcium chloride and bicarbonate first postoperative night. Ongoing need for volume replacement to maintain adequate filling pressures for cardiac output. Will require ongoing meticulous supportive care and once stabilized, diuretics to resolve edema.

2/20/2019: Persistent truncal edema, on diuretic therapy.

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3/6/2019: Significant improvement in edema. Now on intermittent lasix. Ongoing need for surveillance of electrolytes.

4/12/19: The patient has had issues with hypoglycemia associated with bolus feeds. This appears to be improving.

6/19/19: Has tolerated bolus feeds without hypoglycemia in interim since last update. Fasting study planned before discharge by endocrine. Ongoing need for diuretics, electrolyte monitoring and sodium chloride supplementation for hyponatremia.

7/16/19: Acute deterioration on 7/9/19, ongoing TPN support given cardiorespiratory status. Diuretics have been given as appropriate. Requiring manipulation of electrolytes in TPN.

7/27/2019: Continue ongoing surveillance and replacement of electrolytes

8/8/19: Increased edema in past 24 hours, now back on bumex infusion with diuril. Addressing hypochloremic alkalosis with diamox, normal saline IVF.

8/17/2019: Patient with ionized hypocalcemia, hypokalemia, hyperglycemia, metabolic acidosis all as would be expected following cardiac surgery. There will be ongoing surveillance replacement

9/2/19: Metolazone started 8/30 for persistent edema despite bumex and diuril. Good response. Marked electrolyte derangements as is common with use of this diuretic. Requiring aldactone, supplemental potassium, and sodium. Scheduled metolazone q 24 hours 9/1/19. Ongoing close surveillance of fluid status and electrolytes needed.

9/4/2019: Held metolazone and diuril today for elevated BUN/Cr. Electrolyte supplementation decreased.

9/9/2019: In interim, diuril and metolazone restarted. Titrating to effect.

9/10/19: Ongoing titration of diuretics targeting optimal fluid balance. Trial of bumex to lasix today. Diuril unchanged. Metolazone will be given on an as needed basis rather than scheduled.

9/15/19: Increased lasix to 1.5 mg/kg q 6 hours with ongoing diuril q 12h. Still requiring occasional dose of metolazone. Positive fluid balance and edema on exam.

9/17/2019: Continue ongoing surveillance and replacement of electrolytes in the setting of changing diuretic therapy

09/23/2019: Child received tolvaptan with increase in serum sodium as expected.

10/1/19: Reintroduction of loop diuretics. If recurrent fever in absence of infection will stop. Electrolytes requiring close surveillance.

10/22/19: Has not had sustained fever on loop diuretics although still with some intermittent fevers. Edema persistent but improved. Ongoing therapy.

11/17/19: Has continued on diuretic therapy. Ongoing titration based on fluid balance. Ongoing surveillance of electrolytes required.

12/1/2019: There continues to be ongoing electrolyte surveillance and replacement with daily adjustments made in TPN.

Acute respiratory failure with hypoxia and hypercarbia (CMS/HCC)**Assessment & Plan**

Multifactorial including prematurity, marked cardiomegaly and ongoing issues with pulmonary blood flow. Ventilated preoperatively with difficulty, requiring JET ventilation and marginal saturations despite iNO. Early pulmonary interstitial emphysema noted prior to surgery. Postoperatively, requiring significant support, with ongoing use of iNO, FiO2 1.0, and significant pressures to offset abnormal respiratory system compliance. Titrating support as possible, to minimize ongoing barotrauma.

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2/14/19: Some improvement in gas exchange, able to wean FiO2. Lungs with emphysematous appearance at time of chest exploration.

2/20/19: Continues to require full ventilatory support. Chest remains open.

2/24/2019: Remains on full mechanical ventilatory support. We will wean as tolerated

2/26/2019: Patient with evidence of poor gas exchange yesterday. This is likely multifactorial due to not only intrinsic lung disease but issues with pulmonary blood flow. The patient remains on nitric oxide and full mechanical ventilatory support

3/4/19: Improving gas exchange appropriate for physiology; not yet ready ready for significant weaning.

3/6/19: Making slow gains. Has tolerated some decrease in rate.

3/10/19: Difficult to wean ventilation. She has good gas exchange when cardiac output is good. We will attempt to wean as tolerated.

3/13/2019: With improvement of cardiac output over the last several days we have begun weaning mechanical ventilation. Gas exchange remains good

3/21/2019: Patient is tolerating weaning of mechanical ventilation. She will likely be extubated soon.

3/22/2019: Plans are for extubation to high-flow nasal cannula today

3/23/2019: The patient has been extubated to high-flow nasal cannula 12 L. Patient exhibits evidence of reasonable gas exchange despite a paralyzed right hemidiaphragm

3/27/2019: Weaning HFNC, down to 10 L

3/29/2019: Improving gradually, now on 8 LPM

4/6/2019: Continues to require high-flow nasal cannula. This is multifactorial given chronic lung disease, chronic heart failure, as well as enlarged cardiac size.

4/12/2019: High-flow nasal cannula is being weaned slowly. This appears to be tolerated

4/16/2018: The patient has had episodic increased work breathing. This may be secondary to aspiration or chest difficulty secretions.

4/19/2019: Earlier in the week the patient had high-flow nasal cannula increased. We have begun weaning this again. Currently now at 6 liters/minute.

4/23/19: Tolerating 6 lpm with 4lpm with feeds.

4/25/19: Tolerating 4 lpm with some intermittent increase in breathing.

4/27/2019: Worsening difficulty maintaining oxygen saturations, decreased aeration and intermittently increased work breathing caused increase of high-flow back to 15 L with addition of med nebs and albuterol every 3 hr. Diffuse atelectasis noted on chest x-ray.

4/28/19: Stabilizing in past 24 hours with improved respiratory status; able to wean to 10 lpm this morning.

4/29/2019: Continue to have episodes of desaturation and poor aeration, necessary to increase high-flow back up to 15 L and restart meta neb treatments. Low-dose Ativan added for tolerance of IPV treatments. Good response overnight to aggressive pulmonary recruitment.

5/1/10: Prelone started 4/29 x 5 days. Weaning flow gradually. IPV ongoing. Not needing as much sedation.

05/02/2019. High-flow nasal cannula went 8 liters/minute.

5/4/2019: Patient has been transitioned to a standard nasal cannula.

5/6/2019: The patient was transiently on a regular nasal cannula but escalated back to a high-flow nasal cannula on 5/4/2019 in the afternoon. She remains on 6 liters/minute.

5/15/2019: The patient remains on 6 liters/minute of high-flow nasal cannula. She continues to have intermittent episodic airway obstruction and wheezing. She has responded to albuterol. She continues on

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Pulmicort.

May 17, 2019: Patient returned from the cardiac catheterization lab intubated. A bronchoscopy showed otherwise normal upper airway with slight inflammation on the left main bronchus. Significant hypoxemia and V/Q mismatch that improved with inhaled nitric oxide. Significant amount of secretions and the baby was started on broad-spectrum antibiotics.

5/19/2019: Has remained on full ventilatory support, nitric oxide and aggressive chest physiotherapy in last 24 hr. Overall pulmonary function appears to be improving especially with improvement in saturations after transfusion. She should be ready to start weaning on her aggressive treatment of her hypoxemia.

5/20/2019: The patient remains on mechanical ventilatory support. This is been aggressively weaned over the last 24 hr. This is been well tolerated. We will work towards extubation

5/21/2019: Patient extubated last night to HFNC. Reasonable gas exchange, but continued increased work of breathing/marginal respiratory status.

05/25/2019: Placed on isolation. Respiratory pathogen panel sent and revealed rhino virus. Patient remains on high-flow nasal cannula that went from 10 L up to 15 L due to increased work of breathing and secretions.

5/26/2019: IPV treatments every 3 hr added again due to increasing oxygen requirement tachypnea, improved overnight with improved chest x-ray.

5/29/2019: IPV treatments decreased every 6 hr, high-flow currently at 12 liters/minute and overall the child appears to be making some slow steady progress.

5/30/2019: Patient has been increased to 15 liters/minute of high-flow nasal cannula. She has episodic increased work of breathing. She continues to recover from her rhino virus infection

6/5/2019: Child had increasing oxygen requirement with decreasing saturations with worsening cough overnight. High-flow nasal cannula oxygen increased to 20 liters/minute and started back on IPV treatments every 6 hr with some improvement.

June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO₂ was weaned as well as the flow on the nasal cannula. The patient was started on sildenafil

6/17/19: Patient has had interval improvement of respiratory status. Currently on 6 liters/minute with an FiO₂ of 0.35.

6/19/19: Requiring increased flow today for work of breathing and FiO₂ requirements.

6/25/19: Continues on 15 lpm flow. Breath sounds tighter past 24 hours, diuretics increased and now on q 2 hour albuterol.

6/26/2019: The patient continues on high-flow nasal cannula. Subjectively she has been improved since continuous feeds were started. She continues to have variable oxygen requirement.

6/28/19: Interval improvement. Trial of decreased flow to 12 lpm. Albuterol back to q 3 hours

6/30/19: The patient has had gradual interval improvement through the week. The patient has been weaned to 10 liters/minute of high-flow nasal cannula.

7/1/19: Tolerated 8 lpm of flow in past 24 hours. Clinically with good aeration. Weaning sildenafil to off.

7/8/2018: High-flow nasal cannula oxygen has slowly been escalated 15 liters/minute as a child wean off of sildenafil in order to maintain good oxygen saturations and maintain a reasonable work of breathing.

7/9/2019: Patient with acute respiratory arrest in the early morning hours of 7/9/2019. Patient had acute loss of air movement and was difficult to bag mask ventilate. Apparent cause was some mucus plugging.

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Patient was emergently intubated and despite aggressive pulmonary toilet measures it was very difficult oxygen and ventilated. This also likely lead to a pulmonary hypertensive crisis. Despite aggressive pulmonary toilet measures, sedation, neuromuscular blockade, systemic alkalinization, and transfusion there was not much improvement. Patient emergently placed on VA ECMO.

7/14/2018: Patient transitioned off of ECMO in OR. After return from OR patient needing 100% FiO₂ and 20 parts per million of nitric with high ventilatory settings to keep appropriate oxygen saturations.

July 15, 2019: The child had profound hypoxemia with saturations around 30%, after bagging ventilation and suctioning with 100% oxygen and inhaled nitric oxide at 20 parts per million, the baby's oxygen saturations did not improve. After increasing the nitric oxide to 80 parts per million, epinephrine 0.1 micrograms/kg per minute and a fluid bolus, the oxygen saturations started to improve. Echocardiogram showed an open shunt with concerns for increased pulmonary vascular resistance.

7/16/19: Right pneumothorax present on morning CXR which was evacuated. Improving saturations/NIRS through day, requiring volume and vasoactive medications to drive shunt flow. Still requiring FiO₂ upwards of 0.6.

7/18/2019: Patient has had some improvement. Continues with significant hypoxemia. Currently on full mechanical ventilatory support. The patient has not tolerated sildenafil for pulmonary hypertension. We will likely start bosentan.

7/21/2019: The patient remains on full mechanical ventilatory support continuing ongoing titration. Her saturations appear to be more stable in the setting of Bosentan therapy. She continues to require aggressive pulmonary toilet measures.

7/22/2019: Trial of IPV therapy to see whether this improves saturations.

7/27/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension measures. She will likely need tracheostomy for long-term ventilation as a no other means of therapy and support for her chronic lung disease and pulmonary hypertension.

8/2/2019: Patient has had clinical improvement over the last 1-2 days. Continues to require high driving pressure to overcome pulmonary hypertension with epinephrine. Continues on Bosentan. Continues on nitric oxide and full mechanical ventilatory support. The patient has been started on a five day course of Solu-Medrol. This has transiently improved her in the past. She will likely continue to require chronic mechanical ventilation and tracheostomy.

8/4/19: Off epinephrine. Maintaining adequate saturations on < 0.5 FiO₂.

8/8/19: More wet in past 24 hours. Increased distress and less ability to be awake and tolerate ventilatory support. No room for weaning of support.

8/10/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension measures.

8/13/2019: Continues to struggle from labile oxygen saturations despite paralysis and aggressive respiratory support. Will start a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentan.

8/17/2019: Patient is on full mechanical ventilatory support following surgery. This will be titrated appropriately. She remains on inhaled nitric oxide.

8/18/2019: Child decompensated with extremely poor pulmonary compliance and persistent oxygen saturations in the high 50s to low 60s despite paralysis, aggressive analgesia and sedation, suctioning and

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other interventions on conventional mechanical ventilatory support. Ultimately transition to the oscillator with slow pulmonary recruitment and stability overnight.

8/20/2019: Patient with severe chronic lung disease superimposed with likely acute lung injury in the setting of a recent cardiac surgery. There is been no infectious etiology for her decompensation. After some time on high-frequency mechanical ventilation she has been transition to conventional ventilation. She is on systemic steroids for a five day course the and aggressive beta agonist therapy. Overall her prognosis from a chronic lung disease standpoint remains quite guarded

8/25/2019: Patient continues to struggle with underlying chronic lung disease, acute lung injury, single ventricle physiology, profound hypoxemia, airway reactivity. She remains on pressure control ventilation that was started on 08/23 due to high peak inspiratory pressures. Her gas exchange is been reasonable. She remains on a relatively high inspired oxygen not being able to be wean lower than 0.5. She remains on nitric oxide, Bosentan, in sildenafil at escalating doses. She remains on systemic steroids have been weaned to q.12 as well as albuterol at 5 mg an hour.\

8/29/2019: Off of continuous albuterol, steroids weaned to once daily. She continues to have rhonchi, wheezes and poor pulmonary compliance and does not appear to have had a significant response to steroids nor albuterol. She has been reasonably tolerant of cares lately on decreased vecuronium however.

8/31/2019: The patient continues on full mechanical ventilatory support. Unfortunately with discontinuation of her vecuronium she had profound desaturation hypoxemia and neuromuscular blockade is been restarted. She remains on inhaled nitric oxide in deep sedation. She continues to required aggressive pulmonary toilet measures

9/6/2019: The patient remains on full mechanical ventilatory support. She remains on deep sedation. Neuromuscular blockade is being reduced. She continues aggressive pulmonary toilet.

9/9/19: Off neuromuscular blockade infusion. Tolerating much better than in the past.

9/11/2019: The patient remains on full mechanical ventilatory support. Continues to have evidence of poor pulmonary compliance. Continues to have a persistent oxygen requirement with an FiO2 of 0.5-0.6.

9/17/2019: The patient remains on full mechanical ventilatory support. The patient has been on 65-70% oxygen for most of the last 24 hr. Pulmonary compliance continues to be an issue. Prognosis remains quite poor to guarded

9/21/2019: Patient remains on full mechanical ventilatory support and 100% FiO2. Her fluid overload has been compromising her oxygenation and ventilation. Prognosis remains poor.

10/2/2019: The patient remains on full mechanical ventilatory support. There have been some difficulties in ventilation. IMV is been increased. FiO2 is been weaned to 0.75. Gas exchange is somewhat suboptimal

10/5/2019: Patient remains on full mechanical ventilatory support. We have been able to wean the FiO2 somewhat, IMV is been increased due to mild respiratory acidosis

10/10/2019: Patient with complete atelectasis of the left lung requiring aggressive recruitment maneuvers with IPV and bag suctioning.

10/14/2019: The patient has had some improvement over the last several days with aggressive pulmonary toilet measures. She remains on quite stout mechanical ventilatory support. We have been able to wean her FiO2 which is mostly between 40 and 50%. She continues to require deep sedation and neuromuscular blockade. Her prognosis remains quite poor.

10/19/2019: Patient has required increasing FiO2 over the last 48-72 hours. She continues to require relatively deep sedation with intermittent neuromuscular blockade. Prognosis remains poor

10/20/2019: Restarted on low-dose vecuronium due to persistent agitation and need for excessive p.r.n.

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Medications, child was also given a trial of ketamine without significant improvement.

10/25/2019: The patient remains on full mechanical ventilatory support requiring between 40 and 70% oxygen deep sedation, neuromuscular blockade, and aggressive pulmonary toilet interventions to maintain reasonable gas exchange

11/7/2019: Vecuronium infusion stopped today given discussion of withdrawal by family. Vecuronium will be given on prn basis for issues with ventilating or excessive movement.

11/10/2019: Continues to require full ventilatory support. Intermittent increase in PIP's with agitation/airway secretions. Requiring increased oxygen off vecuronium. Vecuronium will be used on PRN basis for excessive movement threatening safety of ETT and ventilatory dyssynchrony with desaturation.

11/17/19: Interval worsening of secretions with tracheal aspirate growing abundant Staph aureus as well as stenotrophomonas maltophilia. Febrile at time culture was drawn. Antibiotics ongoing. Plan 7-10 day course. Vest therapy used in place of IPV given issues with hypotension.

11/19/2019: Patient has had worsening pulmonary compliance with increasing edema as diuretics were held in the setting of hypotension. Peak inspiratory pressures are now in the low to mid 40s. My hope is this will improve with reinstitution of diuretics now that hemodynamics are more stable.

11/25/2019: The patient remains on full mechanical ventilatory support. There has been some improvement in pulmonary compliance with aggressive diuresis however peak pressures remained in the mid 30s.

12/1/2019: Patient remains on full mechanical ventilatory support. She continues on aggressive pulmonary toilet measures.

12/4/2019: CT scan of the chest demonstrates in chronic lung disease changes with ground-glass appearance opacities, bronchiectasis, and multiple areas of atelectasis.

SVT (supraventricular tachycardia) (CMS/HCC)

Assessment & Plan

Began preoperatively, initially treated with esmolol, and later transitioned to amiodarone after developing atrial flutter. Heart irritable at time of surgery, better after atrial reduction. Ongoing support with amiodarone 5 mg/kg/day at time of admission to CICU. Ongoing surveillance planned.

2/21/19: Increased frequency of runs of SVT yesterday morning in the setting of epinephrine at 0.05 mcg/kg/min. Epinephrine decreased (0.03) and amiodarone increased to 10 mg/kg/day with better control.

2/24/2019: Amiodarone reduced to 5 milligrams/kilogram per day yesterday.

3/4/19: Ongoing issues with premature beats/atrial bigeminy, requiring pacing to try to suppress ectopic beats. On esmolol for same. Titrating to minimum dose.

March 7, 2019: The baby was started on oral flecainide with conversion to sinus rhythm.

3/10/2019: The patient remains on flecainide. Patient will be changed to oral amiodarone today.

3/11/2019: The patient remains on flecainide and amiodarone. There was a breakthrough event of SVT yesterday requiring rapid atrial pacing.

3/12/2019: In addition to atrial flutter yesterday the patient also had breakthrough SVT. Flecainide has been increased. It IV amiodarone infusion is been restarted. Patient is in a sinus rhythm this morning. It is slow so we are using temporary pacemaker support augment cardiac output

3/13/2019: Patient has been in a sinus rhythm for the last 24 hr. Temporary pacing is been discontinued.

3/14/2019: Esmolol d/c

03/16/2019: Remains on amiodarone 5 milligram/kilogram per day and flecainide 4 mg enteral every 8 hr.

3/19/2019: Flecainide increased to 5 mg every 8 hr.

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3/23/2019: Patient remains on amiodarone of 5 milligrams/kilogram per day. The patient is also on flecainide. We are awaiting a flecainide level. Once that level has returned we will continue to maximize flecainide therapy prior to reducing amiodarone.

3/29/2019: Ongoing titration of antiarrhythmics per EP service. Flecainide increased in response to low level, amiodarone has been decreased to 2.5 mg/kg/day IV. Plan to eventually transition to oral amiodarone, 5 mg/kg/day. Rhythm has been well controlled.

4/1/2019: Amiodarone transitioned to enteral route today (5 mg/kg/day). Flecainide unchanged, level still low, rhythm remains well controlled.

4/5/2019: Patient remains on amiodarone. Flecainide dose increased yesterday

6/19/19: No breakthrough, continues on amiodarone and flecainide, with dose adjusted for weight.

7/6/2019: No SVT noted. Patient remains on amiodarone and flecainide.

7/9/2019: Flecainide discontinued as patient transition on to VA ECMO support.

7/10/2019: Patient has been transitioned to amiodarone infusion

7/27/2019: We will transition to oral amiodarone at 5 milligrams/kilogram per day

8/3/2019: Patient with multiple PACs and dysrhythmia yesterday. Flecainide has been restarted

9/4/19: Flecainide level slightly subtherapeutic 8/27. No breakthrough tachydysrhythmia on amiodarone and flecainide.

9/20/2018: Patient remains on flecainide and amiodarone. No breakthrough dysrhythmias.

11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic

12/1/2019: Patient continues on flecainide and amiodarone. We continue with ongoing thyroid function surveillance in the setting of amiodarone therapy

Atrial flutter (CMS/HCC)**Assessment & Plan**

Occurred preoperatively, required synchronized cardioversion, followed by amiodarone. In sinus rhythm since 2/4/19. Continued on amiodarone 5 mg/kg/day at time of surgery 2/13/19.

2/24/2019: The patient remains on amiodarone

2/26/2019: Patient had recurrence of atrial flutter this morning. Was rapid atrial paced out of it. Continues on amiodarone.

3/10/2019: Patient transitioned to oral amiodarone

3/12/2019: Patient with worsening atrial flutter in the last 24 hr. Ultimately requiring cardioversion and rapid atrial pacing several times. IV amiodarone is been reinstituted. Flecainide was found to be subtherapeutic. Dosing has been increased.

3/13/2019: Came off pacemaker support with underlying sinus rhythm

3/14/2019: Esmolol was d/c

3/30/2019: Patient remains on flecainide and continuous amiodarone at this time.

4/4/2019: Good control, on enteral amiodarone and flecainide.

4/9/2019: Flecainide level remains subtherapeutic but patient without ectopy. Will remain on current dose.

5/9/19: Flecainide level back from 4/29/19 and is now therapeutic at 0.4. Dose continues as previously. No breakthrough dysrhythmias noted.

6/19/19: Flecainide has been adjusted for weight gain; therapeutic level 6/11/19. Amiodarone ongoing. No breakthrough dysrhythmias noted.

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

7/6/2019: No breakthrough of abnormal rhythms. Patient remains on amiodarone flecainide. Flecainide levels being drawn intermittently.

7/9/2019: Flecainide discontinued. Patient has been transition to IV amiodarone while on VA ECMO support.

7/14/2019: Patient has returned from the OR. We will continue IV amiodarone at this time. Patient off of VA ECMO support.

7/27/2019: We will transition to oral amiodarone

8/4/2019: Developed short runs of SVT. Flecainine restarted 8/2/19.

8/9/2019: Flecainide level suboptimal. Flecainide dose increased.

9/4/19: Most recent level of flecainide checked on 08/27 and was slightly low at 0.18. She has not had breakthrough tachydysrhythmias despite this slightly subtherapeutic level.

9/20/2019: Patient remains on flecainide and amiodarone therapy. No breakthrough dysrhythmias.

11/9/2019: Patient remains on amiodarone and flecainide without breakthrough dysrhythmias.

11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic

12/1/2019: Patient continues on flecainide and amiodarone. We continue with ongoing thyroid function surveillance in the setting of amiodarone therapy

*** Ebstein's anomaly of tricuspid valve***Assessment & Plan*

Severe anomaly with inadequate pulmonary blood flow, marked RA and RV dilatation compromising LV filling and encompassing much of chest. Now s/p modified Starnes operation with fenestrated closure of the tricuspid valve, open atrial septectomy with cardiopulmonary bypass, placement of a 3 mm modified BT shunt, reduction right atrial plasty, and pulmonary valvotomy, Dr. Vincent Tam, 2/13/19. Chest left open.

2/14/19: Mediastinal exploration, to assess recurrent bleeding/effusion posterior to heart, clip placed to isolate MPA from RV to prevent blood from flowing back to RV.

Patient underwent delayed sternal closure 2/22/2019

May 17, 2019: Cardiac catheterization showed decreased diameter of the pulmonary arteries with subsequent balloon dilatation of both pulmonary arteries.

7/14/2019: Patient taken OR by Dr. Tam where she was decannulated from ECMO support, had her BT shunt replaced with a 5.0 mm BT shunt, patch augmentation of right ventricular outflow tract, reduction right atrioplasty, repair of the right common carotid artery and right internal jugular vein. While in the OR the patient had significant desaturations coming off bypass requiring a clip to be placed over the right ventricular outflow tract. With this maneuver saturations and pulmonary blood flow increased.

7/19/2019: Patient underwent delayed sternal closure

8/17/2019: Due to inadequate pulmonary blood flow in significant gradient from the innominate artery to the BT shunt the patient was taken back to the operating room where the BT shunt was taken off the innominate artery at its proximal takeoff and reconnected to the aorta with formation of a central shunt.

10/8/2019: Referrals have been made to Boston Children's Hospital and Texas children's Hospital regarding any further interventions or options to be provided. Both institutions have said that everything has aggressively been done.

11/4/19: Patient has also been denied at Dallas Childrens.

Progress Notes by Jay M Duncan, MD at 12/8/2019 8:34 AM (continued)

Billing Time: I have personally seen and examined this patient and spent 60 minutes of critical care time on this patients behalf.

Coding Queries

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Lori Lee Nessler, MD		Procedure Note	02/01/2019 2110	Response Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nessler, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Lori Lee Nessler, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Lori Lee Nessler, MD		Procedure Note	02/01/2019 2111	Response Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nessler, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Lori Lee Nessler, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Rekha Balla Hamilton, MD		Procedure Note	02/09/2019 1745	Response Received			

Query Message

--- Doc Query Message ---

From: Rekha Balla Hamilton, MD
Sent: 2/9/2019 9:46 PM CST
Subject: Procedure Note

This is an auto-generated reply.



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breaun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Coding Queries (continued)

The following user has specified that this query has been addressed:
Rekha Balla Hamilton, MD : 02/09/2019 - 09:46 PM

END OF REPORT

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AMAuthor: Lane Thomas Lanier, MD
Filed: 12/5/2019 9:42 AM
Status: SignedService: Critical Care
Date of Service: 12/5/2019 7:48 AM
Editor: Lane Thomas Lanier, MD (Physician)
Author Type: Physician
Creation Time: 12/5/2019 7:48 AM**CICU PROGRESS NOTE**

Tinslee Breaun Lewis is a 10 m.o. female admitted for Ebstein's anomaly of tricuspid valve and has been hospitalized for 307 days. The patient underwent a modified Starnes procedure with placement of a 3.0 mm BT shunt as a neonate. She has encountered significant lung disease from heart failure and prematurity, requiring high-flow nasal cannula and ventilation since birth. She has been hospitalized all of her life, most of which has been in the cardiac ICU. Beginning in late June, her respiratory status became more tenuous, requiring more oxygen and flow. She acutely decompensated on 7/9/2019 with profound hypoxemia, requiring emergent intubation and VA ECMO support. Her shunt was upsized to a 5.0 mm shunt on 7/14/2019, and she was able to separate from ECMO in the OR. Despite this, saturations remained marginal and repeat catheterization showed stenosis of the right innominate artery, she was taken back to the OR for shunt revision on 8/16/2019. Unfortunately, she has been unable to wean from ventilatory support since July. She has required neuromuscular blockade for the majority of this time. Given her single ventricle physiology and chronic ventilatory dependence with marked lung dysfunction, her prognosis is dismal. Multiple institutions have been notified regarding her physiology and anatomy and current state. All of the institutions have declined transfer the patient to their respective facility with only one whose decision is pending. Patient remains critically ill in the cardiac ICU with a poor prognosis currently on mechanical ventilatory support, epinephrine, norepinephrine, neuromuscular blockade, and ventilatory support. .

Surgeon: Tam, Vincent K.H, MD**Chief Complaint:** Ebstein's anomaly, pulmonary hypertension, chronic lung disease with respiratory failure.**Operation Date:** 2/13/19. Starnes operation with fenestrated closure of the tricuspid valve, open atrial septectomy with cardiopulmonary bypass, placement of a 3 mm modified BT shunt, reduction right atrial plasty, and pulmonary valvotomy, Dr. Vincent Tam, Chest left open.

--2/14/19: Mediastinal exploration, to assess recurrent bleeding/effusion posterior to heart, clip placed to isolate MPA from RV to prevent blood from flowing back to RV, Dr. Vincent Tam, Chest left open.

--2/22/19: Chest closed

--5/17/19: Diagnostic cardiac catheterization, with balloon angioplasty of the right pulmonary artery

--7/9/19: Emergent cannulation (neck) for VA ECMO

--7/14/19: Decannulated from VA ECMO, placement of a 5.0 mm BT shunt, patch augmentation of the RVOT with opening of the RVOT, reduction right atrioplasty, repair of right common carotid artery, repair of right internal jugular vein. Clip placed on the RVOT after noted desaturations coming off bypass with improvement of saturations, Dr. Vincent Tam, chest left open.

--7/19/19: Chest closed

--8/16/19: Shunt revision, taking the proximal takeoff from the innominate artery and placing it in a central position off the aorta.

Hospital Day: 307

Allergies: Patient has no known allergies.

End of life care

Assessment & Plan

Over the last weeks all of the services (Cardiac Intensive Care, Cardiology and CV surgery) involved in the care of Tinslee have come to the same conclusion that her ongoing care has reached the level of medical futility. And furthermore that we have no additional interventions or treatments to offer her and that she has failed aggressive escalation of her pulmonary shunt to a central shunt due to her underlying chronic lung disease and pulmonary hypertension. Overall this has left her fluid overloaded with marginal pulmonary status, with marked agitation requiring aggressive sedation analgesia and paralysis which we have been unable to wean. In addition, she has been febrile and toxic on her diuretics although we have restarted them on a compassionate basis., she remains on an epinephrine infusion just to facilitate a more neutral fluid balance although she continues to get progressively fluid overloaded. We are also unable to feed her despite multiple attempts to do so.

While the extended family has expressed their concerns that the child is suffering. The child's parents do not recognize this nor do they want to deal with this situation despite all of the physicians expressing their concerns regarding the child's ongoing suffering. Due to this impasse, we have engaged the ethics committee. An Ethics committee meeting was scheduled for yesterday morning with the family invited, and having previously confirmed that they would attend, failed to show up for the meeting. The meeting was held without them unfortunately, the medical case was presented to the Ethics committee members. The committee members suggested possible descalation of our aggressive support measures including diuretics, epinephrine, paralysis and sedation as well as additional medications. However, while the child has been made a DNR, the family has expressed no interest in descalating any of her care putting us in a very precarious situation. While we have tried to wean things in the past we have needed to reinstitute these therapies, including a recent trial off of paralysis this weekend. This leaves the poor child suffering and in limbo without a clear pathway forward.

10/26/2019: A lengthy discussion was held with the patient's mother last night. A letter had been delivered by the nursing supervisor in regards to the upcoming ethics committee and potential binding decisions regarding the patient's care. The mother express significant anger and a lengthy discussion was held regarding the purpose of the meeting, as well as a review of Tinslee's hospital course, current medical problems, and prognosis. The mother reiterated that she does not feel that there is any undue suffering from her daughter. She stated that she still feels like that her daughter will "get better." I encouraged her to take the upcoming meeting seriously and to be present to express her concerns, desires for care, and to explain her thought process in decision making for her daughter.

11/4/19: Ethics committee met 10/30/19 and rendered binding decision to withdraw. Family informed with written letter given to them 10/31/19. In 10 day grace period contacting other centers as per family wishes.



COOK CHILDRENS
MEDICAL CENTER
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Lewis, Tinslee Breaun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

11/10/19: Multiple institutions called during 10 day period. The following institutions denied transfer after review of her records: Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia, Johns Hopkins, Methodist Hospital San Antonio, Boston Children's Hospital, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott Children's in Michigan, LeBonheur Children's in Memphis, University Hospital in San Antonio, and Rady Children's Hospital in San Diego. Family attorney secured temporary restraining order mandating ongoing care today. Administration and legal involved. Medical team continues to provide ongoing aggressive treatment for Tinslee accordingly. DNR rescinded today by mother. She has a full code order now in place.

11/19/2019: Patient's prognosis remains quite poor. We continue to provide aggressive CICU support. We are communicating with other institutions regarding their opinion and potential transfer. The mother has been kept up-to-date when she is at the bedside.

Pulmonary hypertension (CMS/HCC)

Assessment & Plan

Pulmonary hypertension associated with chronic lung disease. On June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO2 was weaned as well as the flow on the nasal cannula. The patient was started on sildenafil. On June 10, 2019 the nitric oxide has been weaned off. BNP was elevated over 500.

6/19/19: Improved bnp (308), continues on sildenafil 1.1 mg q 8 hours.

6/24/19: Sildenafil increased yesterday to 2.3 mg q 8 hours for higher oxygen needs

6/25/19: Worsening aeration, tight breath sounds. Sildenafil decreased back to previous dose.

7/1/19: Weaning sildenafil to off, tolerating thus far.

7/2/2018: Sildenafil is off.

7/9/2019: Patient with worsening hypoxemia and work of breathing and desaturation over the last several days. High-flow a been escalated. Patient placed back on nitric oxide 7/8/2019: Patient with severe hypoxemic decompensation with likely worsening pulmonary hypertension this morning. Patient transitioned on to VA ECMO support.

7/12/2019: Patient remains on VA ECMO support and inhaled nitric oxide.

7/14/2018: Patient decannulated from VA ECMO support in the OR. Patient underwent replacement of her BT shunt with a 5.0 mm BT shunt. Patient was unable to wean off nitric oxide in OR and remains on inhaled nitric oxide at 20 parts per million and 100% FiO2 from the ventilator.

7/18/2019: Patient has had intolerance of sildenafil. Bosentan and will be started today. The patient remains on nitric oxide

7/21/2019: The patient remains on inhaled nitric oxide. There has been improvement in saturations with Bosentan.

7/27/2019: The patient remains on nitric oxide and bosentan

8/2/2019: The patient remains on nitric oxide, Bosentan, mechanical ventilation with high inspired oxygen. She continues to require at high driving pressure to maintain adequate pulmonary blood flow

8/8/19: Nitric oxide increased back from 5 to 10 ppm in past 24 hours for worsening oxygenation especially with agitation.

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

8/11/2019: Inhaled nitric oxide increased back to 20 parts per million.

8/13/2019: Marginally better but still labile on paralysis, are giving a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentan. Child has very small pulmonary arteries attached to her 5 mm shunt likely representing significant anatomic resistance to pulmonary blood flow, cardiac catheterization evaluation today.

8/15/2019: Cardiac catheterization on the 14th revealed a stenosis with a likely 60-80 mm gradient in the innominate artery between the ascending aorta and the takeoff of the BT shunt, this could explain the need for hypertensive blood pressures to maintain adequate oxygen saturations and amenable to surgical correction. Dr. Tam is performing a central shunt today.

8/16/2019: Central shunt delayed until today.

8/18/2019: Bosentan discontinued

8/20/2018: Patient remains on inhaled nitric oxide and Bosentan. It should be noted that cardiac catheterization data demonstrating approximately 1/3 to 1/2 systemic pulmonary artery pressures performed in the setting of deep sedation and paralysis, inhaled nitric oxide, and Bosentan. If the patient demonstrates evidence of pulmonary overcirculation we will begin weaning nitric oxide.

8/22/2019: Patient remains on full mechanical ventilatory support, inspired oxygen, nitric oxide, and Bosentan. We will attempt to start sildenafil today.

8/25/2019: The patient remains on full mechanical ventilatory support, nitric oxide at 20 parts per million, bosentan, and now sildenafil has been escalated to 1 milligram/kilogram every 6 hr.

9/2/19: Patient weaned off nitric oxide this morning. Continues on bosentan and sildenafil.

10/4/19: Sildenafil reduced to 2 mg/kg/day given vasodilation, evidence of pulmonary overcirculation, and hypotension.

11/9/2019: Patient remains on sildenafil and bosentan therapy with reasonable saturations off of vecuronium.

11/16/19: Has required reinstitution of vecuronium for ventilatory dyssynchrony/agitation.

11/17/19: Sildenafil dose has been decreased by 25% given issues with hypotension with adequate PaO₂ on blood gas on 45% oxygen.

11/19/2019: Patient remains on both Bosentan sildenafil. PaO₂ is a are in the high 30s.

12/1/2019: The patient continues on aggressive treatment of pulmonary hypertension with Bosentan, sildenafil, mechanical ventilation, and inspired oxygen.

Acute systolic heart failure (CMS/HCC)

Assessment & Plan

Infant initially with cardiogenic shock in the immediate postoperative period. While shock has resolved, infant continues to have heart failure, requiring epinephrine support. Has variably been on milrinone, currently off.

2/24/2019: Patient continues on aggressive heart failure management. The patient is currently on epinephrine infusion as well as diuretics.

2/26/2019: Patient remains on diuretics. We have discontinued epinephrine in an effort to see if this would help with the dysrhythmia. We will also be more liberal on fluid administration.

2/27/2019; Blood pressure and NIRS lower off epinephrine. Restarted at 0.02 mcg/kg/min with milrinone at 0.3 mcg/kg/min. Gradual improvement noted in perfusion and blood pressure. Ongoing need for titration

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

of vasoactive medications.

3/4/2019: Off epinephrine. Improved perfusion on milrinone. Still with rhythm issues, intermittent atrial bigeminy with some compromise of cardiac output; NIRS remain marginal.

3/10/2019: Patient remains on Milrinone and diuretics. Patient's hemodynamics have been more stable when in a sinus rhythm.

3/28/2019: Milrinone weaned off. Patient remains on Lasix only.

4/19/2019: Patient transitioned to IV Lasix earlier in the week. We will transition back to p.o. Lasix twice daily.

4/22/19: Continues to struggle with fluid balance. Significantly positive balance on twice daily Lasix, increased to q.8 hours today.

4/28/2019: Continues to do better on increased diuretics (q 8 hours)

5/1/19: Continues on increased diuretics, now q 6 hours.

5/7/19: Continues on diuretics, now q.8 hours Lasix.

5/15/2019: Patient has been transitioned to twice daily Lasix.

5/21/19: Now on increased diuretics s/p cath with respiratory failure. Perfusion remains good without other cardiac medications.

6/19/19: Continued need for meticulous attention to fluid status and diuretic therapy. Siladenafil has been added to regimen. BNP down to 308 6/19/19 from 560.1 several days ago.

6/25/19: BNP 351 yesterday. Diuretics increased past 24 hours for tighter breath sounds. Given lack of improvement, team again considering cath

7/1/19: Reasonable week. Support unchanged other than weaning sildenafil to off. Remains on increased diuretics with stable renal indices.

7/7/2019: Worsening hypoxemia resulted in increase in high-flow nasal cannula 20 liters/minute with 80-90% FiO2.

7/9/2019: Patient with clinical decompensation. Placed on epinephrine and Milrinone infusions to augment cardiac output. Patient ultimately transitioned on to veno arterial ECMO support.

7/14/2019: Patient now on epinephrine and Milrinone therapy after upsizing of her shunt in the OR today. Patient decannulated from ECMO support.

7/18/2019: Patient remains on epinephrine. Milrinone will be initiated today due to poor peripheral perfusion. She remains on aggressive pulmonary hypertensive and respiratory support.

7/21/2019: The patient remains on epinephrine infusion as well as pulmonary hypertensive therapies. She is warm and well perfused. We will attempt to wean epinephrine as tolerated. She is on diuretics.

7/27/2019: Patient remains on epinephrine and Milrinone infusions. She remains on diuretics. Given her normal LV function on echocardiogram and the vaso dilated appearance of her exam we will attempt to wean her Milrinone. My hope would be that with better vascular tone we will be able to improve pulmonary blood flow and wean epinephrine.

8/2/2019: Patient remains on a low-dose epinephrine infusion. She has required higher driving pressures to facilitate pulmonary blood flow. She continues on aggressive pulmonary hypertensive support

8/3/2019: Epinephrine infusion has been discontinued. She continues on aggressive pulmonary hypertensive measures. She continues on aggressive diuretics.

8/12/2019: Patient with increasing BNP, intolerance of feeds, fever and desaturations. Patient started on Milrinone at 0.5 micrograms/kilogram per minute. Patient remains on Bumex and Diuril.

8/13/2019: Continues to struggle from lability of oxygen saturations. Milrinone increased to 1

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

microgram/kilogram per minute and diuretics held for now.

8/14/2019: Despite hyperdynamic appearance of heart on echocardiogram the child did respond with less labile oxygen saturations after starting epinephrine, currently at 0.08 micrograms/kilogram per minute.

8/17/2019: Epinephrine has been discontinued in the operating room. The patient remains on Milrinone and aggressive pulmonary hypertensive therapies.

8/18/2019: Restarted on epinephrine due to poor oxygen saturations, however this was likely due to underlying poor pulmonary function and not pulmonary blood flow as echo showed good flow and pulmonary arteries and shunt.

8/20/2019: Patient remains on Milrinone. We are weaning epinephrine as tolerated.

8/21/2019: Patient remains on Milrinone and aggressive diuretic support. Epinephrine is been discontinued. Milrinone will be weaned as tolerated

8/25/2019: Milrinone will be discontinued today. Patient continues on aggressive diuretics. She is quite vasodilated in the setting of sildenafil therapy.

9/8/2019: Patient remains off vasoactive infusions on aggressive diuretics. She continues to have hepatomegaly on exam.

9/17/2019: Diuretics with the exception of Aldactone a been discontinued in the setting of elevated creatinine and persistent fevers felt to be either drug related or secondary to intravascular volume depletion. We will assess BUN and creatinine in need for diuretics over the coming days.

09/18/2019: Patient restarted on Milrinone in hopes of improving cardiac output and improved diuresis.

09/19/2019: Patient started on metolazone IV every 12 hr. Remains on Milrinone now being weaned.

9/20/2019: Milrinone weaned off.

10/2/2019: The patient remains on metolazone, Diuril, and a Bumex infusion has been added. Tolvaptam has been discontinued. An epinephrine infusion is also been added due to hypotension.

10/5/2019: The patient remains on epinephrine infusion, Bosentan, sildenafil which has reduced dosage, Bumex, Diuril. Metolazone is been discontinued.

10/13/2019: Bumex increased to 0.01 milligram/kilogram per hour. Low-dose epinephrine drip discontinued.

10/16/2019: We have had to back off on diuretics considerably given worsening of renal insufficiency. Low-dose epinephrine infusion has been re-initiated. She continues on aggressive pulmonary hypertension measures.

10/22/19: Ongoing titration of diuretics as possible to improve edema; continues to require epinephrine support. On sildenafil 2 mg/kg/day and bosentan.

10/28/2019: The patient remains on epinephrine as well as aggressive pulmonary hypertension measures. Diuretics were reduced significantly through the course of last week due to worsening renal insufficiency. BUN and creatinine have improved and diuretics will be again escalated. This has been an ongoing issue.

11/9/2019: Patient continues on epinephrine and multiple pulmonary hypertensive medications.

11/12/2019: The patient remains on epinephrine to provide adequate driving pressure to promote pulmonary blood flow. She continues on aggressive support for pulmonary hypertension. Diuretics continue however she has not achieved in negative fluid balance and is becoming more edematous.

11/16/2019: Has required increase in epinephrine to 0.04 mcg/kg/min. Marginal blood pressures. Titrating diuretics accordingly.

11/19/2019: Over the course of the last several days hypotension has been a problem. Norepinephrine was added on 11/17/2019 with improvement. Unfortunately diuretics had to be held due to the need for

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

volume expansion. Bumex has been restarted at a low dose and will be advanced today to 0.01 milligrams/kilogram per hour. We will give a single dose of Diuril today.

11/25/2019: The patient remains on epinephrine and norepinephrine. She has responded to diuretics however BUN and creatinine are increasing. We will titrate diuretic support appropriately.

12/1/2019: The patient remains on epinephrine at 0.04 micrograms/kilogram per minute, norepinephrine at 0.02 micrograms/kilogram per minute. There is ongoing titration of diuretic support given renal insufficiency. Currently the patient is on Lasix every 8 hr. Diuril has been discontinued

12/3/2019: Patient transitioned back to Lasix and Diuril every 12 hr.

*** Ebstein's anomaly of tricuspid valve***Assessment & Plan*

Severe anomaly with inadequate pulmonary blood flow, marked RA and RV dilatation compromising LV filling and encompassing much of chest. Now s/p modified Starnes operation with fenestrated closure of the tricuspid valve, open atrial septectomy with cardiopulmonary bypass, placement of a 3 mm modified BT shunt, reduction right atrial plasty, and pulmonary valvotomy, Dr. Vincent Tam, 2/13/19. Chest left open.

2/14/19: Mediastinal exploration, to assess recurrent bleeding/effusion posterior to heart, clip placed to isolate MPA from RV to prevent blood from flowing back to RV.

Patient underwent delayed sternal closure 2/22/2019

May 17, 2019: Cardiac catheterization showed decreased diameter of the pulmonary arteries with subsequent balloon dilatation of both pulmonary arteries.

7/14/2019: Patient taken OR by Dr. Tam where she was decannulated from ECMO support, had her BT shunt replaced with a 5.0 mm BT shunt, patch augmentation of right ventricular outflow tract, reduction right atrioplasty, repair of the right common carotid artery and right internal jugular vein. While in the OR the patient had significant desaturations coming off bypass requiring a clip to be placed over the right ventricular outflow tract. With this maneuver saturations and pulmonary blood flow increased.

7/19/2019: Patient underwent delayed sternal closure

8/17/2019: Due to inadequate pulmonary blood flow in significant gradient from the innominate artery to the BT shunt the patient was taken back to the operating room where the BT shunt was taken off the innominate artery at its proximal takeoff and reconnected to the aorta with formation of a central shunt.

10/8/2019: Referrals have been made to Boston Children's Hospital and Texas children's Hospital regarding any further interventions or options to be provided. Both institutions have said that everything has aggressively been done.

11/4/19: Patient has also been denied at Dallas Childrens.

Fluid overload*Assessment & Plan*

9/22/2019: This child was proven to be toxic on loop diuretics with high fever and increasing diuretic resistant. A multi disciplinary discussion determined that she is not a candidate for renal replacement therapy and that this would likely just increase her suffering. We have however started Zaroxolyn twice daily with minimal effect. Will add scheduled Diuril twice daily to this regimen but it is unlikely to be very effective. During a care conference earlier in the week the family was informed regarding this unfortunate development and that the recommendation of the care team is that further escalation of care should not happen.

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

09/23/2019: Child on Diuril IV every 12 hr and given tolvaptan with good response.

10/1/19: Despite aggressive non loop diuretics, Tinslee remains markedly swollen. Mother has not been able to limit care. Loop diuretics reintroduced. If fever recurs, will stop.

10/6/19: Has responded to bumex infusion favorably with ongoing diuril. Other diuretics serially held/stopped. Edema is improved, but persistent. Renal indices have increased slightly, and dose limited accordingly to 0.005 mg/kg/hr. She has one temp elevation to 38.5 transiently during the week. There have not been persistent fevers as previously. Ongoing surveillance planned.

10/16/2019: We have had to back off on her diuretics significantly. We will follow BUN and creatinine closely.

10/28/2019: With reduction of diuretic burden BUN and creatinine have improved. Bumex will again be increased to 0.01 milligrams/kilogram per hour today.

11/12/2019: Over the last two weeks there has been significant titration of her diuretics. They are titrated in accordance with fluid balance while weighing underlying renal insufficiency. Currently on Bumex 0.01 milligrams/kilogram per hour and Diuril twice daily.

11/17/19: Diuril decreased to once daily given issues with lower blood pressure.

11/19/2019: Patient with worsening edema with a positive 1.5 L fluid balance over the last 72 hr. Bumex will be escalated to 0.01 milligrams/kilogram per hour today and we will give her a single dose of Diuril. We will need to assess her hemodynamics closely with this diuresis.

11/27/19: Continued need for aggressive diuretics. Fluid status currently improved, but BUN/Cr have increased somewhat. Ongoing requirement to titrate diuretics accordingly.

12/1/2019: Patient continues to show evidence of volume overload. We have had to reduce diuretics in the setting of worsening renal insufficiency.

SVT (supraventricular tachycardia) (CMS/HCC)

Assessment & Plan

Began preoperatively, initially treated with esmolol, and later transitioned to amiodarone after developing atrial flutter. Heart irritable at time of surgery, better after atrial reduction. Ongoing support with amiodarone 5 mg/kg/day at time of admission to CICU. Ongoing surveillance planned.

2/21/19: Increased frequency of runs of SVT yesterday morning in the setting of epinephrine at 0.05 mcg/kg/min. Epinephrine decreased (0.03) and amiodarone increased to 10 mg/kg/day with better control.

2/24/2019: Amiodarone reduced to 5 milligrams/kilogram per day yesterday.

3/4/19: Ongoing issues with premature beats/atrial bigeminy, requiring pacing to try to suppress ectopic beats. On esmolol for same. Titrating to minimum dose.

March 7, 2019: The baby was started on oral flecainide with conversion to sinus rhythm.

3/10/2019: The patient remains on flecainide. Patient will be changed to oral amiodarone today.

3/11/2019: The patient remains on flecainide and amiodarone. There was a breakthrough event of SVT yesterday requiring rapid atrial pacing.

3/12/2019: In addition to atrial flutter yesterday the patient also had breakthrough SVT. Flecainide has been increased. It IV amiodarone infusion is been restarted. Patient is in a sinus rhythm this morning. It is slow so we are using temporary pacemaker support augment cardiac output

3/13/2019: Patient has been in a sinus rhythm for the last 24 hr. Temporary pacing is been discontinued.

3/14/2019: Esmolol d/c

03/16/2019: Remains on amiodarone 5 milligram/kilogram per day and flecainide 4 mg enteral every 8 hr.

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3/19/2019: Flecainide increased to 5 mg every 8 hr.

3/23/2019: Patient remains on amiodarone of 5 milligrams/kilogram per day. The patient is also on flecainide. We are awaiting a flecainide level. Once that level has returned we will continue to maximize flecainide therapy prior to reducing amiodarone.

3/29/2019: Ongoing titration of antiarrhythmics per EP service. Flecainide increased in response to low level, amiodarone has been decreased to 2.5 mg/kg/day IV. Plan to eventually transition to oral amiodarone, 5 mg/kg/day. Rhythm has been well controlled.

4/1/2019: Amiodarone transitioned to enteral route today (5 mg/kg/day). Flecainide unchanged, level still low, rhythm remains well controlled.

4/5/2019: Patient remains on amiodarone. Flecainide dose increased yesterday

6/19/19: No breakthrough, continues on amiodarone and flecainide, with dose adjusted for weight.

7/6/2019: No SVT noted. Patient remains on amiodarone and flecainide.

7/9/2019: Flecainide discontinued as patient transition on to VA ECMO support.

7/10/2019: Patient has been transitioned to amiodarone infusion

7/27/2019: We will transition to oral amiodarone at 5 milligrams/kilogram per day

8/3/2019: Patient with multiple PACs and dysrhythmia yesterday. Flecainide has been restarted

9/4/19: Flecainide level slightly subtherapeutic 8/27. No breakthrough tachydysrhythmia on amiodarone and flecainide.

9/20/2018: Patient remains on flecainide and amiodarone. No breakthrough dysrhythmias.

11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic

12/1/2019: Patient continues on flecainide and amiodarone. We continue with ongoing thyroid function surveillance in the setting of amiodarone therapy

Atrial flutter (CMS/HCC)*Assessment & Plan*

Occurred preoperatively, required synchronized cardioversion, followed by amiodarone. In sinus rhythm since 2/4/19. Continued on amiodarone 5 mg/kg/day at time of surgery 2/13/19.

2/24/2019: The patient remains on amiodarone

2/26/2019: Patient had recurrence of atrial flutter this morning. Was rapid atrial paced out of it. Continues on amiodarone.

3/10/2019: Patient transitioned to oral amiodarone

3/12/2019: Patient with worsening atrial flutter in the last 24 hr. Ultimately requiring cardioversion and rapid atrial pacing several times. IV amiodarone is been reinstituted. Flecainide was found to be subtherapeutic. Dosing has been increased.

3/13/2019: Came off pacemaker support with underlying sinus rhythm

3/14/2019: Esmolol was d/c

3/30/2019: Patient remains on flecainide and continuous amiodarone at this time.

4/4/2019: Good control, on enteral amiodarone and flecainide.

4/9/2019: Flecainide level remains subtherapeutic but patient without ectopy. Will remain on current dose.

5/9/19: Flecainide level back from 4/29/19 and is now therapeutic at 0.4. Dose continues as previously. No breakthrough dysrhythmias noted.

6/19/19: Flecainide has been adjusted for weight gain; therapeutic level 6/11/19. Amiodarone ongoing. No

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

breakthrough dysrhythmias noted.

7/6/2019: No breakthrough of abnormal rhythms. Patient remains on amiodarone flecainide. Flecainide levels being drawn intermittently.

7/9/2019: Flecainide discontinued. Patient has been transition to IV amiodarone while on VA ECMO support.

7/14/2019: Patient has returned from the OR. We will continue IV amiodarone at this time. Patient off of VA ECMO support.

7/27/2019: We will transition to oral amiodarone

8/4/2019: Developed short runs of SVT. Flecainine restarted 8/2/19.

8/9/2019: Flecainide level suboptimal. Flecainide dose increased.

9/4/19: Most recent level of flecainide checked on 08/27 and was slightly low at 0.18. She has not had breakthrough tachydysrhythmias despite this slightly subtherapeutic level.

9/20/2019: Patient remains on flecainide and amiodarone therapy. No breakthrough dysrhythmias.

11/9/2019: Patient remains on amiodarone and flecainide without breakthrough dysrhythmias.

11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic

12/1/2019: Patient continues on flecainide and amiodarone. We continue with ongoing thyroid function surveillance in the setting of amiodarone therapy

Infection due to *Stenotrophomonas maltophilia**Assessment & Plan*

Growth of abundant *Stenotrophomonas* from tracheal aspirate 9/26/19. Bactrim initiated 9/28 once culture grew. Plan 14 day course.

10/22/19: Has had fever with discontinuation of bactrim prompting new cultures and starting of bactrim.

Ongoing surveillance for response. Typically has had less fever when treated.

11/4/19: Course of bactrim was complete 10/31/19

11/17/19: Again with abundant *stenotrophomonas* in tracheal aspirate associated with increased secretions. Bactrim initiated overnight.

11/27/19: Completed course of bactrim. Ongoing surveillance.

Staphylococcus aureus infection*Assessment & Plan*

Patient had fever prompting cultures on 11/13/2019. There is abundant growth of *Staph aureus* from the endotracheal tube. There are not significant elevation of inflammatory markers. We will plan on seven days of treatment with oxacillin.

11/27/19: Completed course of oxacillin/bactrim for staphylococcus LRI. Problem resolved.

11/29/19: Again with growth of abundant *Staphylococcus aureus* from ETT in setting of chronic lung disease, secretions and high fever. Vancomycin started 11/28-->oxacillin 11/29. Probable 10 days course.

Fever*Assessment & Plan*

Previously we have proven that she developed a toxic reaction to loop diuretics with high fever and has been off of these for several days.

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9/26/2019: Developed fever again, cultures sent and started on cefepime. Infectious Disease indices do not did appear impressive, it is possible that she is having an adverse reaction to her metolazone or her Diuril.

10/1/19: Cultures positive for Stenotrophomonas from lung as well as Klebsiella in urine. Antibiotics changed to bactrim 9/28/19 as both are sensitive.

11/6/19: No significant fever since 10/24/19. Off antibiotics since 10/31/19. Ongoing surveillance.

11/8/19: Febrile overnight. Cultures sent.

11/14/19: Febrile overnight. Cultures sent.

11/27/19: Completed course of antibiotics for Stenotrophomonas and S. Aureus LRI in past 24 hours. Again febrile overnight without other finding other than thick tracheal secretions. Ongoing close surveillance culturing as indicated.

11/30/19: Grew abundant Staph aureus 11/27. Ongoing treatment with oxacillin with improved secretions. Febrile 11/28. Hypernatremic at time. Correcting with manipulation of diuretics/free water in TPN. Ongoing surveillance.

Difficult intravenous access*Assessment & Plan*

Requiring interventional radiology to place a PICC line on July 29, 2019

Personal history of ECMO*Assessment & Plan*

Patient with profound hypoxemic respiratory failure with worsening pulmonary hypertension requiring ECMO rescue 7/9/2019

7/12/2019: Patient remains on VA ECMO support with excellent perfusion and low lactate levels.

7/14/2019: Patient transitioned off of VA ECMO support with decannulation in the OR.

Chronic lung disease in neonate*Assessment & Plan*

Patient with history of prematurity, complex congenital heart disease, and gross anatomic emphysema seen at the time of initial cardiac surgery. Pulmonary veins are desaturated on cardiac catheterization

7/12/2019: Patient remains on Pulmicort and albuterol therapy and is followed by pulmonology.

7/27/2019: Patient continues to struggle with issues related to underlying chronic lung disease. She will likely require long-term mechanical ventilation.

8/20/2019: Patient with severe chronic lung disease. She has required systemic steroids approximately once a month over the last 3-4 months. She continues on Pulmicort with aggressive beta agonist therapy.

9/11/2019: Patient continues to exhibit evidence of severe chronic lung disease with poor pulmonary compliance with oxygen and diuretic requirements. Has a very poor overall pulmonary prognosis.

12/1/2019: This continues to be a significant problem given poor pulmonary compliance and appearance of chest radiograph.

Electrolyte and fluid disorder*Assessment & Plan*

Requiring ongoing boluses of calcium chloride and bicarbonate first postoperative night. Ongoing need for volume replacement to maintain adequate filling pressures for cardiac output. Will require ongoing

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meticulous supportive care and once stabilized, diuretics to resolve edema.

2/20/2019: Persistent truncal edema, on diuretic therapy.

3/6/2019: Significant improvement in edema. Now on intermittent lasix. Ongoing need for surveillance of electrolytes.

4/12/19: The patient has had issues with hypoglycemia associated with bolus feeds. This appears to be improving.

6/19/19: Has tolerated bolus feeds without hypoglycemia in interim since last update. Fasting study planned before discharge by endocrine. Ongoing need for diuretics, electrolyte monitoring and sodium chloride supplementation for hyponatremia.

7/16/19: Acute deterioration on 7/9/19, ongoing TPN support given cardiorespiratory status. Diuretics have been given as appropriate. Requiring manipulation of electrolytes in TPN.

7/27/2019: Continue ongoing surveillance and replacement of electrolytes

8/8/19: Increased edema in past 24 hours, now back on bumex infusion with diuril. Addressing hypochloremic alkalosis with diamox, normal saline IVF.

8/17/2019: Patient with ionized hypocalcemia, hypokalemia, hyperglycemia, metabolic acidosis all as would be expected following cardiac surgery. There will be ongoing surveillance replacement

9/2/19: Metolazone started 8/30 for persistent edema despite bumex and diuril. Good response. Marked electrolyte derangements as is common with use of this diuretic. Requiring aldactone, supplemental potassium, and sodium. Scheduled metolazone q 24 hours 9/1/19. Ongoing close surveillance of fluid status and electrolytes needed.

9/4/2019: Held metolazone and diuril today for elevated BUN/Cr. Electrolyte supplementation decreased.

9/9/2019: In interim, diuril and metolazone restarted. Titrating to effect.

9/10/19: Ongoing titration of diuretics targeting optimal fluid balance. Trial of bumex to lasix today. Diuril unchanged. Metolazone will be given on an as needed basis rather than scheduled.

9/15/19: Increased lasix to 1.5 mg/kg q 6 hours with ongoing diuril q 12h. Still requiring occasional dose of metolazone. Positive fluid balance and edema on exam.

9/17/2019: Continue ongoing surveillance and replacement of electrolytes in the setting of changing diuretic therapy

09/23/2019: Child received tolvaptan with increase in serum sodium as expected.

10/1/19: Reintroduction of loop diuretics. If recurrent fever in absence of infection will stop. Electrolytes requiring close surveillance.

10/22/19: Has not had sustained fever on loop diuretics although still with some intermittent fevers. Edema persistent but improved. Ongoing therapy.

11/17/19: Has continued on diuretic therapy. Ongoing titration based on fluid balance. Ongoing surveillance of electrolytes required.

12/1/2019: There continues to be ongoing electrolyte surveillance and replacement with daily adjustments made in TPN.

Acute respiratory failure with hypoxia and hypercarbia (CMS/HCC)

Assessment & Plan

Multifactorial including prematurity, marked cardiomegaly and ongoing issues with pulmonary blood flow.

Ventilated preoperatively with difficulty, requiring JET ventilation and marginal saturations despite iNO.

Early pulmonary interstitial emphysema noted prior to surgery. Postoperatively, requiring significant

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

support, with ongoing use of iNO, FiO2 1.0, and significant pressures to offset abnormal respiratory system compliance. Titrating support as possible, to minimize ongoing barotrauma.

2/14/19: Some improvement in gas exchange, able to wean FiO2. Lungs with emphysematous appearance at time of chest exploration.

2/20/19: Continues to require full ventilatory support. Chest remains open.

2/24/2019: Remains on full mechanical ventilatory support. We will wean as tolerated

2/26/2019: Patient with evidence of poor gas exchange yesterday. This is likely multifactorial due to not only intrinsic lung disease but issues with pulmonary blood flow. The patient remains on nitric oxide and full mechanical ventilatory support

3/4/19: Improving gas exchange appropriate for physiology; not yet ready ready for significant weaning.

3/6/19: Making slow gains. Has tolerated some decrease in rate.

3/10/19: Difficult to wean ventilation. She has good gas exchange when cardiac output is good. We will attempt to wean as tolerated.

3/13/2019: With improvement of cardiac output over the last several days we have begun weaning mechanical ventilation. Gas exchange remains good

3/21/2019: Patient is tolerating weaning of mechanical ventilation. She will likely be extubated soon.

3/22/2019: Plans are for extubation to high-flow nasal cannula today

3/23/2019: The patient has been extubated to high-flow nasal cannula 12 L. Patient exhibits evidence of reasonable gas exchange despite a paralyzed right hemidiaphragm

3/27/2019: Weaning HFNC, down to 10 L

3/29/2019: Improving gradually, now on 8 LPM

4/6/2019: Continues to require high-flow nasal cannula. This is multifactorial given chronic lung disease, chronic heart failure, as well as enlarged cardiac size.

4/12/2019: High-flow nasal cannula is being weaned slowly. This appears to be tolerated

4/16/2018: The patient has had episodic increased work breathing. This may be secondary to aspiration or chest difficulty secretions.

4/19/2019: Earlier in the week the patient had high-flow nasal cannula increased. We have begun weaning this again. Currently now at 6 liters/minute.

4/23/19: Tolerating 6 lpm with 4lpm with feeds.

4/25/19: Tolerating 4 lpm with some intermittent increase in breathing.

4/27/2019: Worsening difficulty maintaining oxygen saturations, decreased aeration and intermittently increased work breathing caused increase of high-flow back to 15 L with addition of med nebs and albuterol every 3 hr. Diffuse atelectasis noted on chest x-ray.

4/28/19: Stabilizing in past 24 hours with improved respiratory status; able to wean to 10 lpm this morning.

4/29/2019: Continue to have episodes of desaturation and poor aeration, necessary to increase high-flow back up to 15 L and restart meta neb treatments. Low-dose Ativan added for tolerance of IPV treatments. Good response overnight to aggressive pulmonary recruitment.

5/1/10: Prelone started 4/29 x 5 days. Weaning flow gradually. IPV ongoing. Not needing as much sedation.

05/02/2019. High-flow nasal cannula went 8 liters/minute.

5/4/2019: Patient has been transitioned to a standard nasal cannula.

5/6/2019:: The patient was transiently on a regular nasal cannula but escalated back to a high-flow nasal cannula on 5/4/2019 in the afternoon. She remains on 6 liters/minute.

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5/15/2019: The patient remains on 6 liters/minute of high-flow nasal cannula. She continues to have intermittent episodic airway obstruction and wheezing. She has responded to albuterol. She continues on Pulmicort.

May 17, 2019: Patient returned from the cardiac catheterization lab intubated. A bronchoscopy showed otherwise normal upper airway with slight inflammation on the left main bronchus. Significant hypoxemia and V/Q mismatch that improved with inhaled nitric oxide. Significant amount of secretions and the baby was started on broad-spectrum antibiotics.

5/19/2019: Has remained on full ventilatory support, nitric oxide and aggressive chest physiotherapy in last 24 hr. Overall pulmonary function appears to be improving especially with improvement in saturations after transfusion. She should be ready to start weaning on her aggressive treatment of her hypoxemia.

5/20/2019: The patient remains on mechanical ventilatory support. This is been aggressively weaned over the last 24 hr. This is been well tolerated. We will work towards extubation

5/21/2019: Patient extubated last night to HFNC. Reasonable gas exchange, but continued increased work of breathing/marginal respiratory status.

05/25/2019: Placed on isolation. Respiratory pathogen panel sent and revealed rhino virus. Patient remains on high-flow nasal cannula that went from 10 L up to 15 L due to increased work of breathing and secretions.

5/26/2019: IPV treatments every 3 hr added again due to increasing oxygen requirement tachypnea, improved overnight with improved chest x-ray.

5/29/2019: IPV treatments decreased every 6 hr, high-flow currently at 12 liters/minute and overall the child appears to be making some slow steady progress.

5/30/2019: Patient has been increased to 15 liters/minute of high-flow nasal cannula. She has episodic increased work of breathing. She continues to recover from her rhino virus infection

6/5/2019: Child had increasing oxygen requirement with decreasing saturations with worsening cough overnight. High-flow nasal cannula oxygen increased to 20 liters/minute and started back on IPV treatments every 6 hr with some improvement.

June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO2 was weaned as well as the flow on the nasal cannula. The patient was started on sildenafil

6/17/19: Patient has had interval improvement of respiratory status. Currently on 6 liters/minute with an FiO2 of 0.35.

6/19/19: Requiring increased flow today for work of breathing and FiO2 requirements.

6/25/19: Continues on 15 lpm flow. Breath sounds tighter past 24 hours, diuretics increased and now on q 2 hour albuterol.

6/26/2019: The patient continues on high-flow nasal cannula. Subjectively she has been improved since continuous feeds were started. She continues to have variable oxygen requirement.

6/28/19: Interval improvement. Trial of decreased flow to 12 lpm. Albuterol back to q 3 hours

6/30/19: The patient has had gradual interval improvement through the week. The patient has been weaned to 10 liters/minute of high-flow nasal cannula.

7/1/19: Tolerated 8 lpm of flow in past 24 hours. Clinically with good aeration. Weaning sildenafil to off.

7/8/2018: High-flow nasal cannula oxygen has slowly been escalated 15 liters/minute as a child wean off of sildenafil in order to maintain good oxygen saturations and maintain a reasonable work of breathing.

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7/9/2019: Patient with acute respiratory arrest in the early morning hours of 7/9/2019. Patient had acute loss of air movement and was difficult to bag mask ventilate. Apparent cause was some mucus plugging. Patient was emergently intubated and despite aggressive pulmonary toilet measures it was very difficult oxygen and ventilated. This also likely lead to a pulmonary hypertensive crisis. Despite aggressive pulmonary toilet measures, sedation, neuromuscular blockade, systemic alkalinization, and transfusion there was not much improvement. Patient emergently placed on VA ECMO.

7/14/2018: Patient transitioned off of ECMO in OR. After return from OR patient needing 100% FiO2 and 20 parts per million of nitric with high ventilatory settings to keep appropriate oxygen saturations.

July 15, 2019: The child had profound hypoxemia with saturations around 30%, after bagging ventilation and suctioning with 100% oxygen and inhaled nitric oxide at 20 parts per million, the baby is oxygen saturations did not improved. After increasing the the nitric oxide to 80 parts per million, epinephrine 0.1 micrograms/kilos per minute and a fluid bolus, the oxygen saturations started to improve. Echocardiogram showed an open shunt with concerns for increased pulmonary vascular resistance.

7/16/19: Right pneumothorax present on morning CXR which was evacuated. Improving saturations/NIRS through day, requiring volume and vasoactive medications to drive shunt flow. Still requiring FiO2 upwards of 0.6.

7/18/2019: Patient has had some improvement. Continues with significant hypoxemia. Currently on full mechanical ventilatory support. The patient has not tolerated sildenafil for pulmonary hypertension. We will likely start bosentan

7/21/2019: The patient remains on full mechanical ventilatory support continuing ongoing titration. Her saturations appear to be more stable in the setting of Bosentan therapy. She continues to require aggressive pulmonary toilet measures.

7/22/2019: Trial of IPV therapy to see whether this improves saturations.

7/27/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension measures. She will likely need tracheostomy for long-term ventilation as a no other means of therapy and support for her chronic lung disease and pulmonary hypertension

8/2/2019: Patient has had clinical improvement over the last 1-2 days. Continues to require high driving pressure to overcome pulmonary hypertension with epinephrine. Continues on Bosentan. Continues on nitric oxide and full mechanical ventilatory support. The patient has been started on a five day course of Solu-Medrol. This has transiently improved her in the past. She will likely continue to require chronic mechanical ventilation and tracheostomy.

8/4/19: Off epinephrine. Maintaining adequate saturations on < 0.5 FiO2.

8/8/19: More wet in past 24 hours. Increased distress and less ability to be awake and tolerate ventilatory support. No room for weaning of support.

8/10/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension of measures.

8/13/2019: Continues to struggle from labile oxygen saturations despite paralysis and aggressive respiratory support. Will start a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentin.

8/17/2019: Patient is on full mechanical ventilatory support following surgery. This will be titrated appropriately. She remains on inhaled nitric oxide.

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8/18/2019: Child decompensated with extremely poor pulmonary compliance and persistent oxygen saturations in the high 50s to low 60s despite paralysis, aggressive analgesia and sedation, suctioning and other interventions on conventional mechanical ventilatory support. Ultimately transition to the oscillator with slow pulmonary recruitment and stability overnight.

8/20/2019: Patient with severe chronic lung disease superimposed with likely acute lung injury in the setting of a recent cardiac surgery. There is been no infectious etiology for her decompensation. After some time on high-frequency mechanical ventilation she has been transition to conventional ventilation. She is on systemic steroids for a five day course the and aggressive beta agonist therapy. Overall her prognosis from a chronic lung disease standpoint remains quite guarded

8/25/2019: Patient continues to struggle with underlying chronic lung disease, acute lung injury, single ventricle physiology, profound hypoxemia, airway reactivity. She remains on pressure control ventilation that was started on 08/23 due to high peak inspiratory pressures. Her gas exchange is been reasonable. She remains on a relatively high inspired oxygen not being able to be wean lower than 0.5. She remains on nitric oxide, Bosentan, in sildenafil at escalating doses. She remains on systemic steroids have been weaned to q.12 as well as albuterol at 5 mg an hour.\

8/29/2019: Off of continuous albuterol, steroids weaned to once daily. She continues to have rhonchi, wheezes and poor pulmonary compliance and does not appear to have had a significant response to steroids nor albuterol. She has been reasonably tolerant of cares lately on decreased vecuronium however.

8/31/2019: The patient continues on full mechanical ventilatory support. Unfortunately with discontinuation of her vecuronium she had profound desaturation hypoxemia and neuromuscular blockade is been restarted. She remains on inhaled nitric oxide in deep sedation. She continues to required aggressive pulmonary toilet measures

9/6/2019: The patient remains on full mechanical ventilatory support. She remains on deep sedation. Neuromuscular blockade is being reduced. She continues aggressive pulmonary toilet.

9/9/19: Off neuromuscular blockade infusion. Tolerating much better than in the past.

9/11/2019: The patient remains on full mechanical ventilatory support. Continues to have evidence of poor pulmonary compliance. Continues to have a persistent oxygen requirement with an FiO2 of 0.5-0.6.

9/17/2019: The patient remains on full mechanical ventilatory support. The patient has been on 65-70% oxygen for most of the last 24 hr. Pulmonary compliance continues to be an issue. Prognosis remains quite poor to guarded

9/21/2019: Patient remains on full mechanical ventilatory support and 100% FiO2. Her fluid overload has been compromising her oxygenation and ventilation. Prognosis remains poor.

10/2/2019: The patient remains on full mechanical ventilatory support. There have been some difficulties in ventilation. IMV is been increased. FiO2 is been weaned to 0.75. Gas exchange is somewhat suboptimal

10/5/2019: Patient remains on full mechanical ventilatory support. We have been able to wean the FiO2 somewhat, IMV is been increased due to mild respiratory acidosis

10/10/2019: Patient with complete atelectasis of the left lung requiring aggressive recruitment maneuvers with IPV and bag suctioning.

10/14/2019: The patient has had some improvement over the last several days with aggressive pulmonary toilet measures. She remains on quite stout mechanical ventilatory support. We have been able to wean her FiO2 which is mostly between 40 and 50%. She continues to require deep sedation and neuromuscular blockade. Her prognosis remains quite poor.

10/19/2019: Patient has required increasing FiO2 over the last 48-72 hours. She continues to require

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

relatively deep sedation with intermittent neuromuscular blockade. Prognosis remains poor

10/20/2019: Restarted on low-dose vecuronium due to persistent agitation and need for excessive p.r.n. Medications, child was also given a trial of ketamine without significant improvement.

10/25/2019: The patient remains on full mechanical ventilatory support requiring between 40 and 70% oxygen deep sedation, neuromuscular blockade, and aggressive pulmonary toilet interventions to maintain reasonable gas exchange

11/7/2019: Vecuronium infusion stopped today given discussion of withdrawal by family. Vecuronium will be given on prn basis for issues with ventilating or excessive movement.

11/10/2019: Continues to require full ventilatory support. Intermittent increase in PIP's with agitation/airway secretions. Requiring increased oxygen off vecuronium. Vecuronium will be used on PRN basis for excessive movement threatening safety of ETT and ventilatory dyssynchrony with desaturation.

11/17/19: Interval worsening of secretions with tracheal aspirate growing abundant Staph aureus as well as stenotrophomonas maltophilia. Febrile at time culture was drawn. Antibiotics ongoing. Plan 7-10 day course. Vest therapy used in place of IPV given issues with hypotension.

11/19/2019: Patient has had worsening pulmonary compliance with increasing edema as diuretics were held in the setting of hypotension. Peak inspiratory pressures are now in the low to mid 40s. My hope is this will improve with reinstitution of diuretics now that hemodynamics are more stable.

11/25/2019: The patient remains on full mechanical ventilatory support. There has been some improvement in pulmonary compliance with aggressive diuresis however peak pressures remained in the mid 30s.

12/1/2019: Patient remains on full mechanical ventilatory support. She continues on aggressive pulmonary toilet measures.

12/4/2019: CT scan of the chest demonstrates in chronic lung disease changes with ground-glass appearance opacities, bronchiectasis, and multiple areas of atelectasis.

SUBJECTIVE:

Interval History: Over the past 24 hr the patient has remained hemodynamically stable and in a sinus rhythm. Oxygenation has remained reasonable. The patient did have bloody secretions noted yesterday afternoon which required aggressive suctioning with bicarbonate. Peak pressures have been elevated on the ventilator more so over the last 48 hr than before. The patient had excellent urine output in the setting of diuretics. No fever was noted. The patient was taken to CT for CT of the chest. That study demonstrated signs consistent with chronic lung disease including inferior bronchiectasis and ground-glass opacities. Patient tolerated procedure well and was transition back to the cardiac ICU in stable condition.

Current Support:

Cardiovascular:

Lines

Active :

Name:	Placement date:	Placement time:	Site:	Days:
Arterial Line 08/16/19 Left	08/16/19	1700	Ulnar	110



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

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Ulnar					
DL PICC RED/WHT 07/29/19	07/29/19	1032	Other (Comment)	128	
Left Other (Comment)					

Antiarrhythmic Support Amiodarone, flecainide

Pacemaker: No

Other Cardiac Medications: Lasix, Diuril, Bosentan, sildenafil, epinephrine, norepinephrine

Anticoagulation: Aspirin

Respiratory

Respiratory Support:

SpO2: (!) 80 %

Oxygen Therapy: Supplemental oxygen

Delivery Method: Endotracheal tube

FiO2: 45 %

O2 Flow Rate: 7 L/min

Vent Support:

Ventilator Type: GE - R860

Shared Ventilator Settings

FIO2 (Vent): 35 %

Vent Rate: 35

Ordered PIP/Ppeak: (S) 0 cm H2O

PEEP: 8 cm H2O

MAP (cm H2O): 15

Pressure Support: 12 cm H2O

ETCO2 (mmHg): 30.9 mmHg

Vt (mL): 60 mL

Insp Time: 0.6 sec

I:E Ratio: 1:1.9

Insp Flow (L/sec): 1 L/sec

Trigger Sensitivity Flow (L/min): 1 L/min

Insp Rise: 350

Servo Pressure: 300

Nitric Oxide Used: No

Other gases: none

Lab Blood Gas Reviewed: Yes

Generated on 12/5/19 2:09 PM

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

Ins and Outs:

Admission Weight: 1.81 kg

Weight change:

I/O last 24 hours:

In: 1756.8 (206.7 mL/kg) [I.V.:230.9 (27.2 mL/kg); Blood:198; NG/GT:134.5; IV Piggyback:49.7]

Out: 1461 (171.9 mL/kg) [Urine:1456 (4.8 mL/kg/hr); Emesis/NG output:5]

Drug Calculation Weight: 8.5 kg

No intake/output data recorded.

OBJECTIVE:Physical Assessment:

Last Vital Signs:

Last Vitals

BP	(!) 83/30
Pulse	120
Temp	37.2 °C (99 °F) (Axillary)
Resp	35
SpO2	(!) 80%

GENERAL: Patient lying supine, under neuromuscular blockade on mechanical ventilatory support in no apparent distress.

HEENT: Normocephalic, atraumatic. The anterior fontanelle is open, soft, and flat. Pupils are equal, round, reactive to light bilaterally. There is no scleral icterus noted. There is no nasal flaring. The mucous membranes are moist. Nasotracheal tube in place. Nasogastric tube in place.

NECK: The neck is supple without masses.

CHEST: The midline sternotomy wound is without erythema or exudate. There is symmetrical chest wall movement without retractions. The lungs are coarse to auscultation bilaterally with expiratory wheezing.

HEART: Regular rate and rhythm with a continuous shunt murmur present.

ABDOMEN: The abdomen is large with good bowel sounds. Liver edge is palpable 5 cm below the right costal margin.

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

EXTREMITIES: The extremities are warm with capillary refill less than 3 seconds. Pulses are 2+ in all extremities. There is no deformity to the extremities.

NEURO: Patient intubated, sedated, and under the influence of neuromuscular blockade.

SKIN: No significant rash or jaundice noted.

Gu: Tanner stage I female.

Labs Reviewed: Yes

Labs:

CBC w/diff

Lab Results

Component	Value	Date
White Blood Cell Count	10.35	12/05/2019
Red Blood Cell Count	3.81	12/05/2019
Hemoglobin	11.3	12/05/2019
Hematocrit	35.4	12/05/2019
Mean Corpuscular Volume	92.9 (H)	12/05/2019
Mean Corpuscular Hemoglobin	29.7	12/05/2019
Mean Corpuscular Hemoglobin Content	31.9	12/05/2019
Red Cell Distribution Width	14.9	12/05/2019
Mean Platelet Volume	14.5 (H)	12/05/2019

BMP (Chem 10)

Lab Results

Component	Value	Date
Sodium Level	143 (H)	12/05/2019
Potassium Level	3.5 (L)	12/05/2019
Chloride Level	98	12/05/2019
Blood Urea Nitrogen	31 (H)	12/05/2019
Phosphorus Level	4.7	12/05/2019

ABG

Lab Results

Component	Value	Date
Arterial Blood pH	7.46 (H)	12/05/2019
Arterial Blood PCO2	53 (H)	12/05/2019
Arterial Blood PO2	41 (LL)	12/05/2019
Arterial Blood HCO3	37.7 (H)	12/05/2019
Arterial Blood Total CO2	39.3 (H)	12/05/2019

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

Arterial Blood Base Excess

12.1 (H)

12/05/2019

CHEST XRAY: Chest x-ray obtained on 12/5/2019 was personally reviewed by me. Endotracheal tube is in the mid trachea. Lung fields are reasonably well expanded with some inferior atelectasis noted. There is some scattered atelectasis noted throughout the midportion of the lungs. No signs of pneumothorax or pneumomediastinum. Cardiac silhouette is enlarged but stable in size and appearance from the previous day's film. Independently reviewed film. Reviewed radiologist interpretation.

CT of the chest without contrast on 12/4/2019: Cardiomegaly noted. Multifocal more peripheral patchy nodular opacities in the left lung are probably atelectasis and/or scarring, however atypical infection would be in the differential. Signs consistent with chronic lung disease including bilateral posterior medial lower lobe bronchiectasis associated with volume loss and some ground-glass opacity in the regional lung.

MAR Reviewed: Yes

ASSESSMENT/PLAN

A/B: Patient remains on significant mechanical ventilatory support. Patient continues to sound wheezy on exam and is requiring aggressive pulmonary toilet measures with ongoing scheduled albuterol and Pulmicort therapy. Pulmonology is following. We will titrate the ventilator to achieve appropriate oxygenation ventilation. Blood gas this morning demonstrates appropriate ventilation. We will monitor chest radiographs every other day. Chest CT demonstrated signs consistent with significant chronic lung injury which is likely due to chronic ventilation during most of the patient's life.

CVS: The patient remains on sildenafil, bosentan, amiodarone, flecainide, Lasix, Diuril, epinephrine, norepinephrine. The setting of these medications the patient's cardiac output is adequate in a sedated state as evidenced by a low lactate level, warm exam with good pulses, good urine output. We will continue these medications. The patient's last echocardiogram demonstrated a large right ventricle with depressed function impinging upon the left ventricle which likely inhibits some stroke volume and thus, cardiac output. The patient's liver is enlarged indicating poor RV function/RV congestion. We have been unable to offload the right ventricle with medications. There is some discussion at this time regarding a future cardiac catheterization for the patient. We will discuss this daily. We will continue to monitor echocardiograms as needed and continue the above therapies. We will monitor telemetry closely.

Neuro: Neurologically the patient is habituated to narcotics and benzodiazepines remains on scheduled methadone Ativan. The patient is also on schedule Seroquel and gabapentin. The patient is also on a Precedex infusion. The patient is under the influence of neuromuscular blockade due to frequent significant desaturations associated with pulmonary hypertension when off of neuromuscular blockade. We will monitor the limited neurologic exam closely.

FEN/GI: The patient's abdominal exam is notable for being enlarged from yesterday. Stool output has been poor over the last 24 hr. A glycerin suppository will be administered now. If the patient's abdomen continues

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

to enlarge we will hold feeds. Peak pressures on the ventilator have been increased likely due to a larger abdominal girth. We will continue TPN for the patient. We will monitor electrolytes closely and replace them as needed. We will continue bethanechol, Prevacid, and Ursodiol along with sucralfate. We will try to optimize nutrition daily. We will monitor the abdominal exam closely.

HEME: Patient remains on aspirin prophylaxis for the BT shunt. Patient was noted to have some bleeding from the airway yesterday and was given platelets in the setting of a chronically low platelet count. We will monitor CBCs closely and transfuse blood products as needed. The patient received PRBCs 48 hr ago. The hematocrit today is 35. If FiO2 needs are increasing, we will transfuse PRBCs today.

ID: Patient remains on oxacillin for a total of seven days of therapy for growing MSSA from the airway. The most recent respiratory panel sent earlier this week demonstrates normal flora. We will finish her seven day course and monitor for fever. White blood cell count is normal.

Renal: The patient's BUN is 31 creatinine 0.59. The patient remains on Lasix and Diuril therapy. We will continue these medications and monitor BUN and creatinine levels closely and monitor urine output closely.

Endo: Patient has no issues at this time. We will monitor closely. Recent thyroid function studies were normal.

Lines:

Reason for Central Venous Line: Central Strength Medications

Reason for Foley: Not Applicable (No Foley)

Parents: Mother has been at the bedside. We will update her on the plan of care today.

Others: We will continue to discuss this patient daily with Cardiology and cardiothoracic surgery.

Communication: Plan discussed with multidisciplinary team.

VTE Screen performed:

No, not applicable

Hospital Problem List

	Noted
* (Principal) Ebstein's anomaly of tricuspid valve	2/8/2019
Acute systolic heart failure	2/20/2019
Pulmonary hypertension	6/9/2019
End of life care	10/23/2019
Atrial flutter	2/2/2019
SVT (supraventricular tachycardia)	2/8/2019
Acute respiratory failure with hypoxia and hypercarbia	2/15/2019
Electrolyte and fluid disorder	2/15/2019



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breaun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes by Lane Thomas Lanier, MD at 12/5/2019 7:48 AM (continued)

	Noted
Chronic lung disease in neonate	5/20/2019
Personal history of ECMO	7/9/2019
Fluid overload	9/22/2019
Staphylococcus aureus infection	11/15/2019
Infection due to Stenotrophomonas maltophilia	9/28/2019
Pulmonary atresia	2/1/2019
Difficult intravenous access	7/29/2019
Fever	9/27/2019

Billing Time: I have personally seen and examined this patient and spent 60 minutes of critical care time on this patients behalf.

Coding Queries

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Lori Lee Nesslein, MD		Procedure Note	02/01/20 19 2110	Response Received			

Query Message

--- Doc Query Message ---
From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Lori Lee Nesslein, MD		Procedure Note	02/01/20 19 2111	Response Received			

Query Message

--- Doc Query Message ---
From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Coding Queries (continued)

Sender	Recipient	Type	Subject	Created	Status	Outcome	Respondin g Provider	Response Note
Hb, Backgroun d	Rekha Balla Hamilton, MD		Procedure Note	02/09/20 19 1745	Respon se Received			

Query Message

--- Doc Query Message ---

From: Rekha Balla Hamilton, MD
Sent: 2/9/2019 9:46 PM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Rekha Balla Hamilton, MD : 02/09/2019 - 09:46 PM

END OF REPORT

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM

Author: Ryan Ray Meyer, MD	Service: Critical Care	Author Type: Physician
Filed: 11/21/2019 9:45 AM	Date of Service: 11/21/2019 9:17 AM	Creation Time: 11/21/2019 9:17 AM
Status: Signed	Editor: Ryan Ray Meyer, MD (Physician)	

CICU PROGRESS NOTE

Introduction: Tinslee Breau Lewis is a 9 m.o. female with history of Ebstein's anomaly initially admitted to the cardiac intensive care unit in the early neonatal period following her initial palliative surgery. She has continued to have significant ongoing struggles in the ICU with issues related to her underlying single ventricle physiology, severe chronic lung disease, and pulmonary hypertension. The team continues to provide full intensive care though it is felt that this time that due to her extremely poor prognosis the care that she is receiving is futile.

Surgeon: Tam, Vincent K.H, MD

Allergies: Patient has no known allergies.

Hospital Problem List

	Noted
* (Principal) Ebstein's anomaly of tricuspid valve	2/8/2019
Acute respiratory failure with hypoxia and hypercarbia	2/15/2019
Electrolyte and fluid disorder	2/15/2019
Chronic lung disease in neonate	5/20/2019
Personal history of ECMO	7/9/2019
Staphylococcus aureus infection	11/15/2019
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Pulmonary hypertension	6/9/2019
Pulmonary atresia	2/1/2019
Difficult intravenous access	7/29/2019
Fluid overload	9/22/2019
Fever	9/27/2019
Infection due to <i>Stenotrophomonas maltophilia</i>	9/28/2019
End of life care	10/23/2019

Staphylococcus aureus infection

Assessment & Plan

Patient had fever prompting cultures on 11/13/2019. There is abundant growth of Staph aureus from the endotracheal tube. There are not significant elevation of inflammatory markers. We will plan on seven days of treatment with oxacillin.

End of life care*Assessment & Plan*

Over the last weeks all of the services (Cardiac Intensive Care, Cardiology and CV surgery) involved in the care of Tinslee have come to the same conclusion that her ongoing care has reached the level of medical futility. And furthermore that we have no additional interventions or treatments to offer her and that she has failed aggressive escalation of her pulmonary shunt to a central shunt due to her underlying chronic lung disease and pulmonary hypertension. Overall this has left her fluid overloaded with marginal pulmonary status, with marked agitation requiring aggressive sedation analgesia and paralysis which we have been unable to wean. In addition, she has been febrile and toxic on her diuretics although we have restarted them on a compassionate basis., she remains on an epinephrine infusion just to facilitate a more neutral fluid balance although she continues to get progressively fluid overloaded. We are also unable to feed her despite multiple attempts to do so.

While the extended family has expressed their concerns that the child is suffering. The child's parents do not recognize this nor do they want to deal with this situation despite all of the physicians expressing their concerns regarding the child's ongoing suffering. Due to this impasse, we have engaged the ethics committee. An Ethics committee meeting was scheduled for yesterday morning with the family invited, and having previously confirmed that they would attend, failed to show up for the meeting. The meeting was held without them unfortunately, the medical case was presented to the Ethics committee members. The committee members suggested possible descalation of our aggressive support measures including diuretics, epinephrine, paralysis and sedation as well as additional medications. However, while the child has been made a DNR, the family has expressed no interest in descalating any of her care putting us in a very precarious situation. While we have tried to wean things in the past we have needed to reinstitute these therapies, including a recent trial off of paralysis this weekend. This leaves the poor child suffering and in limbo without a clear pathway forward.

10/26/2019: A lengthy discussion was held with the patient's mother last night. A letter had been delivered by the nursing supervisor in regards to the upcoming ethics committee and potential binding decisions regarding the patient's care. The mother express significant anger and a lengthy discussion was held regarding the purpose of the meeting, as well as a review of Tinslee's hospital course, current medical problems, and prognosis. The mother reiterated that she does not feel that there is any undue suffering from her daughter. She stated that she still feels like that her daughter will "get better." I encouraged her to take the upcoming meeting seriously and to be present to express her concerns, desires for care, and to explain her thought process in decision making for her daughter.

11/4/19: Ethics committee met 10/30/19 and rendered binding decision to withdraw. Family informed with written letter given to them 10/31/19. In 10 day grace period contacting other centers as per family wishes.

11/10/19: Multiple institutions called during 10 day period. The following institutions denied transfer after review of her records: Texas Children's Hospital, Herman Hospital, Dell Children's Hospital, Dallas Children's, Medical City Hospital, Children's Medical Center in Oklahoma City, Children's Hospital of Atlanta, St. Louis Children's Hospital, Children's Hospital of Philadelphia, Johns Hopkins, Methodist Hospital San

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

Antonio, Boston Children's Hospital, Children's Hospital of Los Angeles, Arkansas Children's, CS Mott Children's in Michigan, LeBonheur Children's in Memphis, University Hospital in San Antonio, and Rady Children's Hospital in San Diego. Family attorney secured temporary restraining order mandating ongoing care today. Administration and legal involved. Medical team continues to provide ongoing aggressive treatment for Tinslee accordingly. DNR rescinded today by mother. She has a full code order now in place.

11/19/2019: Patient's prognosis remains quite poor. We continue to provide aggressive CICU support. We are communicating with other institutions regarding their opinion and potential transfer. The mother has been kept up-to-date when she is at the bedside.

Infection due to *Stenotrophomonas maltophilia**Assessment & Plan*

Growth of abundant *Stenotrophomonas* from tracheal aspirate 9/26/19. Bactrim initiated 9/28 once culture grew. Plan 14 day course.

10/22/19: Has had fever with discontinuation of bactrim prompting new cultures and starting of bactrim. Ongoing surveillance for response. Typically has had less fever when treated.

11/4/19: Course of bactrim was complete 10/31/19

11/17/19: Again with abundant *stenotrophomonas* in tracheal aspirate associated with increased secretions. Bactrim initiated overnight.

Fever*Assessment & Plan*

Previously we have proven that she developed a toxic reaction to loop diuretics with high fever and has been off of these for several days.

9/26/2019: Developed fever again, cultures sent and started on cefepime. Infectious Disease indices do not did appear impressive, it is possible that she is having an adverse reaction to her metolazone or her Diuril.

10/1/19: Cultures positive for *Stenotrophomonas* from lung as well as *Klebsiella* in urine. Antibiotics changed to bactrim 9/28/19 as both are sensitive.

11/6/19: No significant fever since 10/24/19. Off antibiotics since 10/31/19. Ongoing surveillance.

11/8/19: Febrile overnight. Cultures sent.

11/14/19: Febrile overnight. Cultures sent.

Fluid overload*Assessment & Plan*

9/22/2019: This child was proven to be toxic on loop diuretics with high fever and increasing diuretic resistant. A multi disciplinary discussion determined that she is not a candidate for renal replacement therapy and that this would likely just increase her suffering. We have however started Zaroxolyn twice daily with minimal effect. Will add scheduled Diuril twice daily to this regimen but it is unlikely to be very effective. During a care conference earlier in the week the family was informed regarding this unfortunate development and that the recommendation of the care team is that further escalation of care should not happen.

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

09/23/2019: Child on Diuril IV every 12 hr and given tolvaptan with good response.

10/1/19: Despite aggressive non loop diuretics, Tinslee remains markedly swollen. Mother has not been able to limit care. Loop diuretics reintroduced. If fever recurs, will stop.

10/6/19: Has responded to bumex infusion favorably with ongoing diuril. Other diuretics serially held/stopped. Edema is improved, but persistent. Renal indices have increased slightly, and dose limited accordingly to 0.005 mg/kg/hr. She has one temp elevation to 38.5 transiently during the week. There have not been persistent fevers as previously. Ongoing surveillance planned.

10/16/2019: We have had to back off on her diuretics significantly. We will follow BUN and creatinine closely.

10/28/2019: With reduction of diuretic burden BUN and creatinine have improved. Bumex will again be increased to 0.01 milligrams/kilogram per hour today.

11/12/2019: Over the last two weeks there has been significant titration of her diuretics. They are titrated in accordance with fluid balance while weighing underlying renal insufficiency. Currently on Bumex 0.01 milligrams/kilogram per hour and Diuril twice daily.

11/17/19: Diuril decreased to once daily given issues with lower blood pressure.

11/19/2019: Patient with worsening edema with a positive 1.5 L fluid balance over the last 72 hr. Bumex will be escalated to 0.01 milligrams/kilogram per hour today and we will give her a single dose of Diuril. We will need to assess her hemodynamics closely with this diuresis.

Difficult intravenous access*Assessment & Plan*

Requiring interventional radiology to place a PICC line on July 29, 2019

Personal history of ECMO*Assessment & Plan*

Patient with profound hypoxemic respiratory failure with worsening pulmonary hypertension requiring ECMO rescue 7/9/2019

7/12/2019: Patient remains on VA ECMO support with excellent perfusion and low lactate levels.

7/14/2019: Patient transitioned off of VA ECMO support with decannulation in the OR.

Pulmonary hypertension (CMS/HCC)*Assessment & Plan*

Pulmonary hypertension associated with chronic lung disease. On June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO2 was weaned as well as the flow on the nasal cannula. The patient was started on sildenafil. On June 10, 2019 the nitric oxide has been weaned off. BNP was elevated over 500.

6/19/19: Improved bnp (308), continues on sildenafil 1.1 mg q 8 hours.

6/24/19: Sildenafil increased yesterday to 2.3 mg q 8 hours for higher oxygen needs

6/25/19: Worsening aeration, tight breath sounds. Sildenafil decreased back to previous dose.

7/1/19: Weaning sildenafil to off, tolerating thus far.

7/2/2018: Sildenafil is off.

7/9/2019: Patient with worsening hypoxemia and work of breathing and desaturation over the last several

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

days. High-flow a been escalated. Patient placed back on nitric oxide 7/8/2019: Patient with severe hypoxemic decompensation with likely worsening pulmonary hypertension this morning. Patient transitioned on to VA ECMO support.

7/12/2019: Patient remains on VA ECMO support and inhaled nitric oxide.

7/14/2018: Patient decannulated from VA ECMO support in the OR. Patient underwent replacement of her BT shunt with a 5.0 mm BT shunt. Patient was unable to wean off nitric oxide in OR and remains on inhaled nitric oxide at 20 parts per million and 100% FiO2 from the ventilator.

7/18/2019: Patient has had intolerance of sildenafil. Bosentan and will be started today. The patient remains on nitric oxide

7/21/2019: The patient remains on inhaled nitric oxide. There has been improvement in saturations with Bosentan.

7/27/2019: The patient remains on nitric oxide and bosentan

8/2/2019: The patient remains on nitric oxide, Bosentan, mechanical ventilation with high inspired oxygen. She continues to require at high driving pressure to maintain adequate pulmonary blood flow

8/8/19: Nitric oxide increased back from 5 to 10 ppm in past 24 hours for worsening oxygenation especially with agitation.

8/11/2019: Inhaled nitric oxide increased back to 20 parts per million.

8/13/2019: Marginally better but still labile on paralysis, are giving a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentin. Child has very small pulmonary arteries attached to her 5 mm shunt likely representing significant anatomic resistance to pulmonary blood flow, cardiac catheterization evaluation today.

8/15/2019: Cardiac catheterization on the 14th revealed a stenosis with a likely 60-80 mm gradient in the innominate artery between the ascending aorta and the takeoff of the BT shunt, this could explain the need for hypertensive blood pressures to maintain adequate oxygen saturations and amenable to surgical correction. Dr. Tam is performing a central shunt today.

8/16/2019: Central shunt delayed until today.

8/18/2019: Bosentan discontinued

8/20/2018: Patient remains on inhaled nitric oxide and Bosentan. It should be noted that cardiac catheterization data demonstrating approximately 1/3 to 1/2 systemic pulmonary artery pressures performed in the setting of deep sedation and paralysis, inhaled nitric oxide, and Bosentan. If the patient demonstrates evidence of pulmonary overcirculation we will begin weaning nitric oxide.

8/22/2019: Patient remains on full mechanical ventilatory support, inspired oxygen, nitric oxide, and Bosentan. We will attempt to start sildenafil today.

8/25/2019: The patient remains on full mechanical ventilatory support, nitric oxide at 20 parts per million, bosentan, and now sildenafil has been escalated to 1 milligram/kilogram every 6 hr.

9/2/19: Patient weaned off nitric oxide this morning. Continues on bosentan and sildenafil.

10/4/19: Sildenafil reduced to 2 mg/kg/day given vasodilation, evidence of pulmonary overcirculation, and hypotension.

11/9/2019: Patient remains on sildenafil and bosentan therapy with reasonable saturations off of vecuronium.

11/16/19: Has required reinstitution of vecuronium for ventilatory dyssynchrony/agitation.

11/17/19: Sildenafil dose has been decreased by 25% given issues with hypotension with adequate PaO2 on

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

blood gas on 45% oxygen.

11/19/2019: Patient remains on both Bosentan sildenafil. PaO2 is a are in the high 30s.

Chronic lung disease in neonate*Assessment & Plan*

Patient with history of prematurity, complex congenital heart disease, and gross anatomic emphysema seen at the time of initial cardiac surgery. Pulmonary veins are desaturated on cardiac catheterization

7/12/2019: Patient remains on Pulmicort and albuterol therapy and is followed by pulmonology.

7/27/2019: Patient continues to struggle with issues related to underlying chronic lung disease. She will likely require long-term mechanical ventilation.

8/20/2019: Patient with severe chronic lung disease. She has required systemic steroids approximately once a month over the last 3-4 months. She continues on Pulmicort with aggressive beta agonist therapy.

9/11/2019: Patient continues to exhibit evidence of severe chronic lung disease with poor pulmonary compliance with oxygen and diuretic requirements. Has a very poor overall pulmonary prognosis.

Acute systolic heart failure (CMS/HCC)*Assessment & Plan*

Infant initially with cardiogenic shock in the immediate postoperative period. While shock has resolved, infant continues to have heart failure, requiring epinephrine support. Has variably been on milrinone, currently off.

2/24/2019: Patient continues on aggressive heart failure management. The patient is currently on epinephrine infusion as well as diuretics.

2/26/2019: Patient remains on diuretics. We have discontinued epinephrine in an effort to see if this would help with the dysrhythmia. We will also be more liberal on fluid administration.

2/27/2019: Blood pressure and NIRS lower off epinephrine. Restarted at 0.02 mcg/kg/min with milrinone at 0.3 mcg/kg/min. Gradual improvement noted in perfusion and blood pressure. Ongoing need for titration of vasoactive medications.

3/4/2019: Off epinephrine. Improved perfusion on milrinone. Still with rhythm issues, intermittent atrial bigeminy with some compromise of cardiac output; NIRS remain marginal.

3/10/2019: Patient remains on Milrinone and diuretics. Patient's hemodynamics have been more stable when in a sinus rhythm.

3/28/2019: Milrinone weaned off. Patient remains on Lasix only.

4/19/2019: Patient transitioned to IV Lasix earlier in the week. We will transition back to p.o. Lasix twice daily.

4/22/19: Continues to struggle with fluid balance. Significantly positive balance on twice daily Lasix, increased to q.8 hours today.

4/28/2019: Continues to do better on increased diuretics (q 8 hours)

5/1/19: Continues on increased diuretics, now q 6 hours.

5/7/19: Continues on diuretics, now q.8 hours Lasix.

5/15/2019: Patient has been transitioned to twice daily Lasix.

5/21/19: Now on increased diuretics s/p cath with respiratory failure. Perfusion remains good without other cardiac medications.

6/19/19: Continued need for meticulous attention to fluid status and diuretic therapy. Siladenafil has been

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

added to regimen. BNP down to 308 6/19/19 from 560.1 several days ago.

6/25/19: BNP 351 yesterday. Diuretics increased past 24 hours for tighter breath sounds. Given lack of improvement, team again considering cath

7/1/19: Reasonable week. Support unchanged other than weaning sildenafil to off. Remains on increased diuretics with stable renal indices.

7/7/2019: Worsening hypoxemia resulted in increase in high-flow nasal cannula 20 liters/minute with 80-90% FiO₂.

7/9/2019: Patient with clinical decompensation. Placed on epinephrine and Milrinone infusions to augment cardiac output. Patient ultimately transitioned on to veno arterial ECMO support.

7/14/2019: Patient now on epinephrine and Milrinone therapy after upsizing of her shunt in the OR today. Patient decannulated from ECMO support.

7/18/2019: Patient remains on epinephrine. Milrinone will be initiated today due to poor peripheral perfusion. She remains on aggressive pulmonary hypertensive and respiratory support.

7/21/2019: The patient remains on epinephrine infusion as well as pulmonary hypertensive therapies. She is warm and well perfused. We will attempt to wean epinephrine as tolerated. She is on diuretics.

7/27/2019: Patient remains on epinephrine and Milrinone infusions. She remains on diuretics. Given her normal LV function on echocardiogram and the vaso dilated appearance of her exam we will attempt to wean her Milrinone. My hope would be that with better vascular tone we will be able to improve pulmonary blood flow and wean epinephrine.

8/2/2019: Patient remains on a low-dose epinephrine infusion. She has required higher driving pressures to facilitate pulmonary blood flow. She continues on aggressive pulmonary hypertensive support

8/3/2019: Epinephrine infusion has been discontinued. She continues on aggressive pulmonary hypertensive measures. She continues on aggressive diuretics.

8/12/2019: Patient with increasing BNP, intolerance of feeds, fever and desaturations. Patient started on Milrinone at 0.5 micrograms/kilogram per minute. Patient remains on Bumex and Diuril.

8/13/2019: Continues to struggle from lability of oxygen saturations. Milrinone increased to 1 microgram/kilogram per minute and diuretics held for now.

8/14/2019: Despite hyperdynamic appearance of heart on echocardiogram the child did respond with less labile oxygen saturations after starting epinephrine, currently at 0.08 micrograms/kilogram per minute.

8/17/2019: Epinephrine has been discontinued in the operating room. The patient remains on Milrinone and aggressive pulmonary hypertensive therapies.

8/18/2019: Restarted on epinephrine due to poor oxygen saturations, however this was likely due to underlying poor pulmonary function and not pulmonary blood flow as echo showed good flow and pulmonary arteries and shunt.

8/20/2019: Patient remains on Milrinone. We are weaning epinephrine as tolerated.

8/21/2019: Patient remains on Milrinone and aggressive diuretic support. Epinephrine is been discontinued. Milrinone will be weaned as tolerated

8/25/2019: Milrinone will be discontinued today. Patient continues on aggressive diuretics. She is quite vasodilated in the setting of sildenafil therapy.

9/8/2019: Patient remains off vasoactive infusions on aggressive diuretics. She continues to have hepatomegaly on exam.

9/17/2019: Diuretics with the exception of Aldactone a been discontinued in the setting of elevated creatinine and persistent fevers felt to be either drug related or secondary to intravascular volume depletion.

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

We will assess BUN and creatinine in need for diuretics over the coming days.

09/18/2019: Patient restarted on Milrinone in hopes of improving cardiac output and improved diuresis.

09/19/2019: Patient started on metolazone IV every 12 hr. Remains on Milrinone now being weaned.

9/20/2019: Milrinone weaned off.

10/2/2019: The patient remains on metolazone, Diuril, and a Bumex infusion has been added. Tolvaptam has been discontinued. An epinephrine infusion is also been added due to hypotension.

10/5/2019: The patient remains on epinephrine infusion, Bosentan, sildenafil which has reduced dosage, Bumex, Diuril. Metolazone is been discontinued.

10/13/2019: Bumex increased to 0.01 milligram/kilogram per hour. Low-dose epinephrine drip discontinued.

10/16/2019: We have had to back off on diuretics considerably given worsening of renal insufficiency. Low-dose epinephrine infusion has been re-initiated. She continues on aggressive pulmonary hypertension measures.

10/22/19: Ongoing titration of diuretics as possible to improve edema; continues to require epinephrine support. On sildenafil 2 mg/kg/day and bosentan.

10/28/2019: The patient remains on epinephrine as well as aggressive pulmonary hypertension measures. Diuretics were reduced significantly through the course of last week due to worsening renal insufficiency. BUN and creatinine have improved and diuretics will be again escalated. This has been an ongoing issue.

11/9/2019: Patient continues on epinephrine and multiple pulmonary hypertensive medications.

11/12/2019: The patient remains on epinephrine to provide adequate driving pressure to promote pulmonary blood flow. She continues on aggressive support for pulmonary hypertension. Diuretics continue however she has not achieved in negative fluid balance and is becoming more edematous.

11/16/2019: Has required increase in epinephrine to 0.04 mcg/kg/min. Marginal blood pressures. Titrating diuretics accordingly.

11/19/2019: Over the course of the last several days hypotension has been a problem. Norepinephrine was added on 11/17/2019 with improvement. Unfortunately diuretics had to be held due to the need for volume expansion. Bumex has been restarted at a low dose and will be advanced today to 0.01 milligrams/kilogram per hour. We will give a single dose of Diuril today.

Electrolyte and fluid disorder

Assessment & Plan

Requiring ongoing boluses of calcium chloride and bicarbonate first postoperative night. Ongoing need for volume replacement to maintain adequate filling pressures for cardiac output. Will require ongoing meticulous supportive care and once stabilized, diuretics to resolve edema.

2/20/2019: Persistent truncal edema, on diuretic therapy.

3/6/2019: Significant improvement in edema. Now on intermittent lasix. Ongoing need for surveillance of electrolytes.

4/12/19: The patient has had issues with hypoglycemia associated with bolus feeds. This appears to be improving.

6/19/19: Has tolerated bolus feeds without hypoglycemia in interim since last update. Fasting study planned before discharge by endocrine. Ongoing need for diuretics, electrolyte monitoring and sodium chloride supplementation for hyponatremia.

7/16/19: Acute deterioration on 7/9/19, ongoing TPN support given cardiorespiratory status. Diuretics have

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

been given as appropriate. Requiring manipulation of electrolytes in TPN.

7/27/2019: Continue ongoing surveillance and replacement of electrolytes

8/8/19: Increased edema in past 24 hours, now back on bumex infusion with diuril. Addressing hypochloremic alkalosis with diamox, normal saline IVF.

8/17/2019: Patient with ionized hypocalcemia, hypokalemia, hyperglycemia, metabolic acidosis all as would be expected following cardiac surgery. There will be ongoing surveillance replacement

9/2/19: Metolazone started 8/30 for persistent edema despite bumex and diuril. Good response. Marked electrolyte derangements as is common with use of this diuretic. Requiring aldactone, supplemental potassium, and sodium. Scheduled metolazone q 24 hours 9/1/19. Ongoing close surveillance of fluid status and electrolytes needed.

9/4/2019: Held metolazone and diuril today for elevated BUN/Cr. Electrolyte supplementation decreased.

9/9/2019: In interim, diuril and metolazone restarted. Titrating to effect.

9/10/19: Ongoing titration of diuretics targeting optimal fluid balance. Trial of bumex to lasix today. Diuril unchanged. Metolazone will be given on an as needed basis rather than scheduled.

9/15/19: Increased lasix to 1.5 mg/kg q 6 hours with ongoing diuril q 12h. Still requiring occasional dose of metolazone. Positive fluid balance and edema on exam.

9/17/2019: Continue ongoing surveillance and replacement of electrolytes in the setting of changing diuretic therapy

09/23/2019: Child received tolvaptan with increase in serum sodium as expected.

10/1/19: Reintroduction of loop diuretics. If recurrent fever in absence of infection will stop. Electrolytes requiring close surveillance.

10/22/19: Has not had sustained fever on loop diuretics although still with some intermittent fevers. Edema persistent but improved. Ongoing therapy.

11/17/19: Has continued on diuretic therapy. Ongoing titration based on fluid balance. Ongoing surveillance of electrolytes required.

Acute respiratory failure with hypoxia and hypercarbia (CMS/HCC)

Assessment & Plan

Multifactorial including prematurity, marked cardiomegaly and ongoing issues with pulmonary blood flow. Ventilated preoperatively with difficulty, requiring JET ventilation and marginal saturations despite iNO.

Early pulmonary interstitial emphysema noted prior to surgery. Postoperatively, requiring significant support, with ongoing use of iNO, FiO2 1.0, and significant pressures to offset abnormal respiratory system compliance. Titrating support as possible, to minimize ongoing barotrauma.

2/14/19: Some improvement in gas exchange, able to wean FiO2. Lungs with emphysematous appearance at time of chest exploration.

2/20/19: Continues to require full ventilatory support. Chest remains open.

2/24/2019: Remains on full mechanical ventilatory support. We will wean as tolerated

2/26/2019: Patient with evidence of poor gas exchange yesterday. This is likely multifactorial due to not only intrinsic lung disease but issues with pulmonary blood flow. The patient remains on nitric oxide and full mechanical ventilatory support

3/4/19: Improving gas exchange appropriate for physiology; not yet ready ready for significant weaning.

3/6/19: Making slow gains. Has tolerated some decrease in rate.

3/10/19: Difficult to wean ventilation. She has good gas exchange when cardiac output is good. We will

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

attempt to wean as tolerated.

3/13/2019: With improvement of cardiac output over the last several days we have begun weaning mechanical ventilation. Gas exchange remains good

3/21/2019: Patient is tolerating weaning of mechanical ventilation. She will likely be extubated soon.

3/22/2019: Plans are for extubation to high-flow nasal cannula today

3/23/2019: The patient has been extubated to high-flow nasal cannula 12 L. Patient exhibits evidence of reasonable gas exchange despite a paralyzed right hemidiaphragm

3/27/2019: Weaning HFNC, down to 10 L

3/29/2019: Improving gradually, now on 8 LPM

4/6/2019: Continues to require high-flow nasal cannula. This is multifactorial given chronic lung disease, chronic heart failure, as well as enlarged cardiac size.

4/12/2019: High-flow nasal cannula is being weaned slowly. This appears to be tolerated

4/16/2018: The patient has had episodic increased work breathing. This may be secondary to aspiration or chest difficulty secretions.

4/19/2019: Earlier in the week the patient had high-flow nasal cannula increased. We have begun weaning this again. Currently now at 6 liters/minute.

4/23/19: Tolerating 6 lpm with 4lpm with feeds.

4/25/19: Tolerating 4 lpm with some intermittent increase in breathing.

4/27/2019: Worsening difficulty maintaining oxygen saturations, decreased aeration and intermittently increased worker breathing caused increase of high-flow back to 15 L with addition of med nebs and albuterol every 3 hr. Diffuse atelectasis noted on chest x-ray.

4/28/19: Stabilizing in past 24 hours with improved respiratory status; able to wean to 10 lpm this morning.

4/29/2019: Continue to have episodes of desaturation and poor aeration, necessary to increase high-flow back up to 15 L and restart meta neb treatments. Low-dose Ativan added for tolerance of IPV treatments. Good response overnight to aggressive pulmonary recruitment.

5/1/10: Prelone started 4/29 x 5 days. Weaning flow gradually. IPV ongoing. Not needing as much sedation.

05/02/2019. High-flow nasal cannula went 8 liters/minute.

5/4/2019: Patient has been transitioned to a standard nasal cannula.

5/6/2019:: The patient was transiently on a regular nasal cannula but escalated back to a high-flow nasal cannula on 5/4/2019 in the afternoon. She remains on 6 liters/minute.

5/15/2019: The patient remains on 6 liters/minute of high-flow nasal cannula. She continues to have intermittent episodic airway obstruction and wheezing. She has responded to albuterol. She continues on Pulmicort.

May 17, 2019: Patient returned from the cardiac catheterization lab intubated. A bronchoscopy showed otherwise normal upper airway with slight inflammation on the left main bronchus. Significant hypoxemia and V/Q mismatch that improved with inhaled nitric oxide. Significant amount of secretions and the baby was started on broad-spectrum antibiotics.

5/19/2019: Has remained on full ventilatory support, nitric oxide and aggressive chest physiotherapy in last 24 hr. Overall pulmonary function appears to be improving especially with improvement in saturations after transfusion. She should be ready to start weaning on her aggressive treatment of her hypoxemia.

5/20/2019: The patient remains on mechanical ventilatory support. This is been aggressively weaned over the last 24 hr. This is been well tolerated. We will work towards extubation

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

5/21/2019: Patient extubated last night to HFNC. Reasonable gas exchange, but continued increased work of breathing/marginal respiratory status.

05/25/2019: Placed on isolation. Respiratory pathogen panel sent and revealed rhino virus. Patient remains on high-flow nasal cannula that went from 10 L up to 15 L due to increased work of breathing and secretions.

5/26/2019: IPV treatments every 3 hr added again due to increasing oxygen requirement tachypnea, improved overnight with improved chest x-ray.

5/29/2019: IPV treatments decreased every 6 hr, high-flow currently at 12 liters/minute and overall the child appears to be making some slow steady progress.

5/30/2019: Patient has been increased to 15 liters/minute of high-flow nasal cannula. She has episodic increased work of breathing. She continues to recover from her rhino virus infection

6/5/2019: Child had increasing oxygen requirement with decreasing saturations with worsening cough overnight. High-flow nasal cannula oxygen increased to 20 liters/minute and started back on IPV treatments every 6 hr with some improvement.

June 8, 2019 the patient has significant hypoxemia and intubation was considered. Due to concerns for pulmonary hypertension associated with chronic lung disease the patient was started on nitric oxide at five parts per million with very good response. The FiO2 was weaned as well as the flow on the nasal cannula. The patient was started on sildenafil

6/17/19: Patient has had interval improvement of respiratory status. Currently on 6 liters/minute with an FiO2 of 0.35.

6/19/19: Requiring increased flow today for work of breathing and FiO2 requirements.

6/25/19: Continues on 15 lpm flow. Breath sounds tighter past 24 hours, diuretics increased and now on q 2 hour albuterol.

6/26/2019: The patient continues on high-flow nasal cannula. Subjectively she has been improved since continuous feeds were started. She continues to have variable oxygen requirement.

6/28/19: Interval improvement. Trial of decreased flow to 12 lpm. Albuterol back to q 3 hours

6/30/19: The patient has had gradual interval improvement through the week. The patient has been weaned to 10 liters/minute of high-flow nasal cannula.

7/1/19: Tolerated 8 lpm of flow in past 24 hours. Clinically with good aeration. Weaning sildenafil to off.

7/8/2018: High-flow nasal cannula oxygen has slowly been escalated 15 liters/minute as a child wean off of sildenafil in order to maintain good oxygen saturations and maintain a reasonable work of breathing.

7/9/2019: Patient with acute respiratory arrest in the early morning hours of 7/9/2019. Patient had acute loss of air movement and was difficult to bag mask ventilate. Apparent cause was some mucus plugging. Patient was emergently intubated and despite aggressive pulmonary toilet measures it was very difficult oxygen and ventilated. This also likely lead to a pulmonary hypertensive crisis. Despite aggressive pulmonary toilet measures, sedation, neuromuscular blockade, systemic alkalinization, and transfusion there was not much improvement. Patient emergently placed on VA ECMO.

7/14/2018: Patient transitioned off of ECMO in OR. After return from OR patient needing 100% FiO2 and 20 parts per million of nitric with high ventilatory settings to keep appropriate oxygen saturations.

July 15, 2019: The child had profound hypoxemia with saturations around 30%, after bagging ventilation and suctioning with 100% oxygen and inhaled nitric oxide at 20 parts per million, the baby is oxygen saturations did not improved. After increasing the the nitric oxide to 80 parts per million, epinephrine 0.1 micrograms/kilos per minute and a fluid bolus, the oxygen saturations started to improve. Echocardiogram

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

showed an open shunt with concerns for increased pulmonary vascular resistance.

7/16/19: Right pneumothorax present on morning CXR which was evacuated. Improving saturations/NIRS through day, requiring volume and vasoactive medications to drive shunt flow. Still requiring FiO2 upwards of 0.6.

7/18/2019: Patient has had some improvement. Continues with significant hypoxemia. Currently on full mechanical ventilatory support. The patient has not tolerated sildenafil for pulmonary hypertension. We will likely start bosentan

7/21/2019: The patient remains on full mechanical ventilatory support continuing ongoing titration. Her saturations appear to be more stable in the setting of Bosentan therapy. She continues to require aggressive pulmonary toilet measures.

7/22/2019: Trial of IPV therapy to see whether this improves saturations.

7/27/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension measures. She will likely need tracheostomy for long-term ventilation as a no other means of therapy and support for her chronic lung disease and pulmonary hypertension

8/2/2019: Patient has had clinical improvement over the last 1-2 days. Continues to require high driving pressure to overcome pulmonary hypertension with epinephrine. Continues on Bosentan. Continues on nitric oxide and full mechanical ventilatory support. The patient has been started on a five day course of Solu-Medrol. This has transiently improved her in the past. She will likely continue to require chronic mechanical ventilation and tracheostomy.

8/4/19: Off epinephrine. Maintaining adequate saturations on < 0.5 FiO2.

8/8/19: More wet in past 24 hours. Increased distress and less ability to be awake and tolerate ventilatory support. No room for weaning of support.

8/10/2019: The patient remains on full mechanical ventilatory support as well as aggressive pulmonary hypertension of measures.

8/13/2019: Continues to struggle from labile oxygen saturations despite paralysis and aggressive respiratory support. Will start a trial of Iloprost today.

8/14/2019: No clinical response to Iloprost and increased risk of bronchospasm, discontinued. It is likely that we have the maximum pulmonary vaso dilatory effect already in place with the nitric oxide and bosentin.

8/17/2019: Patient is on full mechanical ventilatory support following surgery. This will be titrated appropriately. She remains on inhaled nitric oxide.

8/18/2019: Child decompensated with extremely poor pulmonary compliance and persistent oxygen saturations in the high 50s to low 60s despite paralysis, aggressive analgesia and sedation, suctioning and other interventions on conventional mechanical ventilatory support. Ultimately transition to the oscillator with slow pulmonary recruitment and stability overnight.

8/20/2019: Patient with severe chronic lung disease superimposed with likely acute lung injury in the setting of a recent cardiac surgery. There is been no infectious etiology for her decompensation. After some time on high-frequency mechanical ventilation she has been transition to conventional ventilation. She is on systemic steroids for a five day course the and aggressive beta agonist therapy. Overall her prognosis from a chronic lung disease standpoint remains quite guarded

8/25/2019: Patient continues to struggle with underlying chronic lung disease, acute lung injury, single ventricle physiology, profound hypoxemia, airway reactivity. She remains on pressure control ventilation that was started on 08/23 due to high peak inspiratory pressures. Her gas exchange is been reasonable.



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breaun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

She remains on a relatively high inspired oxygen not being able to be wean lower than 0.5. She remains on nitric oxide, Bosentan, in sildenafil at escalating doses. She remains on systemic steroids have been weaned to q.12 as well as albuterol at 5 mg an hour.\

8/29/2019: Off of continuous albuterol, steroids weaned to once daily. She continues to have rhonchi, wheezes and poor pulmonary compliance and does not appear to have had a significant response to steroids nor albuterol. She has been reasonably tolerant of cares lately on decreased vecuronium however.

8/31/2019: The patient continues on full mechanical ventilatory support. Unfortunately with discontinuation of her vecuronium she had profound desaturation hypoxemia and neuromuscular blockade is been restarted. She remains on inhaled nitric oxide in deep sedation. She continues to required aggressive pulmonary toilet measures

9/6/2019: The patient remains on full mechanical ventilatory support. She remains on deep sedation. Neuromuscular blockade is being reduced. She continues aggressive pulmonary toilet.

9/9/19: Off neuromuscular blockade infusion. Tolerating much better than in the past.

9/11/2019: The patient remains on full mechanical ventilatory support. Continues to have evidence of poor pulmonary compliance. Continues to have a persistent oxygen requirement with an FiO2 of 0.5-0.6.

9/17/2019: The patient remains on full mechanical ventilatory support. The patient has been on 65-70% oxygen for most of the last 24 hr. Pulmonary compliance continues to be an issue. Prognosis remains quite poor to guarded

9/21/2019: Patient remains on full mechanical ventilatory support and 100% FiO2. Her fluid overload has been compromising her oxygenation and ventilation. Prognosis remains poor.

10/2/2019: The patient remains on full mechanical ventilatory support. There have been some difficulties in ventilation. IMV is been increased. FiO2 is been weaned to 0.75. Gas exchange is somewhat suboptimal

10/5/2019: Patient remains on full mechanical ventilatory support. We have been able to wean the FiO2 somewhat, IMV is been increased due to mild respiratory acidosis

10/10/2019: Patient with complete atelectasis of the left lung requiring aggressive recruitment maneuvers with IPV and bag suctioning.

10/14/2019: The patient has had some improvement over the last several days with aggressive pulmonary toilet measures. She remains on quite stout mechanical ventilatory support. We have been able to wean her FiO2 which is mostly between 40 and 50%. She continues to require deep sedation and neuromuscular blockade. Her prognosis remains quite poor.

10/19/2019: Patient has required increasing FiO2 over the last 48-72 hours. She continues to require relatively deep sedation with intermittent neuromuscular blockade. Prognosis remains poor

10/20/2019: Restarted on low-dose vecuronium due to persistent agitation and need for excessive p.r.n. Medications, child was also given a trial of ketamine without significant improvement.

10/25/2019: The patient remains on full mechanical ventilatory support requiring between 40 and 70% oxygen deep sedation, neuromuscular blockade, and aggressive pulmonary toilet interventions to maintain reasonable gas exchange

11/7/2019: Vecuronium infusion stopped today given discussion of withdrawal by family. Vecuronium will be given on prn basis for issues with ventilating or excessive movement.

11/10/2019: Continues to require full ventilatory support. Intermittent increase in PIP's with agitation/airway secretions. Requiring increased oxygen off vecuronium. Vecuronium will be used on PRN basis for excessive movement threatening safety of ETT and ventilatory dyssynchrony with desaturation.

11/17/19: Interval worsening of secretions with tracheal aspirate growing abundant Staph aureus as well as

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

stenotrophomonas maltophilia. Febrile at time culture was drawn. Antibiotics ongoing. Plan 7-10 day course. Vest therapy used in place of IPV given issues with hypotension.

11/19/2019: Patient has had worsening pulmonary compliance with increasing edema as diuretics were held in the setting of hypotension. Peak inspiratory pressures are now in the low to mid 40s. My hope is this will improve with reinstitution of diuretics now that hemodynamics are more stable.

SVT (supraventricular tachycardia) (CMS/HCC)*Assessment & Plan*

Began preoperatively, initially treated with esmolol, and later transitioned to amiodarone after developing atrial flutter. Heart irritable at time of surgery, better after atrial reduction. Ongoing support with amiodarone 5 mg/kg/day at time of admission to CICU. Ongoing surveillance planned.

2/21/19: Increased frequency of runs of SVT yesterday morning in the setting of epinephrine at 0.05 mcg/kg/min. Epinephrine decreased (0.03) and amiodarone increased to 10 mg/kg/day with better control.

2/24/2019: Amiodarone reduced to 5 milligrams/kilogram per day yesterday.

3/4/19: Ongoing issues with premature beats/atrial bigeminy, requiring pacing to try to suppress ectopic beats. On esmolol for same. Titrating to minimum dose.

March 7, 2019: The baby was started on oral flecainide with conversion to sinus rhythm.

3/10/2019: The patient remains on flecainide. Patient will be changed to oral amiodarone today.

3/11/2019: The patient remains on flecainide and amiodarone. There was a breakthrough event of SVT yesterday requiring rapid atrial pacing.

3/12/2019: In addition to atrial flutter yesterday the patient also had breakthrough SVT. Flecainide has been increased. IV amiodarone infusion is been restarted. Patient is in a sinus rhythm this morning. It is slow so we are using temporary pacemaker support augment cardiac output

3/13/2019: Patient has been in a sinus rhythm for the last 24 hr. Temporary pacing is been discontinued.

3/14/2019: Esmolol d/c

03/16/2019: Remains on amiodarone 5 milligram/kilogram per day and flecainide 4 mg enteral every 8 hr.

3/19/2019: Flecainide increased to 5 mg every 8 hr.

3/23/2019: Patient remains on amiodarone of 5 milligrams/kilogram per day. The patient is also on flecainide. We are awaiting a flecainide level. Once that level has returned we will continue to maximize flecainide therapy prior to reducing amiodarone.

3/29/2019: Ongoing titration of antiarrhythmics per EP service. Flecainide increased in response to low level, amiodarone has been decreased to 2.5 mg/kg/day IV. Plan to eventually transition to oral amiodarone, 5 mg/kg/day. Rhythm has been well controlled.

4/1/2019: Amiodarone transitioned to enteral route today (5 mg/kg/day). Flecainide unchanged, level still low, rhythm remains well controlled.

4/5/2019: Patient remains on amiodarone. Flecainide dose increased yesterday

6/19/19: No breakthrough, continues on amiodarone and flecainide, with dose adjusted for weight.

7/6/2019: No SVT noted. Patient remains on amiodarone and flecainide.

7/9/2019: Flecainide discontinued as patient transition on to VA ECMO support.

7/10/2019: Patient has been transitioned to amiodarone infusion

7/27/2019: We will transition to oral amiodarone at 5 milligrams/kilogram per day

8/3/2019: Patient with multiple PACs and dysrhythmia yesterday. Flecainide has been restarted

9/4/19: Flecainide level slightly subtherapeutic 8/27. No breakthrough tachydysrhythmia on amiodarone

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

and flecainide.

9/20/2018: Patient remains on flecainide and amiodarone. No breakthrough dysrhythmias.

11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic

Atrial flutter (CMS/HCC)*Assessment & Plan*

Occurred preoperatively, required synchronized cardioversion, followed by amiodarone. In sinus rhythm since 2/4/19. Continued on amiodarone 5 mg/kg/day at time of surgery 2/13/19.

2/24/2019: The patient remains on amiodarone

2/26/2019: Patient had recurrence of atrial flutter this morning. Was rapid atrial paced out of it. Continues on amiodarone.

3/10/2019: Patient transitioned to oral amiodarone

3/12/2019: Patient with worsening atrial flutter in the last 24 hr. Ultimately requiring cardioversion and rapid atrial pacing several times. IV amiodarone is been reinstituted. Flecainide was found to be subtherapeutic. Dosing has been increased.

3/13/2019: Came off pacemaker support with underlying sinus rhythm

3/14/2019: Esmolol was d/c

3/30/2019: Patient remains on flecainide and continuous amiodarone at this time.

4/4/2019: Good control, on enteral amiodarone and flecainide.

4/9/2019: Flecainide level remains subtherapeutic but patient without ectopy. Will remain on current dose.

5/9/19: Flecainide level back from 4/29/19 and is now therapeutic at 0.4. Dose continues as previously. No breakthrough dysrhythmias noted.

6/19/19: Flecainide has been adjusted for weight gain; therapeutic level 6/11/19. Amiodarone ongoing. No breakthrough dysrhythmias noted.

7/6/2019: No breakthrough of abnormal rhythms. Patient remains on amiodarone flecainide. Flecainide levels being drawn intermittently.

7/9/2019: Flecainide discontinued. Patient has been transition to IV amiodarone while on VA ECMO support.

7/14/2019: Patient has returned from the OR. We will continue IV amiodarone at this time. Patient off of VA ECMO support.

7/27/2019: We will transition to oral amiodarone

8/4/2019: Developed short runs of SVT. Flecainine restarted 8/2/19.

8/9/2019: Flecainide level suboptimal. Flecainide dose increased.

9/4/19: Most recent level of flecainide checked on 08/27 and was slightly low at 0.18. She has not had breakthrough tachydysrhythmias despite this slightly subtherapeutic level.

9/20/2019: Patient remains on flecainide and amiodarone therapy. No breakthrough dysrhythmias.

11/9/2019: Patient remains on amiodarone and flecainide without breakthrough dysrhythmias.

11/19/2019: Patient remains on flecainide and amiodarone. Flecainide level sent 11/15/2019 was therapeutic

*** Ebstein's anomaly of tricuspid valve***Assessment & Plan*

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

Severe anomaly with inadequate pulmonary blood flow, marked RA and RV dilatation compromising LV filling and encompassing much of chest. Now s/p modified Starnes operation with fenestrated closure of the tricuspid valve, open atrial septectomy with cardiopulmonary bypass, placement of a 3 mm modified BT shunt, reduction right atrial plasty, and pulmonary valvotomy, Dr. Vincent Tam, 2/13/19. Chest left open. 2/14/19: Mediastinal exploration, to assess recurrent bleeding/effusion posterior to heart, clip placed to isolate MPA from RV to prevent blood from flowing back to RV.

Patient underwent delayed sternal closure 2/22/2019

May 17, 2019: Cardiac catheterization showed decreased diameter of the pulmonary arteries with subsequent balloon dilatation of both pulmonary arteries.

7/14/2019: Patient taken OR by Dr. Tam where she was decannulated from ECMO support, had her BT shunt replaced with a 5.0 mm BT shunt, patch augmentation of right ventricular outflow tract, reduction right atrioplasty, repair of the right common carotid artery and right internal jugular vein. While in the OR the patient had significant desaturations coming off bypass requiring a clip to be placed over the right ventricular outflow tract. With this maneuver saturations and pulmonary blood flow increased.

7/19/2019: Patient underwent delayed sternal closure

8/17/2019: Due to inadequate pulmonary blood flow in significant gradient from the innominate artery to the BT shunt the patient was taken back to the operating room where the BT shunt was taken off the innominate artery at its proximal takeoff and reconnected to the aorta with formation of a central shunt.

10/8/2019: Referrals have been made to Boston Children's Hospital and Texas children's Hospital regarding any further interventions or options to be provided. Both institutions have said that everything has aggressively been done.

11/4/19: Patient has also been denied at Dallas Childrens.

Subjective:

Interval History: Tinslee , over the past 24 hr, has remained intubated on full mechanical vent support with FiO2 40% oxygen saturations in the upper 70s with some lability noted in her blood pressures. Overall, her blood pressure has improved and her norepinephrine was decreased down to 0.2 microgram/kilogram per minute with epinephrine remaining at 0.04 microgram/kilogram per minute. She remains on Bumex drip at 0.01 milligram/kilogram per hour and received a spot dose of Diuril last night in the was placed on scheduled Diuril IV every 12 hr this morning. Overall she appears more fluid overloaded. She remains afebrile with no new signs/symptoms of occult infection. She remains NPO and on TPN/lipids with hypoactive to absent bowel sounds. Currently she is adequately perfused. From a sedation standpoint she remains on a Precedex drip at 1 microgram/kilogram per hour. Chest remains on vecuronium at 0.05 milligram/kilogram per hour.

Cardiovascular:

Lines

Active :

Name:	Placement date:	Placement time:	Site:	Days:
Arterial Line 08/16/19 Left Ulnar	08/16/19	1700	Ulnar	96



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breaun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

DL PICC RED/WHT 07/29/19	07/29/19	1032	Other (Comment)	114
Left Other (Comment)				

Antiarrhythmic Support: Amiodarone. Flecainide.

Pacemaker: No.

Other Cardiac Medications: Diuril. Epinephrine drip. Norepinephrine drip. Sildenafil. Bosentan.

Anticoagulation: Aspirin (quarter dose baby aspirin daily)

Respiratory:

Respiratory Support: Intubated/full mechanical vent support: Mode SIMV-PC VG, FiO2 40%, IMV rate 32, peep eight, pressure support 12, tidal volume 60, I time 0.6, and peak inspiratory pressure 35.

Other gases: None.

Lab Blood Gas Reviewed: Yes

Ins and Outs:

Admission Weight: 1.81 kg

Weight change:

I/O last 24 hours:

In: 1605.9 (200.7 mL/kg) [I.V.:322.3 (40.3 mL/kg); NG/GT:71.1; IV Piggyback:318.6]

Out: 1444 (180.5 mL/kg) [Urine:1444 (5 mL/kg/hr)]

Drug Calculation Weight: 8 kg

I/O this shift:

In: 192.6 [I.V.:40.4; NG/GT:16.8; IV Piggyback:64.4]

Out: 103 [Urine:103]

Physical Assessment:

Last Vital Signs:

Last Vitals

BP

(!) 110/48 (BP Location: Right
leg)

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

Pulse 112
Temp (!) 36.4 °C (97.5 °F) (Rectal)
Resp 32
SpO2 (!) 76%

General: Intubated on mechanical vent support. On Precedex and paralytic drip. Adequately perfused. Persistent ongoing total body anasarca. Adequately perfused.

HEENT: Moderate facial/periorbital edema. Pupils equally round sluggishly reactive bilaterally. Sclera nonicteric. Nasal enteric feeding tube in place. Nasotracheal intubation. Mucous membranes moist.

Neck: Edematous. Supple.

Chest: Moderate nonpitting chest wall edema. Adequate chest wall excursion. Slightly coarse breath sounds with adequate air movement all lung fields. No significant wheezes, rales, rhonchi noted.

Heart: Regular rate and rhythm. Audible shunt murmur. No rub. No gallop. Easily palpable pulses distally. Brisk capillary refill distally. Toes/fingers slightly warm to the touch. Adequate color.

Abdomen: Round. Full. Hypoactive to absent bowel sounds.

Extremities: No movement noted in extremities. Easily palpable pulses distally brisk capillary refill distally. Mild-to-moderate peripheral edema, nonpitting.

Neuro: Patient on Precedex drip and blood dose vecuronium drip. No movement noted. Pupils equally round sluggishly reactive bilaterally.

Skin: Adequately perfused. Persistent total body anasarca, nonpitting.

Gu: No Foley catheter in place.

Labs Reviewed: Yes.

Chest XRay: Support devices: Endotracheal tube tip above the carina. Enteric tube extends at least into the stomach with the tip not visible on this exam.

Chest: Stable cardiomegaly following sternotomy. Confluent LEFT greater than RIGHT basilar airspace opacities (atelectasis versus pneumonia the primary considerations) are similar. More generalized central predominant edema/infiltrate pattern is similar. No evidence of pleural fluid or air.

IMPRESSION:

Stable radiographic appearance of the chest.

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

MAR Reviewed: Yes.

Daily Assessment/Plan:

Airway/Breathing: Intubated/mechanical vent support on FiO2 40% with oxygen saturations in the upper 70s. IMV rate currently 32 with tidal volume of 40. Blood gases as noted below with peak pressures in the mid 30s. Patient receiving aggressive pulmonary toilet. She continues on her Bosentan and sildenafil for anti pulmonary hypertension therapy. Chest x-ray as noted above.

Results from last 7 days

Lab	Units	11/21/19 0355	11/21/19 0106	11/20/19 1613
POCT PH, ARTERIAL		7.40	7.37	7.34*
POCT PCO2, ARTERIAL	mmHg	57*	57*	57*
POCT PO2, ARTERIAL	mmHg	46*	43*	44*
POCT HCO3, ARTERIAL	mmol/L	35.3*	33.0*	30.8*
POCT BASE EXCESS, ARTERIAL	mmol/L	8.9*	6.3*	3.9*

Cardiovascular: *Some lability noted in blood pressures.* Nor been Afrin down to 0.02 microgram/kilogram per minute and epinephrine remains at 0.04 microgram/kilogram per minute. Patient back on diuretic support Bumex 0.01 milligram/kilogram per hour and Diuril IV every 12 hr. Child remains on anti pulmonary hypertension medications as noted above. On amiodarone and flecainide in sinus rhythm. On aspirin for shunt clot prophylaxis.

Neuro: Nonfocal exam. On Precedex at 1 microgram/kilogram per hour seven vecuronium at 0.05 milligram/kilogram per hour. Child remains on a methadone 2.5 mg IV every 6 hr and Ativan 2.6 mg IV every 6 hr. Child is also on Seroquel and gabapentin.

FEN/GI: NPO. On TPN/lipids. Now Bumex 0.01 milligram/kilogram per hour and Diuril IV every 12 hr. Child remains on Ursodiol. Abdominal exam as noted above.

Results from last 7 days



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

Lab	Units	11/21/19 0356	11/20/19 1613		11/18/19 0328
SODIUM	mmol/L	143*	--	< >	142
SODIUM GEM	mmol/L	--	140	< >	--
POTASSIUM	mmol/L	3.3*	--	< >	3.6*
POTASSIUM GEM	mmol/L	--	3.5*	< >	--
CHLORIDE	mmol/L	100	--	< >	101
CARBON DIOXIDE LEVEL	mmol/L	30*	--	< >	29*
BUN	mg/dL	22*	--	< >	18*
CREATININE	mg/dL	0.63*	--	< >	0.59*
CALCIUM	mg/dL	10.1	--	< >	9.9
PROTEIN TOTAL	g/dL	--	--	--	6.1
BILIRUBIN TOTAL	mg/dL	--	--	--	2.3*
ALK PHOS	U/L	--	--	--	677*
ALT	U/L	--	--	--	21
AST	U/L	--	--	--	31
GLUCOSEGEM	mg/dL	--	112*	< >	--

< > = values in this interval not displayed.

Lab Results

Component	Value	Date
Calcium Level	10.1	11/21/2019
Phosphorus Level	6.2	11/21/2019

Lab Results

Component	Value	Date
Triglycerides Level	76	11/18/2019
Triglycerides Level	123	11/11/2019
Triglycerides Level	103	11/04/2019

Lab Results

Component	Value	Date
Albumin	3.2	11/21/2019

HEME: No bleeding issues. On quarter dose baby aspirin daily. Monitoring CBC.

Results from last 7 days

Generated on 11/21/19 10:11 AM

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

Lab	Units	11/21/19 0356
WBC	x10e3/uL	9.66
HGB	g/dL	10.9
HCT	%	33.6
PLATELETS	x10e3/uL	73*
NEUTRO MAN	%	64.5
LYMPHO PCT MAN	%	21.6
MONO PCT MAN	%	11.2

Results from last 7 days

Lab	Units	11/14/19 1542
PROTHROMB TIME INTERNATIONA L RATIO		1.4
ACTIVATED PARTIAL THROMBOPLAS T TIME	SECONDS	61*

Infectious Disease: Currently afebrile. Child is on Bactrim IV every 8 hr with plans for a 10 day course.

Renal: Currently on Bumex 0.01 milligram/kilogram per hour. It been held earlier this week due to some hypotension and need for volume as well as norepinephrine. Blood pressure though still somewhat labile seems to be improved and with the reduction in or epinephrine IV Diuril was rescheduled. Will monitor strict ins and outs as well as being creatinine. No Foley catheter.

Endocrine: No current issues. No hydrocortisone, sildenafil, or insulin required at this time.

Lines:

Reason for Central Venous Line: Difficult Access

Reason for Foley: Not Applicable (No Foley)

Parents: Mother is at the bedside. We are keeping her up-to-date.

Communication: Plan discussed with multidisciplinary team.



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes by Ryan Ray Meyer, MD at 11/21/2019 9:17 AM (continued)

Billing Time: I have personally seen and examined this patient and spent 65 minutes of critical care time on this patients behalf.

Coding Queries

Sender	Recipient	Type	Subject	Created	Status	Outcome	Respondin g Provider	Response Note
Hb, Backgroun d	Lori Lee Nesslein, MD		Procedure Note	02/01/20 19 2110	Respon se Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Respondin g Provider	Response Note
Hb, Backgroun d	Lori Lee Nesslein, MD		Procedure Note	02/01/20 19 2111	Respon se Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Respondin g Provider	Response Note
Hb, Backgroun d	Rekha Balla Hamilton, MD		Procedure Note	02/09/20 19 1745	Respon se Received			

Query Message

--- Doc Query Message ---

From: Rekha Balla Hamilton, MD
Sent: 2/9/2019 9:46 PM CST
Subject: Procedure Note



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Coding Queries (continued)

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Rekha Balla Hamilton, MD : 02/09/2019 - 09:46 PM

END OF REPORT



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Echocardiogram Request [44424127]

Electronically signed by: **Ryan Ray Meyer, MD on 11/18/19 0934**

Status: **Completed**

This order may be acted on in another encounter.

Ordering user: Ryan Ray Meyer, MD 11/18/19 0934

Ordering provider: Ryan Ray Meyer, MD

Screening Form

General Information

Patient Name: Lewis, Tinslee Breun

MRN: M4123323

Date of Birth: 2/1/19

Home Phone: 817-349-5499

Legal Sex: Female

Procedure

ECHOCARDIOGRAM
REQUEST

Ordering Provider

Ryan Ray Meyer, MD
682-885-4193

Authorizing Provider

Ryan Ray Meyer, MD
682-885-4193

Appointment Information

11/18/2019 9:50 AM
CCMC ECHO IP
CCMC ECHO LAB

Screening Form Questions

No questions have been answered for this form.

Echo Cardiogram - Scan on 11/18/2019 6:12 PM (below)



CookChildren's

Pediatric Cardiology Echo Lab

801 Seventh Avenue
Fort Worth, Texas 76104
(882)885-4195



Name: LEWIS, TINSLEE BREUN	Study Date: 11/18/2019 09:57 AM	BP: 82/45 mmHg	HR: 113
MRN: M4123323	Visit Number: 1015678564	Patient Location: CICU	
DOB: 02/01/2019	Gender: Female	Height: 60 cm	
Age: 9 mos		Weight: 8 kg	
Reason For Study: f/u echo		BSA: 0.34 m ²	
History: EBSTEIN'S ANOMALY, BT SHUNT			
Medications:			
Ordering Physician: MEYER, RYAN			
Performed By: Sanchez, Sandro			

MMode/2D Measurements & Calculations

FS: 46.6 %

EF(Teich): 79.2 %

Doppler Measurements & Calculations

MV E max vel: 128.0 cm/sec	MV V2 max: 156.9 cm/sec	Ao V2 max: 226.7 cm/sec	TV V2 max: 160.2 cm/sec
MV A max vel: 149.2 cm/sec	MV max PG: 9.9 mmHg	Ao max PG: 20.6 mmHg	TV max PG: 10.3 mmHg
MV E/A: 0.86	MV V2 mean: 96.6 cm/sec		
	MV mean PG: 4.5 mmHg		
	MV V2 VTI: 24.1 cm		

LPA max vel: 108.0 cm/sec

Pediatric Measurements & Calculations

ase Ao max PG: 19.4 mmHg	dese Ao max PG: 5.0 mmHg	LPA max PG: 4.7 mmHg
ase Ao max vel: 220.0 cm/sec	dese Ao max vel: 112.3 cm/sec	

History

Patient status post Starnes with pulmonary valvotomy and BT shunt for Ebstein's anomaly. Clip was then placed on the main pulmonary artery. Status post cardiac arrest and subsequent surgery for insertion of larger 5 mm diameter BT shunt and decannulation from ECMO. Subsequent innominate artery stenosis s/p central shunt placement.

Type of Study

This echocardiogram contains M-mode, 2D, color and spectral doppler analysis.

Position

Apex to the left. Visceroatrial sinus solitus, d-ventricular looping and normally related great vessels.

Veins

Normal systemic venous drainage. Some images suggest a trivial linear cast near the IVC/RA junction. Pulmonary veins enter the left atrium but each individual vein is not identified.

Atrium

Large secundum atrial septal defect with unobstructed right to left shunting.

AV valves

Starnes patch with two small fenestrations; to-fro flow noted with mildly accelerated inflow and peak RV to RA gradient 25 mmHg. (SBP 74/39). Mild for acceleration across the mitral valve with a mean gradient of ~3.5mmHg. Mild mitral regurgitation.

Ventricles

Mildly hypoplastic right ventricle with moderate hypertrophy and depressed right ventricular contractility. No evidence of ventricular level shunting. Bowing of the ventricular septum is seen into the left ventricle. Hyperdynamic left ventricular systolic function.

Semilunar valves

Retrograde flow seen in the main pulmonary artery from the central shunt. Trileaflet aortic valve with normal systolic flow.

Mildly narrowed left ventricular outflow tract (peak gradient 23mmHg) possibly related to bowing of the ventricular septum.

Mild aortic valve insufficiency.

Vessels

No evidence of a coarctation of the aorta. Holodiastolic flow reversal seen in the arch consistent with large left to right aortopulmonary shunt. The central shunt is widely patent with restrictive left-to-right shunting (peak aortopulmonary gradient 61 mmHg)

Flow well seen into the main and proximal branch pulmonary arteries. Normal left aortic arch.

Coronaries

The origin of the coronary arteries are suggested to be appropriate from the aortic root.

Fluid

No pericardial effusion.

Xcelera Classic Z-Scores

Measurement Name	Value	Z-Score	Predicted	Normal Range	Measurement Name	Value	Z-Score	Predicted	Normal Range
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11/18/2019

IVSd	0.52 cm	1.1	0.42	0.24 - 0.60	LVIDd	3.3 cm	3.5	2.4	1.9 - 2.9
LVIDs	1.7 cm	1.2	1.5	1.1 - 1.9	LVPWd	0.60 cm	2.9	0.35	0.18 - 0.52

Boston Z-Scores

Measurement Name	Value	Z-Score	Predicted	Normal Range	Measurement Name	Value	Z-Score	Predicted	Normal Range
Ao root diam(2D) (vs. BSA(Haycock))	1.7 cm	3.0	1.3	1.0 - 1.6	AoV annu area (vs. BSA(Haycock))	1.0 cm²	2.0	0.73	0.45 - 1.00
AoV annu diam(2D) (vs. BSA(Haycock))	1.1 cm	1.8	0.96	0.78 - 1.14	MV annu diam(4ch) (vs. BSA(Haycock))	1.6 cm	1.4	1.4	1.1 - 1.7

Interpretation Summary

Patient status post Stame's with pulmonary valvotomy and BT shunt for Ebstein's anomaly. Clip was then placed on the main pulmonary artery. Status post cardiac arrest and subsequent surgery for insertion of larger 5 mm diameter BT shunt and decannulation from ECMO. Subsequent innominate artery stenosis with conversion to central shunt

Large secundum atrial septal defect with unobstructed right to left shunting. No VSD
Starnes patch with two small fenestrations; to-fro flow noted with mildly accelerated inflow and peak RV to RA gradient 25 mmHg. (SBP 74/39).
Mild for acceleration across the mitral valve with a mean gradient of ~3.5mmHg. Mild mitral regurgitation
Hyperdynamic left ventricular systolic function.
Mildly narrowed left ventricular outflow tract (peak gradient 23mmHg) possibly related to bowing of the ventricular septum.
Mild aortic valve insufficiency.
Mildly hypoplastic right ventricle with moderate hypertrophy and depressed right ventricular contractility
Holodiastolic flow reversal seen in the arch consistent with large left to right aortopulmonary shunt. The central shunt is widely patent with restrictive left-to-right shunting (peak aortopulmonary gradient 61 mmHg)
Flow well seen into the main and proximal branch pulmonary arteries.
No pericardial effusion.

Reading Physician: Electronically Authenticated by: MD Kris Woldu on: 11/18/2019 06:11 PM

Ordering Physician: MEYER, RYAN

Referring Physician:

Performed By: Sanchez, Sandro



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Echocardiogram Request [44424127]

Resulted: 11/18/19 1812, Result status: Final
result

Ordering provider: Ryan Ray Meyer, MD 11/18/19 0934
Accession number: US234777-19

Performed: 11/18/19 0946 - 11/18/19 1134
Resulting lab: CVXCELERA

Components

Component	Value	Reference Range	Flag	Lab
BSA	0.41	m2	—	—

Order-Level Documents:

Echo Cardiogram - Scan on 11/18/2019 6:12 PM (below)



Pediatric Cardiology Echo Lab
801 Seventh Avenue
Fort Worth, Texas 76104
(817)885-4195



Name: LEWIS, TINSLEE BREUN	Study Date: 11/18/2019 09:57 AM	BP: 82/45 mmHg	HR: 113
MRN: M4123323	Visit Number: 1015678564	Patient Location: CICU	
DOB: 02/01/2019	Gender: Female	Height: 60 cm	
Age: 9 mos		Weight: 8 kg	
Reason For Study: flu echo		BSA: 0.34 m ²	
History: EBSTEIN'S ANOMALY, BT SHUNT			
Medications:			
Ordering Physician: MEYER, RYAN			
Performed By: Sanchez, Sandro			

M-Mode/2D Measurements & Calculations

FS: 46.6 %
EF(Teich): 79.2 %

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MV A max vel: 149.2 cm/sec	MV max PG: 9.9 mmHg	Ao max PG: 20.6 mmHg	TV max PG: 10.3 mmHg
MV E/A: 0.86	MV V2 mean: 96.6 cm/sec		
	MV mean PG: 4.5 mmHg		
	MV V2 VTI: 24.1 cm		

LPA max vel: 108.0 cm/sec

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asc Ao max PG: 19.4 mmHg	desc Ao max PG: 5.0 mmHg	LPA max PG: 4.7 mmHg
asc Ao max vel: 220.0 cm/sec	desc Ao max vel: 112.3 cm/sec	

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AV valves

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The origin of the coronary arteries are suggested to be appropriate from the aortic root.

Fluid

No pericardial effusion.

Xcelera Classic Z-Scores

Measurement Name	Value	Z-Score	Predicted	Normal Range	Measurement Name	Value	Z-Score	Predicted	Normal Range
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Order-Level Documents: (continued)

Page 2 of 2

IVSd	0.53 cm	1.1	0.42	0.24 - 0.60	LVESd	3.3 cm	3.0	2.4	1.9 - 2.9
LVESd	3.7 cm	3.2	1.5	1.1 - 1.9	LVESF	0.60 cm	0.39	0.18 - 0.52	

Boston Z-Scores

Measurement Name	Value	Z-Score	Predicted	Normal Range	Measurement Name	Value	Z-Score	Predicted	Normal Range
Ao root diam(2D) (vs. BSA(Haycock))	1.7 cm	3.0	1.3	1.0 - 1.6	AoV annu area (vs. BSA(Haycock))	1.0 cm²	2.0	0.73	0.45 - 1.00
AoV annu diam(2D) (vs. BSA(Haycock))	1.1 cm	1.8	0.96	0.78 - 1.14	MV annu diam(4ch) (vs. BSA(Haycock))	1.6 cm	1.4	1.4	1.1 - 1.7

Interpretation Summary

Patient status post Stame's with pulmonary valvotomy and BT shunt for Ebstein's anomaly. Clip was then placed on the main pulmonary artery. Status post cardiac arrest and subsequent surgery for insertion of larger 5 mm diameter BT shunt and decannulation from ECMO. Subsequent innominate artery stenosis with conversion to central shunt

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Stames patch with two small fenestrations; to-fro flow noted with mildly accelerated inflow and peak RV to RA gradient 25 mmHg. (SBP 74/39).

Mild for acceleration across the mitral valve with a mean gradient of ~3.5mmHg. Mild mitral regurgitation

Hyperdynamic left ventricular systolic function.

Mildly narrowed left ventricular outflow tract (peak gradient 23mmHg) possibly related to bowing of the ventricular septum.

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Holodiastolic flow reversal seen in the arch consistent with large left to right aortopulmonary shunt. The central shunt is widely patent with restrictive left-to-right shunting (peak aortopulmonary gradient 61 mmHg)

Flow well seen into the main and proximal branch pulmonary arteries.

No pericardial effusion.

Reading Physician: Electronically Authenticated by: MD Kris Woldu on: 11/18/2019 06:11 PM

Ordering Physician: MEYER, RYAN

Referring Physician:

Performed By: Sanchez, Sandro

11/18/2019



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Order-Level Documents: (continued)

Coding Queries

Sender	Recipient	Response Type	Subject	Created	Status	Outcome	Respondin g Provider	Response Note
Hb, Background d	Lori Lee Nesslein, MD		Procedure Note	02/01/20 19 2110	Response Received			

Query Message

--- Doc Query Message ---
From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Respondin g Provider	Response Note
Hb, Background d	Lori Lee Nesslein, MD		Procedure Note	02/01/20 19 2111	Response Received			

Query Message

--- Doc Query Message ---
From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Respondin g Provider	Response Note
Hb, Background d	Rekha Balla Hamilton, MD		Procedure Note	02/09/20 19 1745	Response Received			

Query Message

--- Doc Query Message ---
From: Rekha Balla Hamilton, MD
Sent: 2/9/2019 9:46 PM CST
Subject: Procedure Note

This is an auto-generated reply.
The following user has specified that this query has been addressed:
Rekha Balla Hamilton, MD : 02/09/2019 - 09:46 PM



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breaun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Coding Queries (continued)

END OF REPORT



Pediatric Cardiology Echo Lab

801 Seventh Avenue

Fort Worth, Texas 76104

(682)885-4195



Name: LEWIS, TINSLEE BREAU	Study Date: 12/06/2019 03:10 PM	BP:	HR:
MRN: M4123323	Visit Number: 1015678564	Patient Location: CCMCECHO	
DOB: 02/01/2019 (M/d/yyyy)	Gender: Female	Height: 60 cm	
Age: 10 mos		Weight: 8 kg	
Reason For Study: eval function/repair/shunt/fenestration		BSA: 0.34 m ²	
History:			
Medications:			
Ordering Physician: DUNCAN, JAY			
Performed By:			

Doppler Measurements & Calculations

TR max vel: 231.3 cm/sec

TR max PG: 21.9 mmHg

History

10 month old girl with Ebstein's malformation of tricuspid valve and surgery at 2-weeks age for Starnes procedure with pulmonary valvotomy and 3 mm diameter Blalock Taussig shunt and with subsequent clip on main pulmonary artery, and then with cardiac arrest at 5-months age requiring transient VA ECMO support and subsequent surgery for insertion of larger 5 mm diameter right BT shunt and with catheterization for balloon dilation of innominate artery and right pulmonary artery at 6-months age followed by repeat surgery to convert systemic to pulmonary artery shunt from innominate artery to ascending aorta.

Type of Study

This echocardiogram contains M-mode, 2D, color and spectral doppler analysis.

Position

Levocardia. Visceroatrial situs solitus, d-ventricular looping and normally related great vessels.

Veins

Normal systemic venous drainage. Dilated inferior vena cava and hepatic veins. Four pulmonary veins seen to the left atrium. Normal pulmonary vein velocity.

Atrium

Normal right atrial size. Normal left atrial size. Large secundum atrial septal defect with unrestricted right to left shunt.

AV valves

Ebstenoid tricuspid valve with displaced leaflets deep in right ventricular cavity and with septal leaflet beginning at annular level and adherent to ventricular septum

Starnes patch horizontally across tricuspid annulus and with two perforations with to and fro flow and with insufficiency in systolic at velocity indicating right ventricular systolic pressure of 35 mm and with inflow at velocity of 1.6 M/sec. Normal appearing morphology of the mitral valve with normal diastolic inflow.

Ventricles

Mildly hypoplastic right ventricle with fair contractility. Left ventricle with generalized myocardial hypertrophy and with good contractility and minimal dynamic outflow narrowing. Intact ventricular septum.

Semilunar valves

Hypoplastic right ventricular outflow tract with echogenic clip not well imaged and with no flow

Pulmonic valve not imaged. Normal trileaflet aortic valve with systolic outflow at peak Doppler velocity of 2 M/sec

Small central aortic valve insufficiency.

Vessels

Normal size aorta. Normal left aortic arch. There is laminar flow in the ascending and descending aorta without evidence of coarctation by 2-D imaging.

Hypoplastic pulmonary artery confluence with bilateral flow demonstrated. Central Gore tex shunt from ascending aorta to right pulmonary artery at Doppler velocity of 4.1 M/sec indicating 67 mm pressure gradient.

Coronaries

Right and left coronary arteries appear normal by 2-D imaging with normal color flow map in the left coronary artery.

Fluid

No significant pericardial effusion. No pleural effusion.

Interpretation Summary

10 month old girl with Ebstein's malformation of tricuspid valve and surgery at 2-weeks age for Starnes procedure with pulmonary valvotomy and 3 mm diameter Blalock Taussig shunt and with subsequent clip on main pulmonary artery, and then with cardiac arrest at 5-months age requiring transient VA ECMO support and subsequent surgery for insertion of larger 5 mm diameter right BT shunt and with catheterization for balloon dilation of innominate artery and right pulmonary artery at 6-months age followed by repeat surgery to convert systemic to pulmonary artery shunt from innominate artery to ascending aorta

Left ventricle with generalized myocardial hypertrophy and with good contractility and minimal dynamic outflow narrowing

Normal trileaflet aortic valve with systolic outflow at peak Doppler velocity of 2 M/sec

Small central aortic valve insufficiency

Right and left coronary arteries appear normal by 2-D imaging with normal color flow map in the left coronary artery.



12/6/2019

Normal left aortic arch
Slightly hypoplastic right ventricle with fair contractility
Hypoplastic right ventricular outflow tract and pulmonary annulus with primarily retrograde flow
Ebsteinoid tricuspid valve with displaced leaflets deep in right ventricular cavity and with septal leaflet beginning at annular level and adherent to ventricular septum
Starnes patch horizontally across tricuspid annulus and with two perforations with to and fro flow and with insufficiency in systolic at velocity indicating right ventricular systolic pressure of 39 mm and with inflow at velocity of 1.9 M/sec
Central Gore tex shunt from ascending aorta to right pulmonary artery at Doppler velocity of 4.1 M/sec indicating 67 mm pressure gradient
Hypoplastic pulmonary artery confluence with bilateral flow demonstrated
Large secundum atrial septal defect with unrestricted right to left shunt
No significant pericardial effusion

Reading Physician: Electronically Authenticated by: MD Stephen Lai on: 12/06/2019 06:03 PM

Ordering Physician: DUNCAN, JAY

Referring Physician:

Performed By:

This acknowledgment is signed by Trinity Lewis ("Ms. Lewis") as the parent of minor patient Tinslee Lewis.

Ms. Lewis has asked Cook Children's Medical Center to perform a new cardiac catheterization (the "Procedure") on Tinslee.

Ms. Lewis acknowledges that Cook has disclosed to her that, due to Tinslee's health, the Procedure carries a serious risk of injury and/or death. Ms. Lewis also acknowledges that Cook does not recommend the Procedure for Tinslee as it sees little or no medical benefit. Ms. Lewis further confirms that she understands that Boston Children's may not accept Tinslee as a patient despite undergoing the Procedure. Ms. Lewis has also had the opportunity to discuss this situation with her legal counsel.

Despite these facts, Ms. Lewis, via her signature below, formally requests that Cook perform the Procedure on Tinslee even though it may cause a serious or fatal injury to Tinslee.

Trinity Lewis

Trinity Lewis

Dec 9, 19

Date

Witness: K. Bergman Dec 9, 2019

witness C. Kinsey 12-9-2019 0439



copy 1:3



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Cardiac Catheterization [45246233]

Electronically signed by: **Lindsay O Howell, RN on 12/09/19 0744**

Status: **Completed**

This order may be acted on in another encounter.

Ordering user: Lindsay O Howell, RN 12/09/19 0744

Ordering provider: Jay M Duncan, MD

Sensis - Scan on 12/9/2019 1:38 PM (below)



Name: LEWIS, TINSLEE

Patient ID:M4123323

Admission ID: OT251005-19

Case Number: 19-586

Examination Date: 12/9/2019

08:19:00

DOB: 2/1/2019

BSA: 0.42 m²

Height: 68 cm

Age: 10 Months

Weight: 11.1 kg

Sex: Female

INVASIVE CARDIOVASCULAR LABORATORY

CARDIOLOGIST : Kuo James MD

Procedure

93531-RHC & Retro LHC Congenitl Anomalies

93567-Inject Aortic Aortagram

93568-Inject Pulmonary Angiograms

93566-Inject Right Ventriculogram/Right
Atrium

36011-Innominate, Hepatic renal, 1st order

93463-Challenge Test

93565-Inject Left VentriculogramV/Left Atrium

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

Hemodynamic Summary

Pressures [mmHg] & Gradients

Condition 1: Air Rest

HR	SVC	IVC	RA	RV	PA R.Pr	PA L.Pr	PVW L.Up
103 bpm	(A/V/M)	(A/V/M)	(A/V/M)	(S/D/E)	(S/D/M)	(S/D/M)	(S/D/M)
	19/17/16	20/17/16	21/17/16	37/5/7	31/26/28	29/26/28	33/24/28
	PV L.Up	PV R.Up	PV L.Lo	PV R.Lo	LA	LV	AO Asc
	(A/V/M)	(A/V/M)	(A/V/M)	(A/V/M)	(A/V/M)	(S/D/E)	(S/D/M)
	38/20/21	21/19/18	22/19/18	24/22/21	23/19/18	90/12/18	73/38/55
	AO Desc	ART R.Fe					
	(S/D/M)	(S/D/M)					
	79/37/56	90/36/60					

Condition 2: 100% Oxygen

HR	SVC	RV	PA L.Pr	PVW L.Lo	PV L.Up	PV L.Lo	LA
100 bpm	(A/V/M)	(S/D/E)	(S/D/M)	(S/D/M)	(A/V/M)	(A/V/M)	(A/V/M)
	20/18/18	41/9/9	30/27/29	24/23/22	28/18/17	21/19/18	26/17/16
	ART R.Fe						
	(S/D/M)						
	89/35/58						

Saturations

Condition 1: Air Rest

HB	SVC	RA	RV	PA R.Pr	PA L.Pr	PV L.Up	PV R.Up
13.30 g/100 ml	57.0 %	78.0 %	68.0 %	76.0 %	75.0 %	74.0 %	90.0 %
	PV L.Lo	PV R.Lo	LA	LV	ART R.Fe		
	77.0 %	74.0 %	72.0 %	76.0 %	78.0 %		

Condition 2: 100% Oxygen

HB	SVC	RV	PA L.Pr	PV L.Up	PV L.Lo	LA	ART R.Fe
13.30 g/100 ml	70.0 %	81.0 %	91.0 %	86.0 %	98.0 %	89.0 %	88.0 %

Cardiac Output (Flows) and Shunts

Condition 2: 100% Oxygen

CO Type	CO(l/min)	CI(l/min/m ²)	Injection/Venous Site	Sample/Arterial Site
Fick Shunts				
Pulm. Flow:	4.76 l/min	Pulm. Flow Index:	11.24 l/min/m ²	Pulm./Syst. Flow Ratio: 2.33
Syst. Flow:	2.04 l/min	Syst. Flow Index:	4.82 l/min/m ²	
L-R Flow:	3.49 l/min	L-R Flow Ratio:	0.73	
R-L Flow:	0.76 l/min	R-L Flow Ratio:	0.37	

Calculated values

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

Condition 1: Air Rest
CO Type

Condition 2: 100% Oxygen
CO Type Fick
Pulm A-V O₂ [ml/l] 14.2
Syst A-V O₂ [ml/l] 33.1
Predicted Oxygen Consumption [ml/min] 67.5
Pulmonary Vascular Resistance [mmHg/(l/min)] 2.73
Systemic Vascular Resistance [mmHg/(l/min)] 26.96
Total Pulmonary Resistance [mmHg/(l/min)] 6.09
Total Systemic Resistance [mmHg/(l/min)] 28.43
TPR/TSR res ratio 0.21

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

PERFORMING PHYSICIANS

Physician 1: Kuo James MD Physician 2 :

PERSONNEL

Name	Function
Kuo James MD	Physician
Schartz Teresa MD	Anesthesiologist
Gosdzinski Lica	CRNA
Stephens Angela BSRN	Nurse
Woods Gloria BSRT(R)	Scrub
Palin Becky AASRT (R)	Scrub
Jones Freddie RN	Circulate
Adams Katie BSRN	Circulate
Howell Lindsay BSRN	Cardiac Cath Nurse Coordinator
Dawson David L BSRT(R)	Monitor

INDICATIONS

Indications	Comments
Ebstein's Anomaly - Q22.5	
Pulmonary Valve Atresia - Q22.0	
Status Post op - Z98.89	s/p BT shunt
HTN, Secondary Pulmonary - I27.2	

PROCEDURES

93531-RHC & Retro LHC Congenitl Anomalies
93567-Inject Aortic Aortogram
93568-Inject Pulmonary Angiograms
93566-Inject Right Ventriculogram/Right Atrium
36011-Innominate, Hepatic renal, 1st order
93463-Challenge Test
93565-Inject Left Ventriculogram/Left Atrium

PRE PROCEDURE ASSESSMENTS

Informed Consent	Allergies	Transportation	Pt Origin	Pt Status	Procedure Status
Yes	NKDA	Bed	CICU	Inpatient	Elective

LAB RESULTS

HGB	HCT	WBC	PLT	PT	PTT
13.30	41.80	10.00	67.00		
INR	GLU	K+	NA+	BUN	Creatinine
	98.00	4.50	141.00	28.00	0.53

EVENT TIMES

Cath Report

Page 4 (20)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²
Patient In 09:29	Patient Prepped 10:05
Begin Time 10:15	End Time 13:07
Patient Leave 13:36	

BLOOD GAS RESULTS

Time	Site	Ph	PCO2	PO2	BE	Saturation	Bicarb
10:22	ART R.Fe	7.32	63.00	40.00	4.60	70.00	21.50
12:16	PV L.Lo	7.46	37.00	163.00	2.50	100.00	26.30
12:13	ART R.Fe	7.42	46.00	51.00	4.50	86.00	29.80
12:30	SVC	7.38	55.00	27.00	5.90	49.00	32.50
12:48	PA L.Pr	7.43	44.00	50.00	4.30	86.00	29.20

PROCEDURE NOTES

Time	Comment
08:26:18	Patient will be warmed with Stryker Mistral Air S/N 160241826
08:26:20	Patient will be warmed with Olympic Warm Light S/N 13782.
08:26:23	Blood Gas will be ran using GEM 3500 Blood Gas Analyzer S/N 13032858.
08:26:24	Sats will be ran using AVOX SAT Analyzer S/N 2423.
08:26:25	Act will be ran using Hemochron Elite ACT Analyzer S/N SE5314.
08:26:31	Three 50 ml bottle(s) of Omnipaque 350 setup for procedure.
09:29:24	Patient entered room intubated, monitored. EKG and BP/O2 sat monitors applied. Time out performed: Patient and procedure confirmed with all staff.
09:30:07	PICC line positioned I.T saphenous vein :see anesthesia's records
09:30:24	IV started RT hand :see anesthesia's records .
09:30:43	ART line positioned in left ulna artery; see anesthesia's records
10:05:53	Bilateral groins prepped with Chloraprep. Patient draped in sterile fashion.
10:13:35	Time out repeated: Physician present @ bedside
10:13:58	Siemens Acuson Freestyle S/N (21)002109 used for vascular access.
10:15:22	Procedure Started in Rt Femoral Area
10:18:09	Right femoral vein Angiogram Performed - 2ml Omnipaque Hand Injection. PA only
10:19:21	Right femoral vein Angiogram Performed - 1ml Omnipaque Hand Injection. PA only
10:22:58	Arterial Access: 4 FR standard sheath inserted into right femoral artery .
10:27:00	Activated Clotting Time : 185 seconds.
10:27:47	Venous Access: 4 FR standard sheath inserted into left femoral vein.
10:28:00	Family notified status of patient and procedure by L. Howell, RN.
10:28:10	4 FR 65 cm Terumo Catheter inserted into left femoral vein.
10:28:55	Heparin PF Dose and concentration confirmed with two nurses
10:53:01	Family notified status of patient and procedure by L. Howell, RN.
10:53:54	3.3fr 55cm Pigtail inserted into right femoral artery
11:01:52	AAO Angiogram Performed - 10ml Omnipaque: 10ml/sec; 800 PSI. PA / LAT
11:02:40	3.3fr 55cm Pigtail out; 3.3fr 55cm JR 1 inserted into right femoral artery
11:09:52	3.3fr 55cm JR 1 out; 4fr 70cm JR 1.5 inserted into right femoral artery
11:10:19	2.8fr 110cm Progreat inserted through 4fr 70cm JR 1.5 into right femoral artery
11:20:56	LPA Angiogram Performed - 2ml Omnipaque Hand Injection. PA / LAT
11:24:25	Family notified status of patient and procedure by L. Howell, RN.
11:26:32	RPA Angiogram Performed - 2ml Omnipaque Hand Injection. PA / LAT
11:29:33	Activated Clotting Time : 206 seconds.
11:30:21	2.8fr 110cm Progreat out.
11:31:03	BT shunt (PA) Angiogram Performed - 3ml Omnipaque Hand Injection.

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

PA / LAT
11:33:57 4 FR 65 cm Terumo Catheter out; 4fr 70cm JR 2.5 inserted into left femoral vein.
11:39:21 2.8fr 110cm Progreat inserted through 4fr 70cm JR 2.5 into right femoral artery
11:43:08 2.8fr 110cm Progreat and 4fr 70cm JR 2.5 out; 4fr 65cm Terumo into right femoral artery
11:52:22 Activated Clotting Time : 213 seconds.
11:52:30 Family notified status of patient and procedure by K. Laskee, RN.
12:30:23 Activated Clotting Time : 185 seconds
12:30:49 Family notified status of patient and procedure by K. Laskee, R
12:33:44 Innominate Angiogram Performed - 4ml Omnipaque Hand Injection. PA/LAT
12:41:37 RV Angiogram Performed - 4ml Omnipaque Hand Injection. PA/LAT
12:59:47 AAO Angiogram Performed - 3ml Omnipaque Hand Injection. PA/LAT
13:00:06 4fr 70cm JR 2.5 catheter out.
13:00:26 3.3fr 55cm Pigtail inserted into right femoral artery
13:04:03 I.V. Angiogram Performed 10 ml Omnipaque; 10ml/sec; 600PSI. RAO 20 Caudal 10/LAO 70 Cranial
13:07:23 Procedure complete
13:08:42 Sheath(s) and Catheters pulled. Syvek Patch and manual pressure applied to bilateral femoral groin area(s).
13:09:02 Post ECG: Unchanged without ectopy 98 bpm.
13:09:04 I.V. unchanged.
13:09:05 Estimated Blood Loss – 10 ml. Specimen taken? Yes
13:09:08 No additional 50ml bottle(s) of Omnipaque 350 used. Total bottle(s)– Three
13:09:09 Two Kidneys are visualized.
13:29:10 EKG pads removed; No abnormal markings.
13:30:06 Site Status: Hemostasis obtained; Pressure held for 20 min bilateral femoral groin(s). Pressure dressings applied. No restraint applied to maintain hemostasis.
13:36:23 Patient transferred to CICU intubated, monitored. Monitored via L. REYNOLDS MD, L. GOSDZINSKI CRNA. A. STEPHENS RN. Report given by L. GOSDZINSKI CRNA. Patient out of room.

MEDICATIONS

Time	Medication	Amount	Units	Route	Given By
10:28	Heparin PF	420	Units	IV	Gosdzinski Lica
12:30	Heparin PF	420	Units	IV	Gosdzinski Lica

X-RAY DATA

Plane	Total area dose cGym2	Tot. fluoro time (minutes)
A	221.54	34.52
B	435.05	22.62

POST PROCEDURE DATA

Contrast Type	Amount Infused (ml)	Blood Loss Total (ml)
Omnipaque 350	38.00	10

FINDINGS

Catheterization findings
14

Above data represents preliminary results. Edited final results in PedsCath.



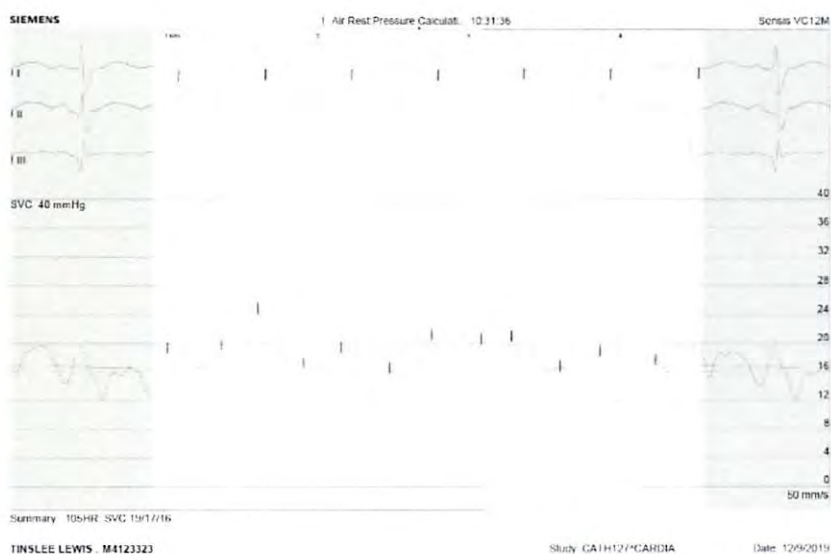
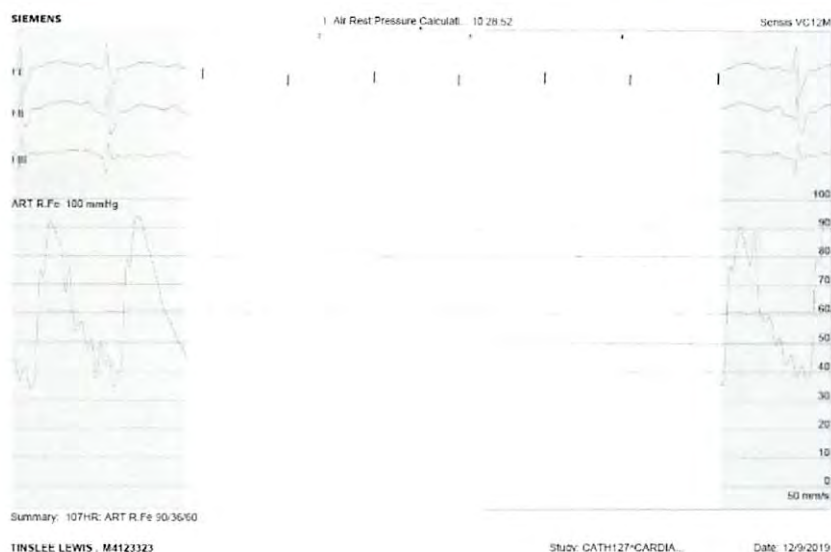
COOK CHILDRENS
MEDICAL CENTER
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FORT WORTH TX 76104-
2733

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

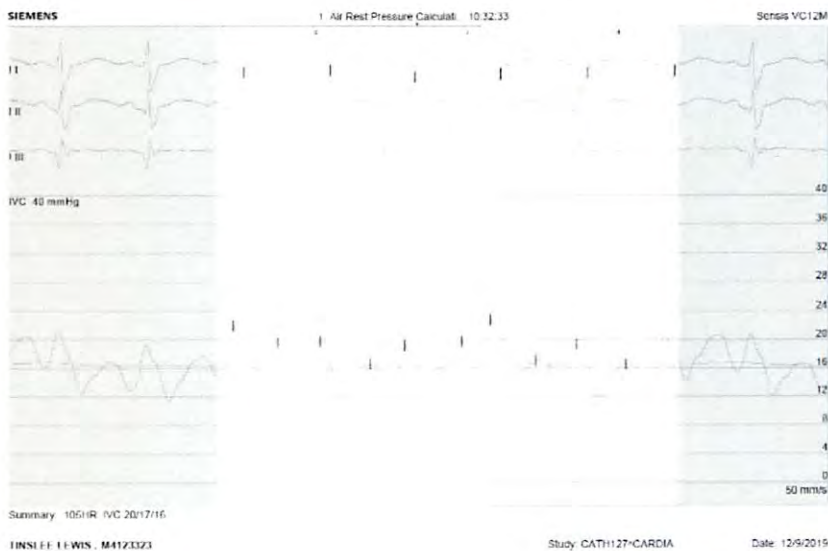
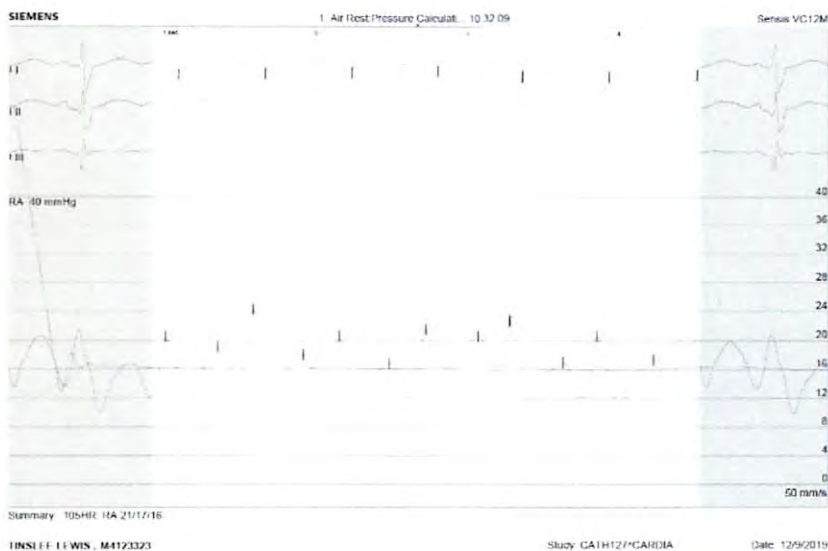
Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

Kuo James MD

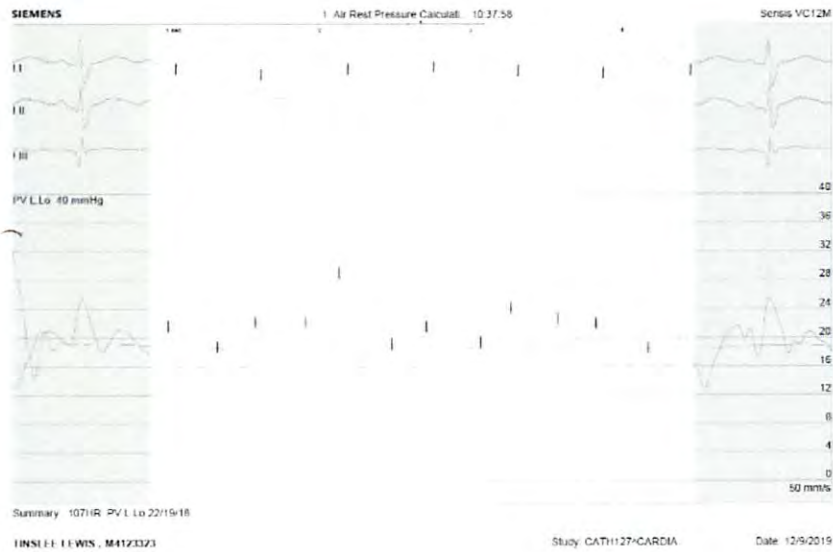
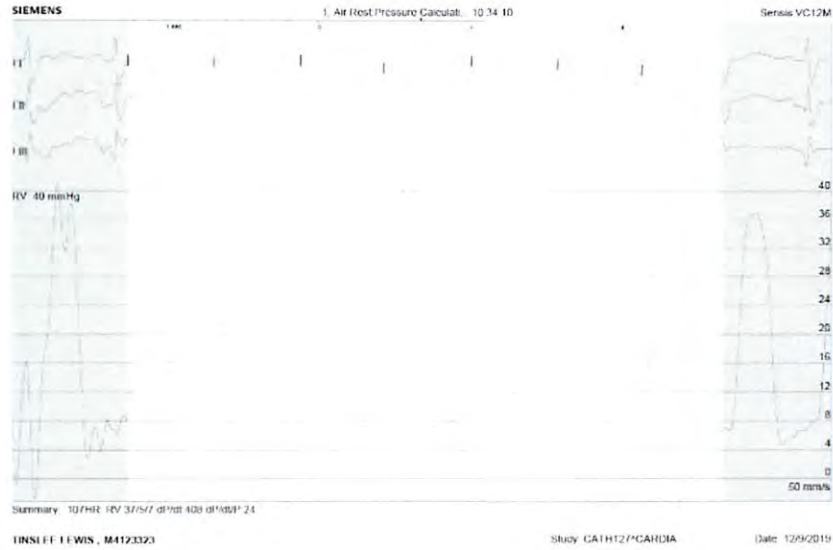
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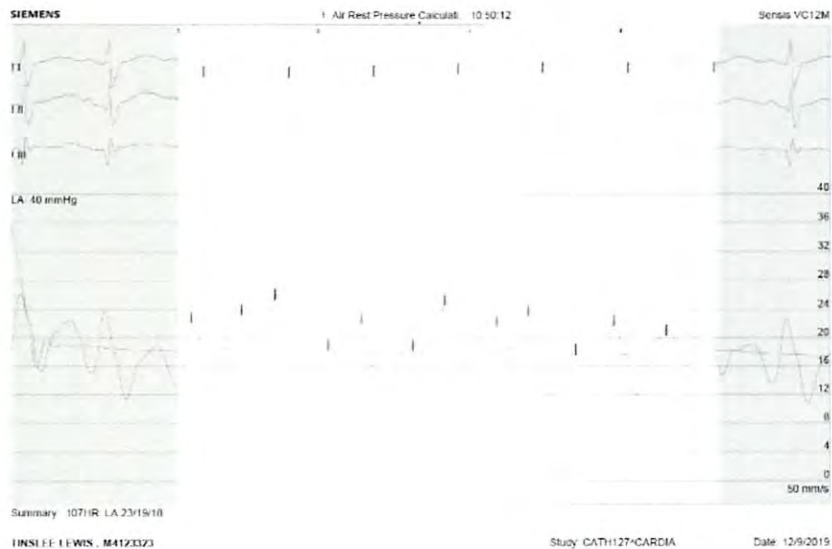
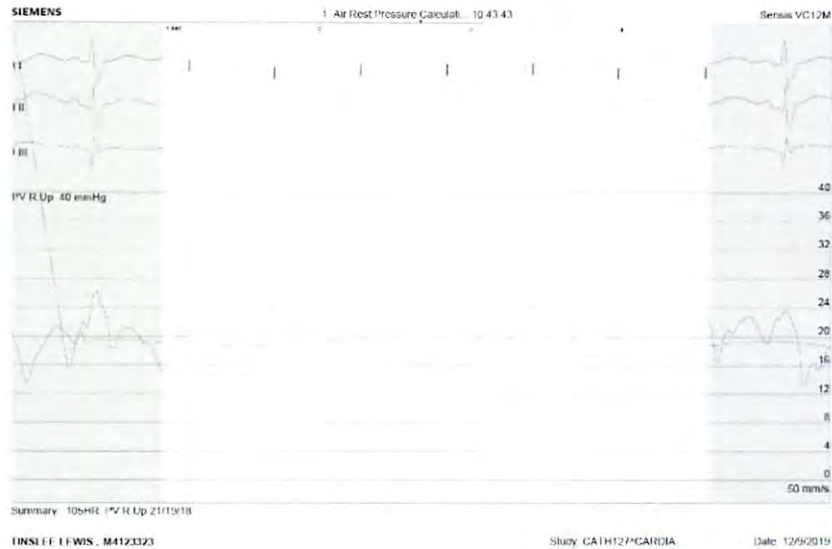
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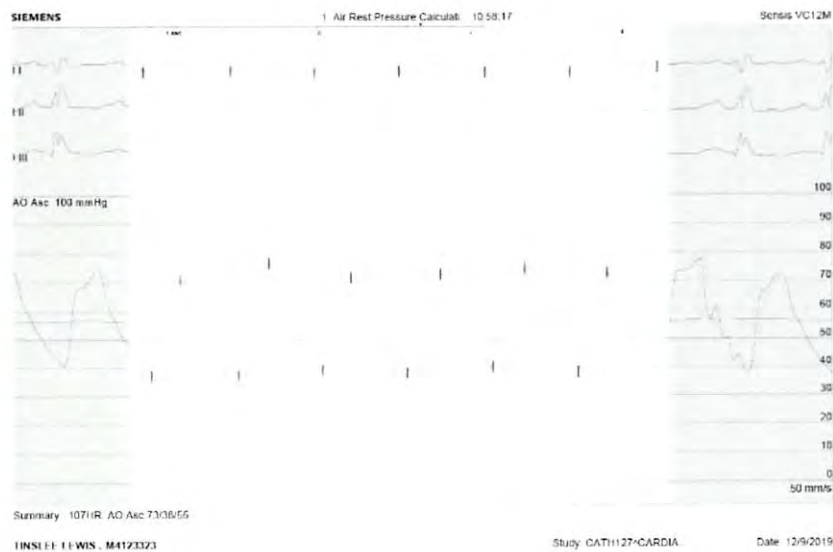
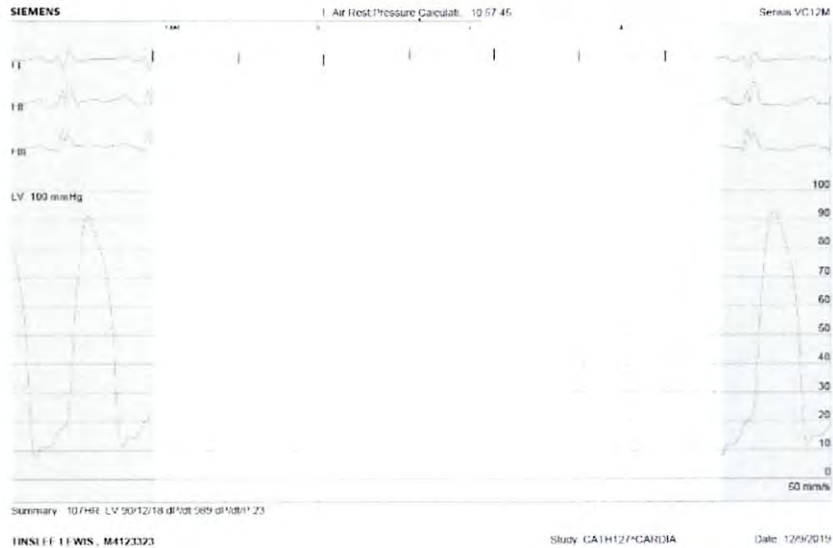
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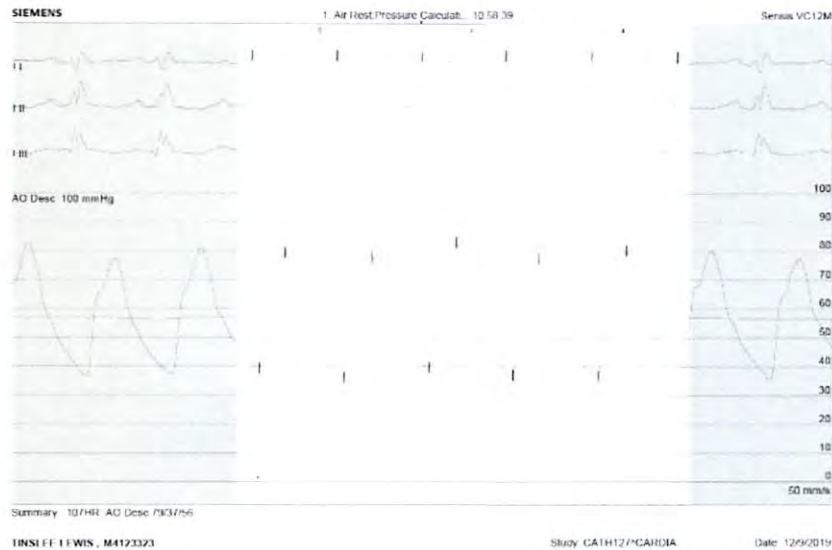
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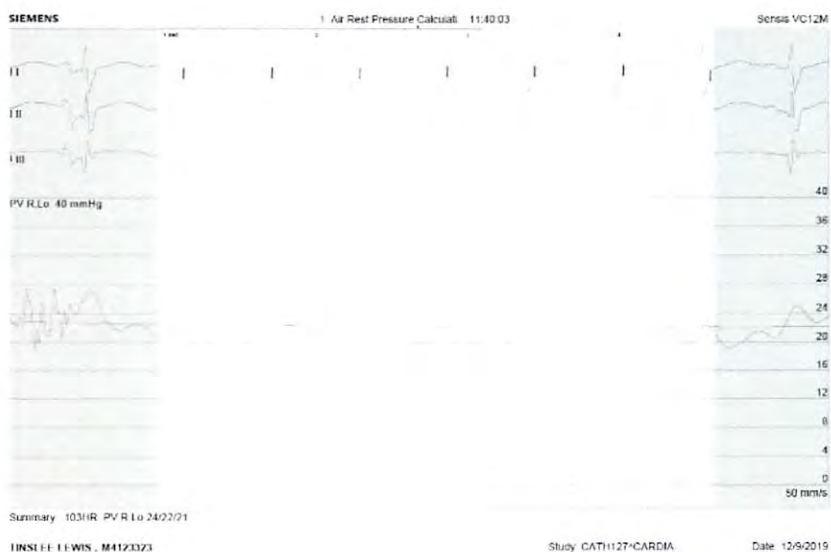
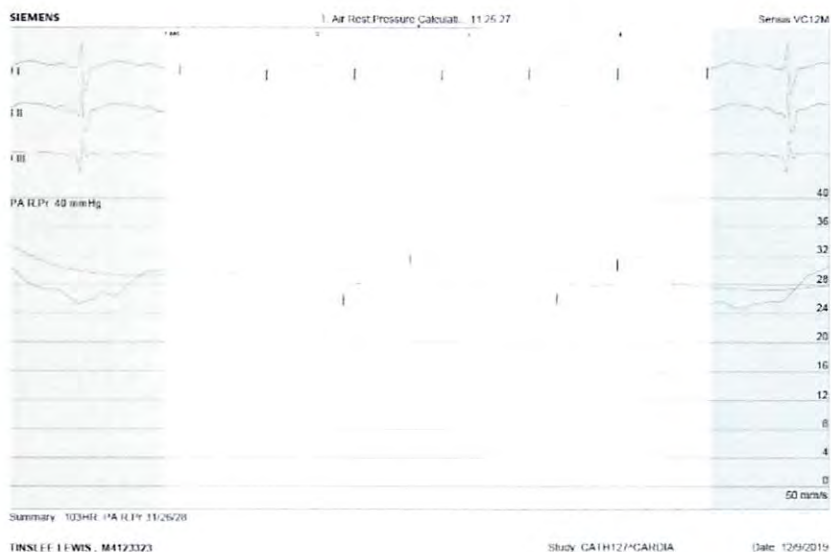
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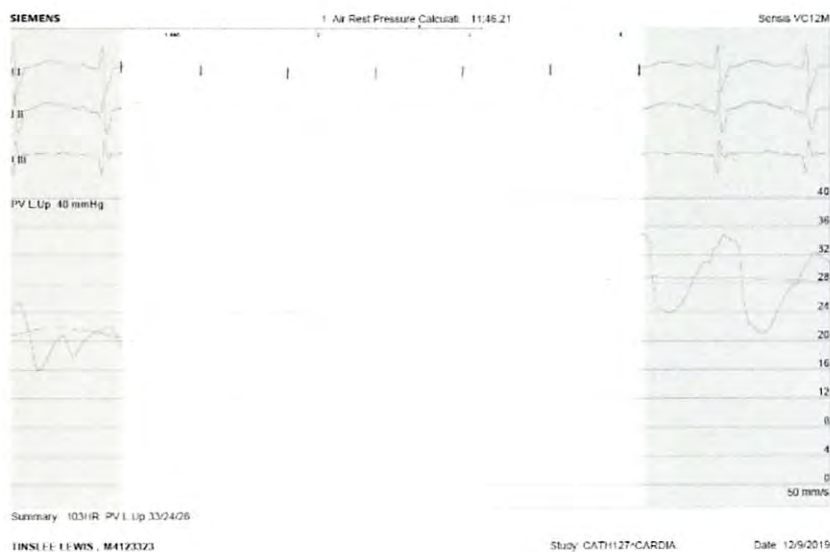
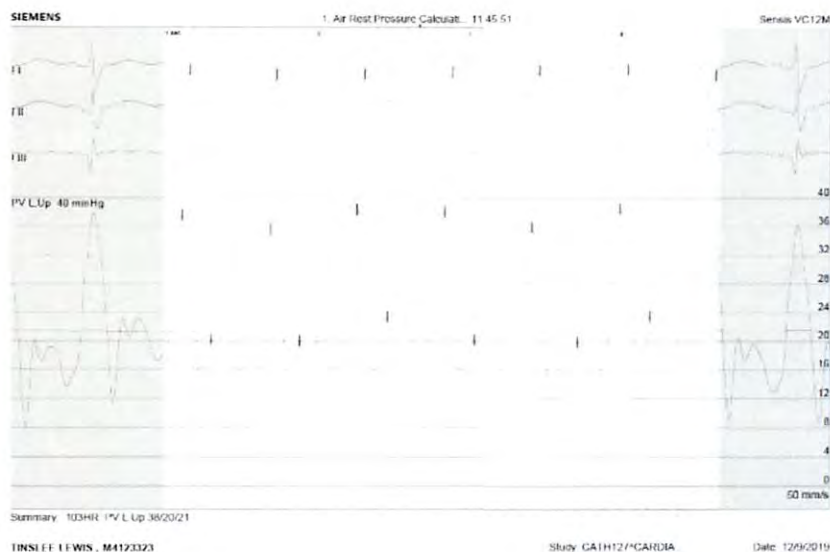
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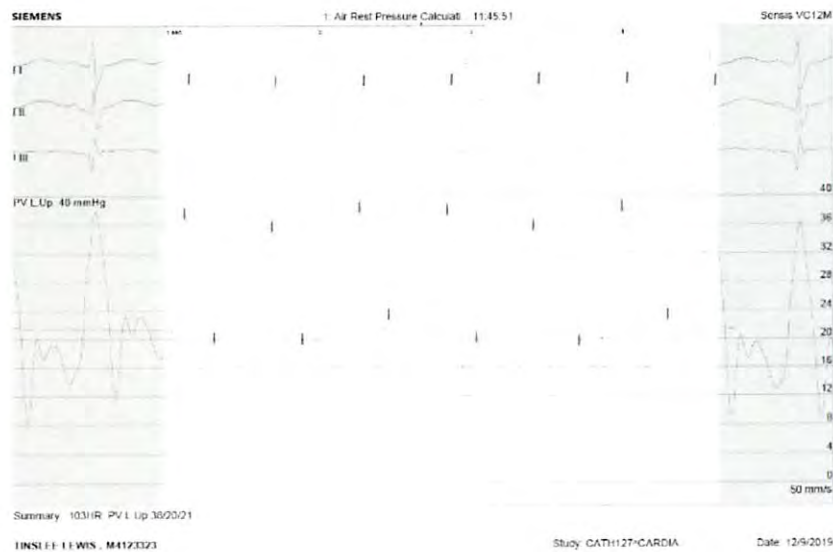
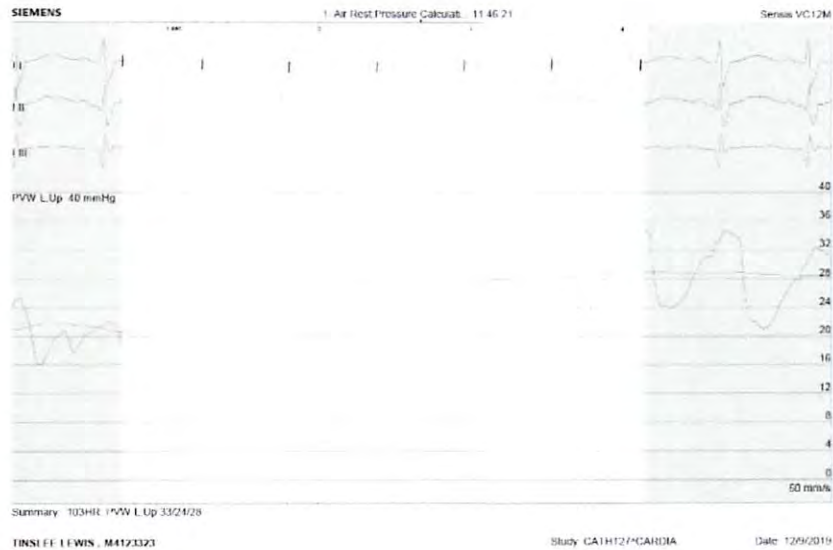
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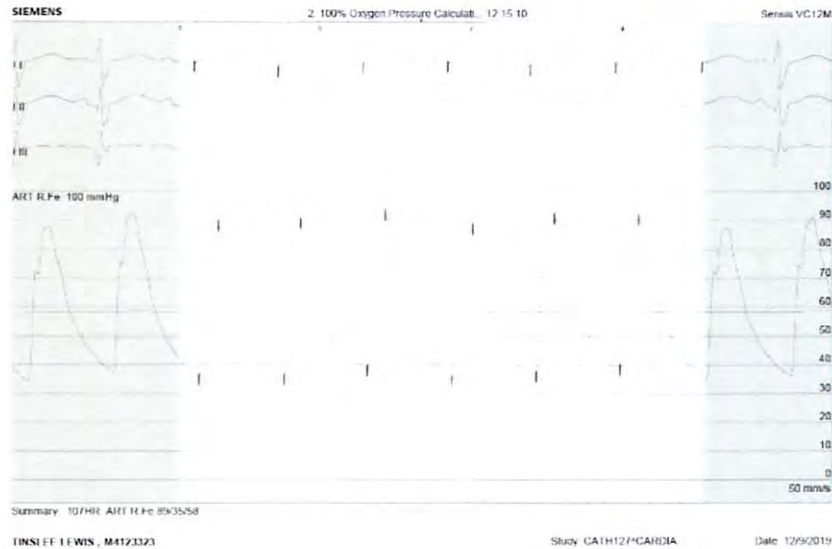
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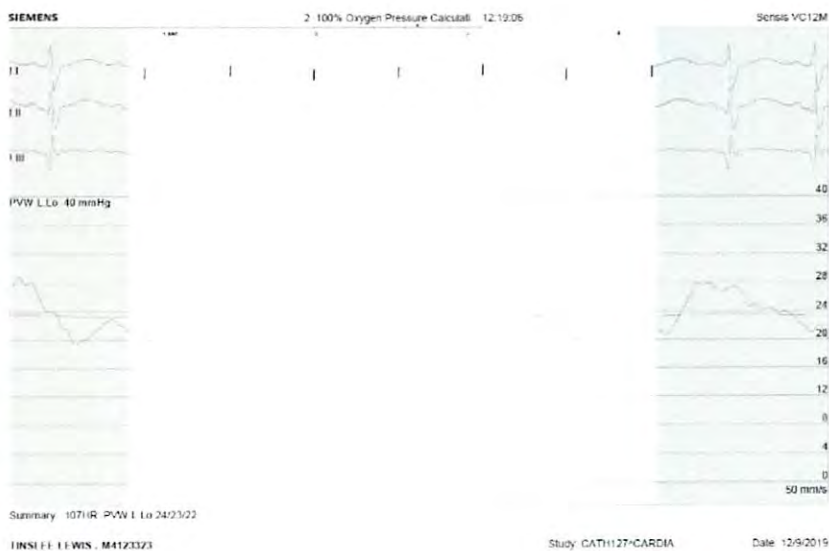
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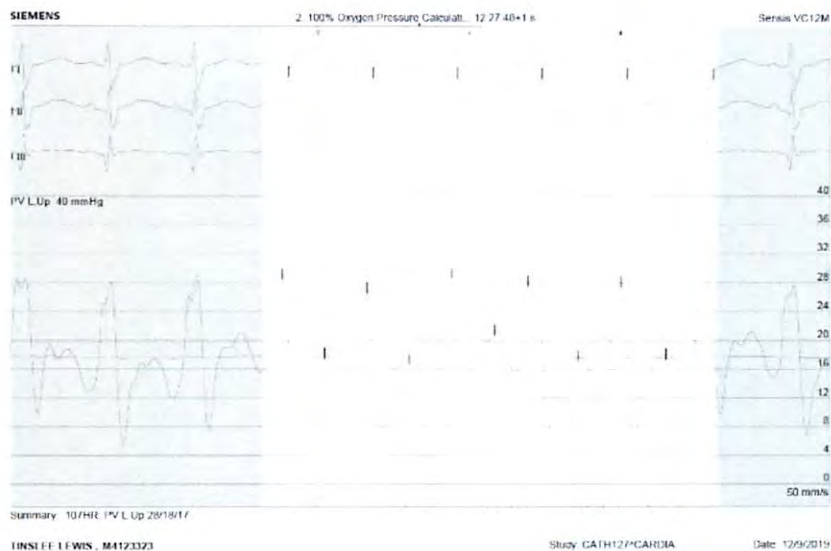
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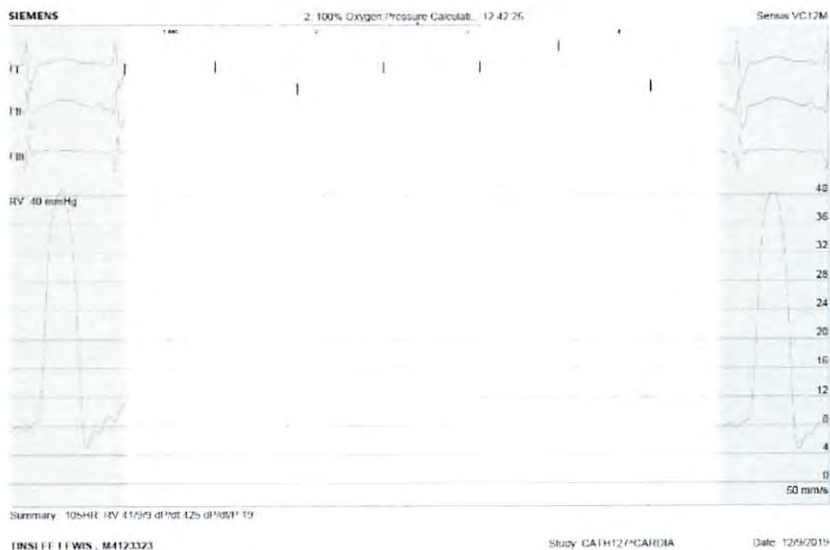
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COOK CHILDRENS
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2733

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Ped Cath - Scan on 12/9/2019 3:52 PM (below)

Lewis, Tinslee Breun

MRN: M4123323 Acct. #: 1015678564
Birth Date: 02/01/2019
Cath Date: 12/09/2019
Cath #: 19-586 Acc. #: OT251005-19
Age at cath: 10 months
Gender: Female

Attending: James A. Kuo MD
Fellow:
Referring:

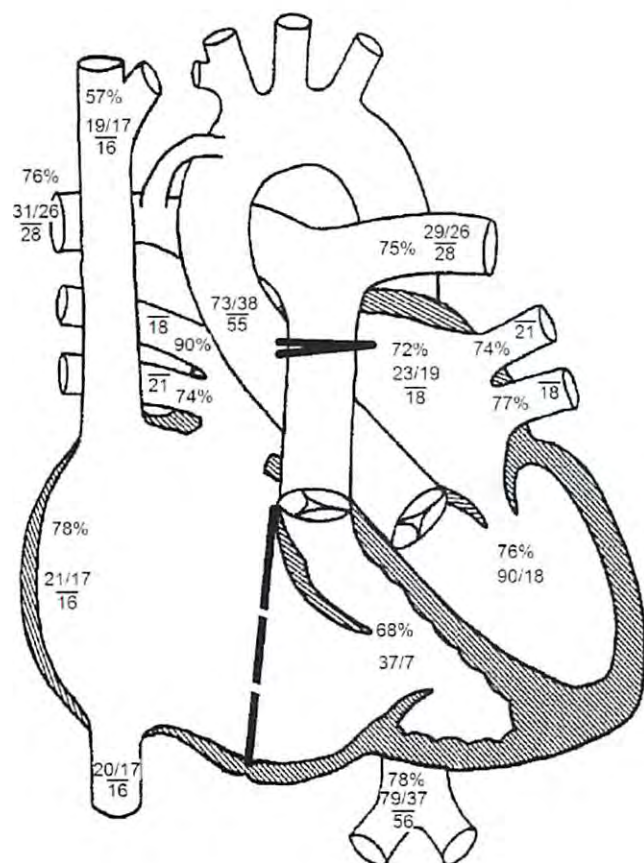
Height: 68.0 cm Weight: 11.1 kg
BSA = 0.43 m2
Fluoro: 57.14 min Contrast: 38.00 mL
Radiation Dose: 95.60 mGy 656.59 cGy-cm2
Vein: Left femoral 4fr
Artery: Right femoral 4fr

Air Rest

Qp = 7.46 L/min (17.36 L/min/m2)
Qs = 2.07 L/min (4.82 L/min/m2)
Rp = 1.34 units (0.58 units x m2)
Rs = 19.29 units (8.30 units x m2)
Qp/Qs = 3.60 : 1 | Rp/Rs = 0.07

100% Oxygen

Qp = 6.22 L/min (14.47 L/min/m2)
Qs = 2.07 L/min (4.82 L/min/m2)
Rp = 1.77 units (0.76 units x m2)
Rs = 19.29 units (8.30 units x m2)
Qp/Qs = 3.00 : 1 | Rp/Rs = 0.09



Arrows indicate catheter course.

Diagnoses / Procedures

370. Ebstein's anomaly

Comments

10 month old ex-32 week premie with lung disease and Ebstein anomaly s/p Starnes procedure with atrial septectomy, 3 mm RMBTS, pulmonary valvotomy, and reduction right atrial plasty (2/13/19 - Tam), s/p mediastinal exploration with clip placed to isolate MPA from RV due to PI (2/14/19 - Tam), s/p delayed sternal closure 2/22/19. Proximal RPA angioplasty on 5/17/19. Cardiac arrest requiring VA ECMO 7/9/19. Upsizing of BTS to 5 mm with successful ECMO decannulation (7/14/19 - Tam). Persistent cyanosis. Balloon angioplasty of innominate artery and proximal RPA (8/14/19). Subsequently underwent BTS takedown and conversion to 5 mm central shunt with innominate artery repair (8/16/19 - Tam).

Cardiac Catheterization [45246233]

Resulted: 12/09/19 1516, Result status: Final
result

Ordering provider: Jay M Duncan, MD 12/09/19 0744

Resulted by: James Andrew Kuo, MD

Performed: 12/09/19 0929 - 12/09/19 1336

Accession number: OT251005-19

Resulting lab: CVSENSIS

Narrative:

REPORT TITLE: Cardiac Catheterization

DATE OF BIRTH: 2/01/19

DATE OF PROCEDURE: 12/69/19

PROCEDURES:

1. Right and left heart catheterization.
2. Oxygen challenge.

INTRODUCTION: Tinslee is a 10-month old ex 32-week premie with Ebstein's anomaly and chronic lung disease. She is status post Starnes procedure with atrial septectomy, placement of a 3mm right modified Blalock-Taussig shunt, pulmonary valvotomy, and reduction of right atrial plasty on 2/13/19 by Dr. Vincent Tam. She is status post mediastinal exploration with clip placed to isolate the main pulmonary artery from the right ventricle due to significant pulmonary insufficiency on 2/15/19 by Dr. Tam. She is status post delayed sternal closure on 2/22/19. She underwent a cardiac catheterization with proximal right pulmonary artery angioplasty through the Blalock-Taussig shunt on 5/17/19. She has had a prolonged hospitalization due to respiratory insufficiency as well as history of atrial tachycardia, which was previously difficult to manage. She is currently on amiodarone and flecainide. She had a cardiac arrest requiring placement of VA ECMO on 7/9/19. She went to the operating room to undergo upsizing of the Blalock-Taussig shunt to a 5mm Blalock-Taussig shunt with successful ECMO decannulation on 7/14/19 by Dr. Tam. She had persistent cyanosis and required high doses of epinephrine drip to maintain relative hypertension to keep her oxygen saturations at an appropriate level. She underwent cardiac catheterization on 8/14/19 and was found to have proximal innominate artery stenosis. She underwent balloon angioplasty of the innominate artery and proximal right pulmonary artery. This unfortunately did not make a significant difference and she subsequently underwent Blalock-Taussig shunt takedown and conversion to 5 mm central shunt with innominate artery repair on 8/16/19 by Dr. Vincent Tam. She continues with cyanosis as well as a complicated prolonged hospitalization. She is sedated and paralyzed and on both epinephrine and norepinephrine drips. She was referred for cardiac catheterization.

MEDICATIONS: The procedure was performed under general anesthesia. Following placement of venous and arterial sheaths, systemic heparin was administered.

COMMENTS: Her weight was 11.1 kg. Her height was 68 cm. Body surface area was 0.43m². The patient was already intubated in the cardiac ICU and was transferred to the cardiac catheterization laboratory for induction of general anesthesia. her groins were prepped and draped in the usual sterile fashion. On previous catheterization, her right femoral vein was noted to be obstructed. However she recently underwent ultrasound of her

lower extremities and it was reported that her femoral veins bilaterally were still patent. Because of this, I initially attempted access in the right femoral vein. Under ultrasound guidance there was a femoral vein identified. This was accessed with a needle, though the wire would not pass up into the iliac vein. A 20 gauge Angiocath was placed over the wire and venogram was performed. This demonstrated occlusion of the right femoral vein with collateral vessels to the paravertebral system. The Angiocath was removed. The right femoral artery was accessed and a 4 French sheath was placed. With ultrasound guidance, 4 French sheath was placed in the left femoral vein. Hemodynamics and angiography were performed through the venous sheath using a 4-French Terumo Glide catheter. hemodynamics and angiography were performed through the arterial sheath using a 3.3-French pigtail catheter. Baseline hemodynamics were performed on 35% FiO2. From the venous sheath, I was most easily able to access the left lower pulmonary vein. It was difficult to access the left upper pulmonary vein, and ultimately a small lower branch was accessed. I had to take a large atrial loop to access the right-sided veins. Because of the large loop as well as catheter movement with the cardiac cycle, it was difficult to maintain stable positioning within the right-sided pulmonary veins. I attempted to push the catheter far out distally to obtain a pulmonary vein wedge pressure, but could only be obtained in the left upper pulmonary vein. Of note, while trying to access the left upper pulmonary vein, she went into supraventricular tachycardia. This lasted about 1-2 minutes. Ultimately this was broken by a catheter induced premature atrial contraction. No other prolonged arrhythmias throughout the procedure. The central shunt was difficult to access. Initially attempted with a JR1.0 coronary catheter and 0.025 guidewire. The wire which traversed the shunt into the proximal pulmonary artery, but the catheter would not course through the shunt. Ultimately, I was able to access the shunt using a JR1.5 coronary catheter and microcatheter. While the microcatheter could advance into the branch pulmonary arteries, the coronary catheter would not. Pressure measurements in the branch pulmonary arteries were obtained with the microcatheter. Repeat hemodynamics were performed on 100% FiO2. I was not able to access the right-sided pulmonary veins in this condition. Left lower pulmonary vein saturation increased to 100%, though the PO2 was only 163 mm Hg. At the conclusion the case the venous and arterial sheaths were removed and hemostasis was achieved using manual pressure, Syvek, and groin dressing. She tolerated the procedure well. She was transferred back to the cardiac ICU in stable condition.

PRESSURE AND SATURATION DATA: See peds cath diagram. Baseline hemodynamics performed on 35% FiO2. Superior vena cava saturation was 57%. Right atrial saturation was 78%. Right ventricular saturation was 68%. Left atrial saturation was 72%. Left upper pulmonary vein saturation 74%. Left lower pulmonary vein saturation 77%. Right upper pulmonary vein saturation 90%. Right lower pulmonary vein saturation 74%. Left ventricle saturation 76%. Descending aorta saturation 78%.

Superior vena cava A wave pressure was 19, V wave pressure 17 and mean pressure of 16. Inferior vena cava A wave pressure was 20, V wave pressure was 17, and a mean of 16. Right atrial A wave pressure was 21, V wave pressure 17 and a mean of 16. Right ventricular systolic pressure was 37 with an end diastolic pressure of 7. Left atrial A wave pressure was 23, V wave pressure 19 and a mean of 18. Left upper pulmonary vein A-wave pressure was 28, a V-wave pressure was 20, and a mean of 21. Left lower

pulmonary vein A-wave pressure was 22, V-wave pressure was 19, and a mean pressure of 18. Right upper pulmonary vein A-wave pressure was 21, V-wave pressure was 19, and a mean pressure of 18. Right lower pulmonary vein A-wave pressure was 24, V-wave pressure was 22, and a mean pressure of 21. Left upper pulmonary vein wedge pressure was 33/24 and a mean of 28. Left ventricle systolic pressure was 90 with a end-diastolic pressure 18. Ascending aorta pressure was 73/38 with a mean of 56. Descending aorta pressure was 79/37 with a mean of 56.

Using an assumed oxygen consumption of 157 ml/min/m² and a measured hemoglobin of 13.3 gm/dL and averaging pulmonary vein saturations, the QP was 17.36 liters/min/m² with a QS of 4.82 liters/min/m². QP:QS was 3.6. Pulmonary vascular resistance was 0.58 Woods units x m². Systemic vascular resistance was 8.30 Woods units x m².

On 100% FiO₂:

Superior vena cava saturation was 70%. Right ventricular saturation was 81%. Left atrial saturation was 89%. Left upper pulmonary vein saturation 86%. Left lower pulmonary vein saturation 98%. Descending aorta saturation 88%.

Superior vena cava A wave pressure was 20, V wave pressure 18 and mean pressure of 18. Right ventricular systolic pressure was 41 with an end diastolic pressure of 9. Left atrial A wave pressure was 26, V wave pressure 17 and a mean of 16. Left upper pulmonary vein A-wave pressure was 28, a V-wave pressure was 18, and a mean of 17. Left lower pulmonary vein A-wave pressure was 21, V-wave pressure was 19, and a mean pressure of 18. Left lower pulmonary vein wedge pressure was 24/23 and a mean of 22. Left pulmonary artery pressure was 30/27 with a mean of 29. Descending aorta pressure was 89/35 with a mean of 58.

Using an assumed oxygen consumption of 157 ml/min/m² and a measured hemoglobin of 13.3 gm/dL and averaging pulmonary vein saturations, the QP was 14.47 liters/min/m² with a QS of 4.82 liters/min/m². QP:QS was 3.0. Pulmonary vascular resistance was 0.76 Woods units x m². Systemic vascular resistance was 8.30 Woods units x m².

CINEANGIOGRAPHY: The first two injections were venograms in the right femoral vein. They demonstrated occlusion of the right femoral vein with large collateralization to the paravertebral system.

The next injection was into the aortic root. this demonstrates left aortic arch. No significant aortic insufficiency. Two coronary artery system is noted. Flow is seen through the central shunt into the branch pulmonary arteries. The proximal right pulmonary artery measures 6.5 mm and the proximal left pulmonary artery measures 7.2 mm in diameter. In the lateral projection, the shunt measures 4.2 mm in diameter. There is abnormal appearance of the distal arborization. There appears to be unobstructed pulmonary venous return to the left atrium.

The next injection was into the microcatheter in the left pulmonary artery. Flow is primarily seen into the left upper lobe and there is abnormal distal arborization. Two upper pulmonary veins are noted with a larger superior vein and a smaller inferior branch.

The next injection was into the microcatheter in the right pulmonary artery. flow is primarily seen into the posterior and superior portion of the lower lobe. There does appear to be abnormal distal arborization.

The next injection was into the aortic arch near the origin of the central shunt. This did not delineate the shunt as well as I had hoped. Though it can be seen as widely patent without stenosis and the branch pulmonary arteries appear similar as described previously.

The next injection was into the innominate vein. This demonstrates widely patent innominate vein draining to the right superior vena cava. No left superior vena cava is noted. The proximal end of the superior vena cava is slightly more anterior on the right atrium than usual.

The next injection was into the right ventricle. This demonstrates hypoplastic right ventricle with at least mildly depressed systolic function. No significant outflow is seen. There is regurgitation through 2 fenestrations in the tricuspid valve patch. Dilated right atrium is noted.

The next injection was into the left ventricle. This demonstrates a good size left ventricle with good systolic function. There is catheter-induced mitral regurgitation. The left ventricular outflow tract appears slightly narrowed but is widely patent.

DIAGNOSES:

1. Ebstein's anomaly and chronic lung disease. She is status post Starnes procedure with atrial septectomy, a 3mm right modified Blalock-Taussig shunt, pulmonary valvotomy and reduction of right atrial plasty on 2/13/19 by Dr. Tam.
2. Status post mediastinal exploration with clip placed to isolate the main pulmonary artery from the right ventricle due to pulmonary insufficiency on 2/15/19 by Dr. Tam.
3. Status post delayed sternal closure on 2/22/19.
4. Right pulmonary artery stenosis status post balloon angioplasty on 5/17/19.
5. History of atrial tachycardia which, currently on amiodarone and flecainide.
6. Status post cardiac arrest requiring placement of VA ECMO on 7/9/19.
7. Status post upsizing of the Blalock-Taussig shunt to a 5mm Blalock-Taussig shunt with successful ECMO decannulation on 7/14/19 by Dr. Tam.
9. Status post balloon angioplasty of the innominate artery and right pulmonary artery on 8/14/19.
10. Status post Blalock-Taussig shunt takedown and conversion to 5 mm central shunt with innominate artery repair on 8/16/19 by Dr. Vincent Tam.

DISCUSSION: Tinslee continues to have findings of chronic lung disease. It is difficult to get completely accurate branch pulmonary artery pressures given that I can only access stem with a microcatheter. I will relay the results of the catheterization to the inpatient cardiology team. I discussed the results of catheterization with her mother who had all of her questions answered and voiced understanding.



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Order-Level Documents:

Sensis - Scan on 12/9/2019 1:38 PM (below)



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Adm: 2/1/2019, D/C: —

Order-Level Documents: (continued)



Cook Children's Medical Center
Ft Worth , Texas 76104
Cook Children's Healthcare System

Name: **LEWIS, TINSLEE**

Patient ID: M4123323

Admission ID: OT251005-19

Case Number: 19-586

Examination Date: 12/9/2019

DOB: 2/1/2019

Height: 68 cm

Weight: 11.1 kg

08:19:00

BSA: 0.42 m²

Age: 10 Months

Sex: Female

INVASIVE CARDIOVASCULAR LABORATORY

CARDIOLOGIST : Kuo James MD

Procedure

93531-RHC & Retro LHC Congenital Anomalies

93567-Inject Aortic Aortogram

93568-Inject Pulmonary Angiograms

93566-Inject Right Ventriculogram/Right
Atrium

36011-Innominate, Hepatic renal, 1st order

93463-Challenge Test

93565-Inject Left VentriculogramV/Left Atrium

Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

Hemodynamic Summary

Pressures [mmHg] & Gradients

Condition 1: Air Rest

HR	SVC	IVC	RA	RV	PA R.Pr	PA L.Pr	PVW L.Up
103 bpm	(A/V/M)	(A/V/M)	(A/V/M)	(S/D/E)	(S/D/M)	(S/D/M)	(S/D/M)
	19/17/16	20/17/16	21/17/16	37/5/7	31/26/28	29/26/28	33/24/28
	PV L.Up	PV R.Up	PV L.Lo	PV R.Lo	LA	LV	AO Asc
	(A/V/M)	(A/V/M)	(A/V/M)	(A/V/M)	(A/V/M)	(S/D/E)	(S/D/M)
	38/20/21	21/19/18	22/19/18	24/22/21	23/19/18	90/12/18	73/38/55
	AO Desc	ART R.Fe					
	(S/D/M)	(S/D/M)					
	79/37/56	90/36/60					

Condition 2: 100% Oxygen

HR	SVC	RV	PA L.Pr	PVW L.Lo	PV L.Up	PV L.Lo	LA
100 bpm	(A/V/M)	(S/D/E)	(S/D/M)	(S/D/M)	(A/V/M)	(A/V/M)	(A/V/M)
	20/18/18	41/9/9	30/27/29	24/23/22	28/18/17	21/19/18	26/17/16
	ART R.Fe						
	(S/D/M)						
	89/35/58						

Saturations

Condition 1: Air Rest

HB	SVC	RA	RV	PA R.Pr	PA L.Pr	PV L.Up	PV R.Up
13.30 g/100 ml	57.0 %	78.0 %	68.0 %	76.0 %	75.0 %	74.0 %	90.0 %
	PV L.Lo	PV R.Lo	LA	LV	ART R.Fe		
	77.0 %	74.0 %	72.0 %	76.0 %	78.0 %		

Condition 2: 100% Oxygen

HB	SVC	RV	PA L.Pr	PV L.Up	PV L.Lo	LA	ART R.Fe
13.30 g/100 ml	70.0 %	81.0 %	91.0 %	86.0 %	98.0 %	89.0 %	88.0 %

Cardiac Output (Flows) and Shunts

Condition 2: 100% Oxygen

CO Type	CO (l/min)	CI (l/min/m ²)	Injection/Venous Site	Sample/Arterial Site
Fick Shunts				
Pulm. Flow:	4.76 l/min	Pulm. Flow Index:	11.24 l/min/m ²	Pulm./Syst. Flow Ratio: 2.33
Syst. Flow:	2.04 l/min	Syst. Flow Index:	4.82 l/min/m ²	
L-R Flow:	3.49 l/min	L-R Flow Ratio:	0.73	
R-L Flow:	0.76 l/min	R-L Flow Ratio:	0.37	

Calculated values



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Lewis, Tinslee Breun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

Condition 1: Air Rest
CO Type

Condition 2: 100% Oxygen

CO Type	Fick
Pulm A-V O ₂ [ml/l]	14.2
Syst A-V O ₂ [ml/l]	33.1
Predicted Oxygen Consumption [ml/min]	67.5
Pulmonary Vascular Resistance [mmHg/(l/min)]	2.73
Systemic Vascular Resistance [mmHg/(l/min)]	26.96
Total Pulmonary Resistance [mmHg/(l/min)]	6.09
Total Systemic Resistance [mmHg/(l/min)]	28.43
TPR/TSR res ratio	0.21

Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

PERFORMING PHYSICIANS

Physician 1: Kuo James MD Physician 2 :

PERSONNEL

Name	Function
Kuo James MD	Physician
Schartz Teresa MD	Anesthesiologist
Gosdzinski Lica	CRNA
Stephens Angela BSRN	Nurse
Woods Gloria BSRT(R)	Scrub
Palin Becky AASRT (R)	Scrub
Jones Freddie RN	Circulate
Adams Katie BSRN	Circulate
Howell Lindsay BSRN	Cardiac Cath Nurse Coordinator
Dawson David L BSRT(R)	Monitor

INDICATIONS

Indications	Comments
Ebstein's Anomaly - Q22.5	
Pulmonary Valve Atresia - Q22.0	
Status Post op - Z98.89	s/p BT shunt
HTN, Secondary Pulmonary - I27.2	

PROCEDURES

93531-RHC & Retro LHC Congenitl Anomalies
93567-Inject Aortic Aortagram
93568-Inject Pulmonary Angiograms
93566-Inject Right Ventriculogram/Right Atrium
36011-Innominate, Hepatic renal, 1st order
93463-Challenge Test
93565-Inject Left VentriculogramV/Left Atrium

PRE PROCEDURE ASSESSMENTS

Informed Consent	Allergies	Transportation	Pt Origin	Pt Status	Procedure Status
Yes	NKDA	Bed	CICU	Inpatient	Elective

LAB RESULTS

HGB	HCT	WBC	PLT	PT	PTT
13.30	41.80	10.00	67.00		
INR	GLU	K+	NA+	BUN	Creatinine
	98.00	4.50	141.00	28.00	0.53

EVENT TIMES

Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

Patient In 09:29	Patient Prepped 10:05	Begin Time 10:15	End Time 13:07	Patient Leave 13:36
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BLOOD GAS RESULTS

Time	Site	Ph	PCO2	PO2	BE	Saturation	Bicarb
10:22	ART R.Fe	7.32	63.00	40.00	4.60	70.00	21.50
12:16	PV L.Lo	7.46	37.00	163.00	2.50	100.00	26.30
12:13	ART R.Fe	7.42	46.00	51.00	4.50	86.00	29.80
12:30	SVC	7.38	55.00	27.00	5.90	49.00	32.50
12:48	PA L.Pr	7.43	44.00	50.00	4.30	86.00	29.20

PROCEDURE NOTES

Time	Comment
08:26:18	Patient will be warmed with Stryker Mistral Air S/N 160241826
08:26:20	Patient will be warmed with Olympic Warm Light S/N 13782.
08:26:23	Blood Gas will be ran using GEM 3500 Blood Gas Analyzer S/N 13032858.
08:26:24	Sats will be ran using AVOX SAT Analyzer S/N 2423.
08:26:25	Act will be ran using Hemochron Elite ACT Analyzer S/N SE5314.
08:26:31	Three 50 ml bottle(s) of Omnipaque 350 setup for procedure.
09:29:24	Patient entered room intubated, monitored. EKG and BP/O2 sat monitors applied. Time out performed: Patient and procedure confirmed with all staff.
09:30:07	PICC line positioned LT saphenous vein ;see anesthesia's records
09:30:24	IV started RT hand ;see anesthesia's records .
09:30:43	ART line positioned in left ulna artery: see anesthesia's records
10:05:53	Bilateral groins prepped with Chloraprep. Patient draped in sterile fashion.
10:13:35	Time out repeated: Physician present @ bedside
10:13:58	Siemens Acuson Freestyle S/N (21)002109 used for vascular access.
10:15:22	Procedure Started in Rt Femoral Area
10:18:09	Right femoral vein Angiogram Performed - 2ml Omnipaque Hand Injection. PA only
10:19:21	Right femoral vein Angiogram Performed - 1ml Omnipaque Hand Injection. PA only
10:22:58	Arterial Access: 4 FR standard sheath inserted into right femoral artery .
10:27:00	Activated Clotting Time : 185 seconds.
10:27:47	Venous Access: 4 FR standard sheath inserted into left femoral vein.
10:28:00	Family notified status of patient and procedure by L. Howell, RN.
10:28:10	4 FR 65 cm Terumo Catheter inserted into left femoral vein.
10:28:55	Heparin PF Dose and concentration confirmed with two nurses
10:53:01	Family notified status of patient and procedure by L. Howell, RN.
10:53:54	3.3fr 55cm Pigtail inserted into right femoral artery
11:01:52	AAO Angiogram Performed - 10ml Omnipaque: 10ml/sec: 800 PSI. PA / LAT
11:02:40	3.3fr 55cm Pigtail out, 3.3fr 55cm JR 1 inserted into right femoral artery
11:09:52	3.3fr 55cm JR 1 out; 4fr 70cm JR 1.5 inserted into right femoral artery
11:10:19	2.8fr 110cm Progreat inserted through 4fr 70cm JR 1.5 into right femoral artery
11:20:56	LPA Angiogram Performed - 2ml Omnipaque Hand Injection. PA / LAT
11:24:25	Family notified status of patient and procedure by L. Howell, RN.
11:26:32	RPA Angiogram Performed - 2ml Omnipaque Hand Injection. PA / LAT
11:29:33	Activated Clotting Time : 206 seconds.
11:30:21	2.8fr 110cm Progreat out.
11:31:03	BT shunt (PA) Angiogram Performed - 3ml Omnipaque Hand Injection.

Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

PA / LAT
11:33:57 4 FR 65 cm Terumo Catheter out; 4fr 70cm JR 2.5 inserted into left femoral vein.
11:39:21 2.8fr 110cm Progreat inserted through 4fr 70cm JR 2.5 into right femoral artery
11:43:08 2.8fr 110cm Progreat and 4fr 70cm JR 2.5 out; 4fr 65cm Terumo into right femoral artery
11:52:22 Activated Clotting Time : 213 seconds.
11:52:30 Family notified status of patient and procedure by K. Laskee, RN.
12:30:23 Activated Clotting Time : 185 seconds.
12:30:49 Family notified status of patient and procedure by K. Laskee, R
12:33:44 Innominate Angiogram Performed - 4ml Omnipaque Hand Injection. PA/LAT
12:41:37 RV Angiogram Performed - 4ml Omnipaque Hand Injection. PA/LAT
12:59:47 AAO Angiogram Performed - 3ml Omnipaque Hand Injection. PA/LAT
13:00:06 4fr 70cm JR 2.5 catheter out.
13:00:26 3.3fr 55cm Pigtail inserted into right femoral artery
13:04:03 LV Angiogram Performed 10 ml Omnipaque; 10ml/sec; 600PSI. RAO 20 Caudal 10/LAO 70 Cranial
13:07:23 Procedure complete
13:08:42 Sheath(s) and Catheters pulled. Syvek Patch and manual pressure applied to bilateral femoral groin area(s).
13:09:02 Post ECG: Unchanged without ectopy 98 bpm.
13:09:04 I.V. unchanged.
13:09:05 Estimated Blood Loss - 10 ml Specimen taken? Yes
13:09:08 No additional 50ml bottle(s) of Omnipaque 350 used . Total bottle(s)- Three .
13:09:09 Two Kidneys are visualized.
13:29:10 EKG pads removed; No abnormal markings.
13:30:06 Site Status: Hemostasis obtained; Pressure held for 20 min bilateral femoral groin(s). Pressure dressings applied. No restraint applied to maintain hemostasis.
13:36:23 Patient transferred to CICU intubated, monitored. Monitored via L. REYNOLDS MD, L. GOSDZINSKI CRNA, A. STEPHENS RN. Report given by L. GOSDZINSKI CRNA. Patient out of room.

MEDICATIONS

Time	Medication	Amount	Units	Route	Given By
10:28	Heparin PF	420	Units	IV	Gosdzinski Lica
12:30	Heparin PF	420	Units	IV	Gosdzinski Lica

X-RAY DATA

Plane	Total area dose cGym2	Tot. fluoro time (minutes)
A	221.54	34.52
B	435.05	22.62

POST PROCEDURE DATA

Contrast Type	Amount Infused (ml)	Blood Loss Total (ml)
Omnipaque 350	38.00	10

FINDINGS

Catheterization findings
14

Above data represents preliminary results. Edited final results in PedsCath.



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Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

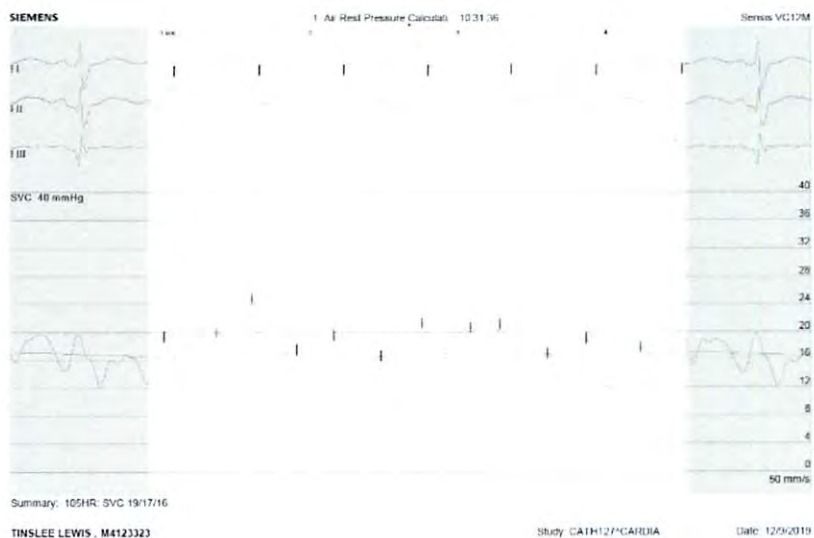
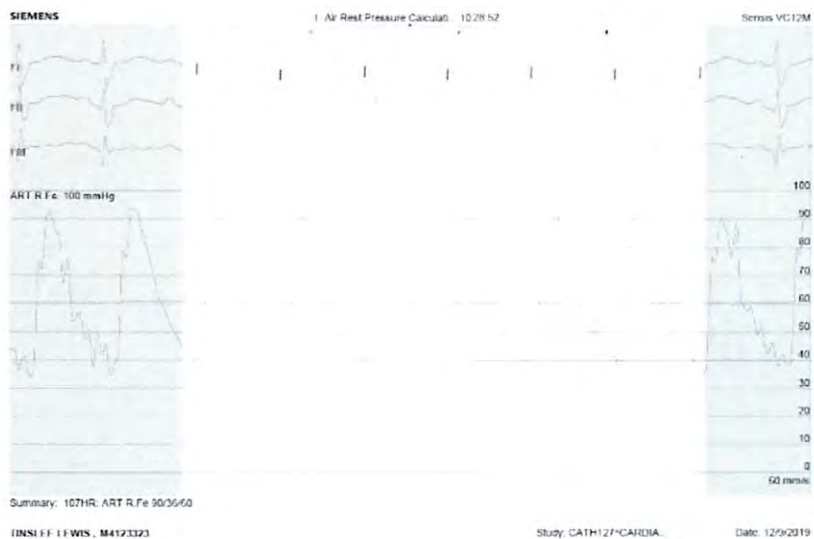
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²

Kuo James MD

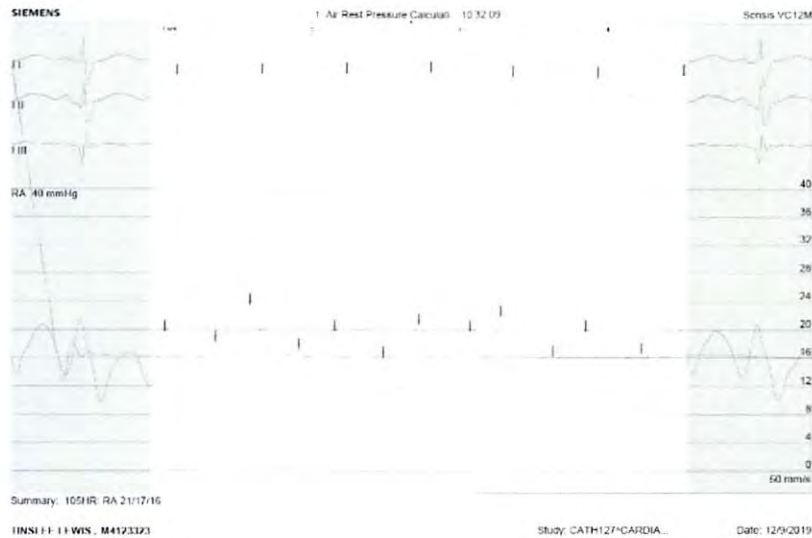
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



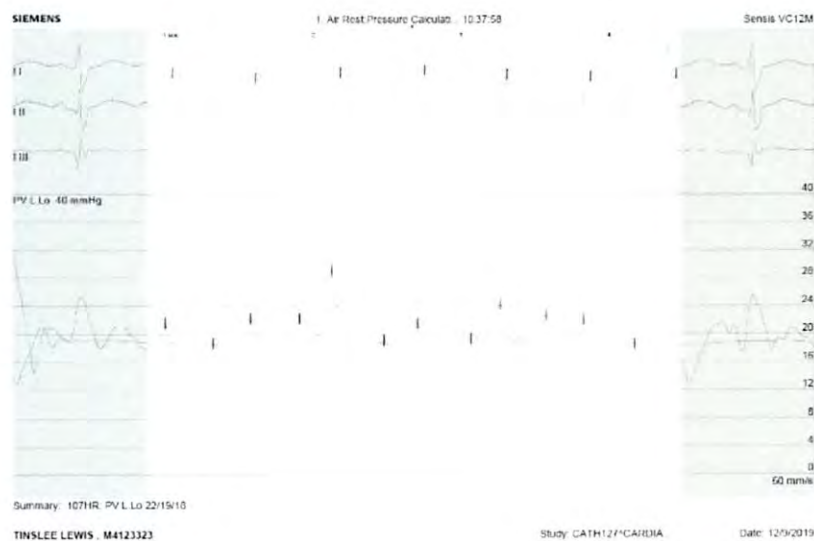
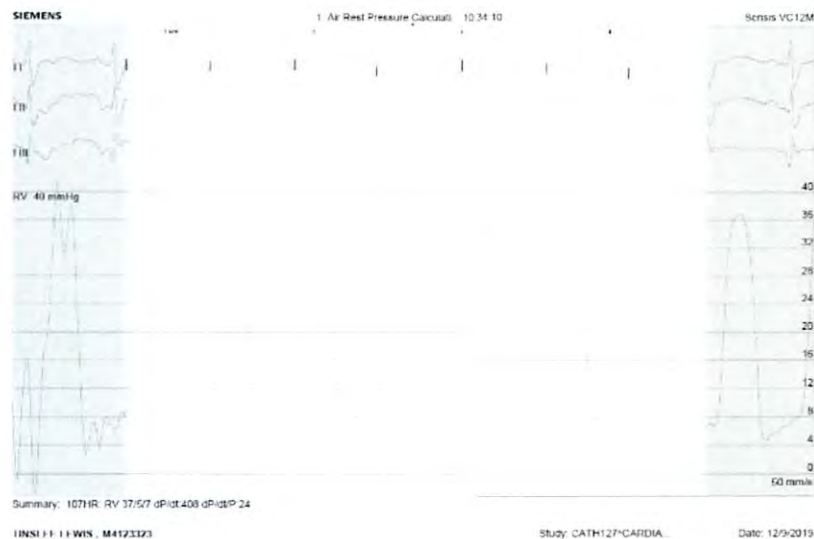
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



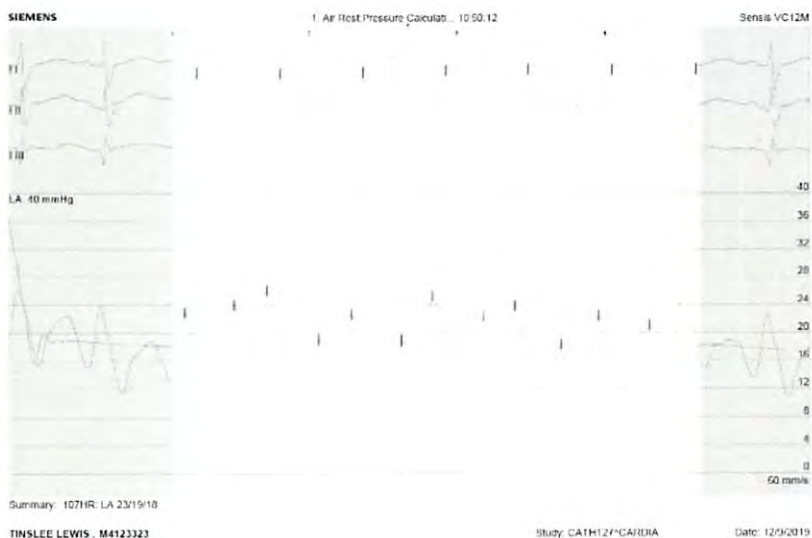
Order-Level Documents: (continued)

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Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



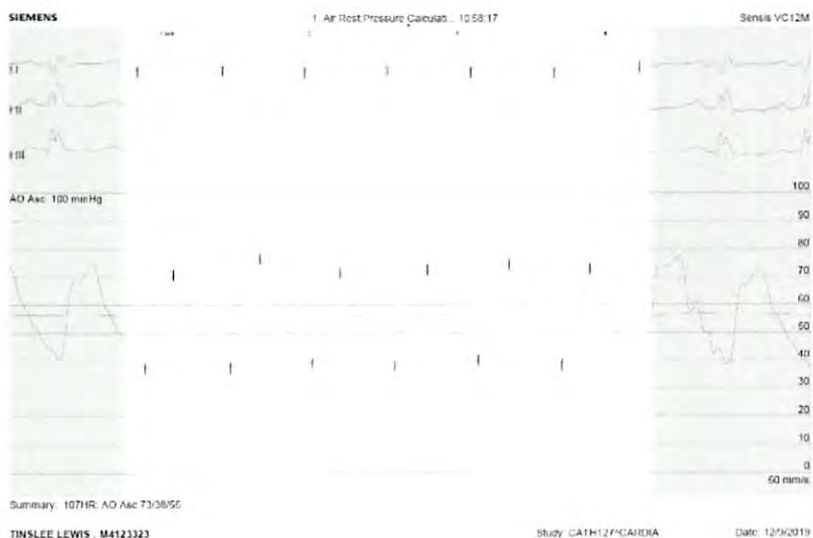
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



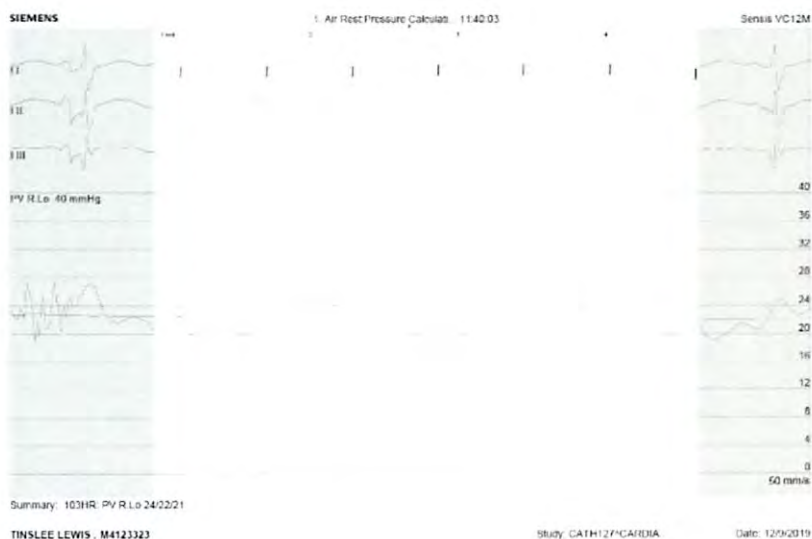
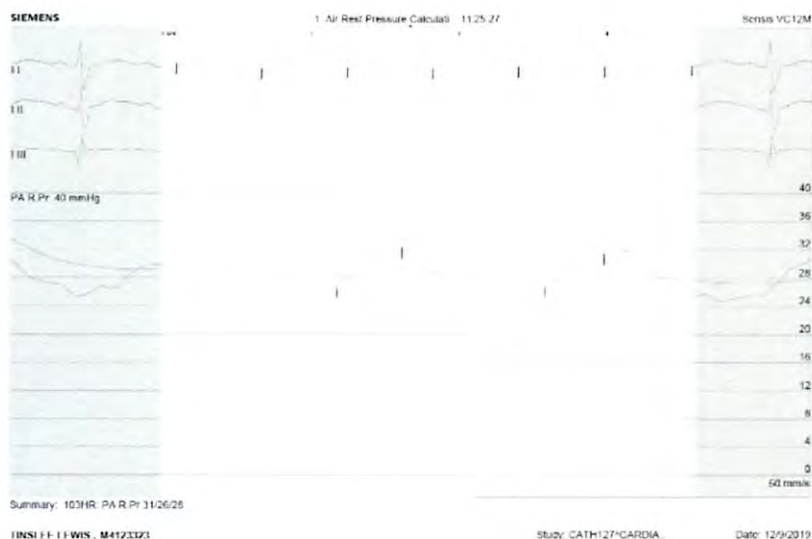
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



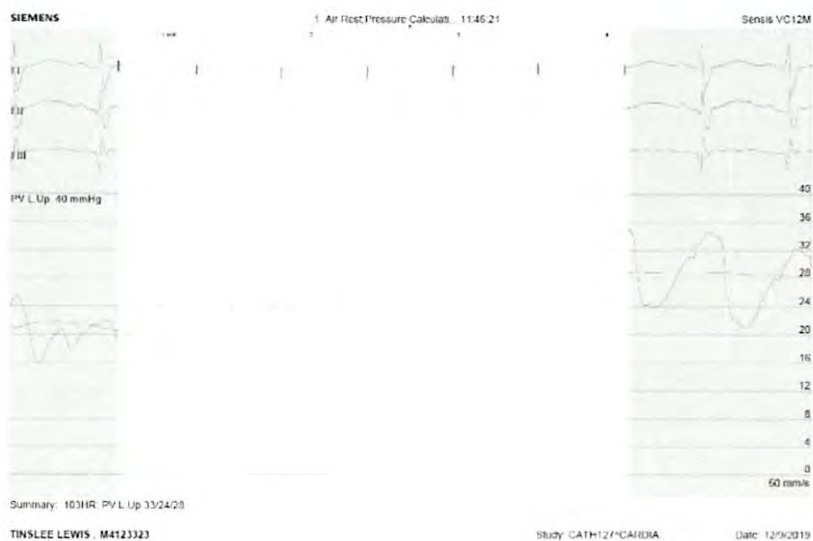
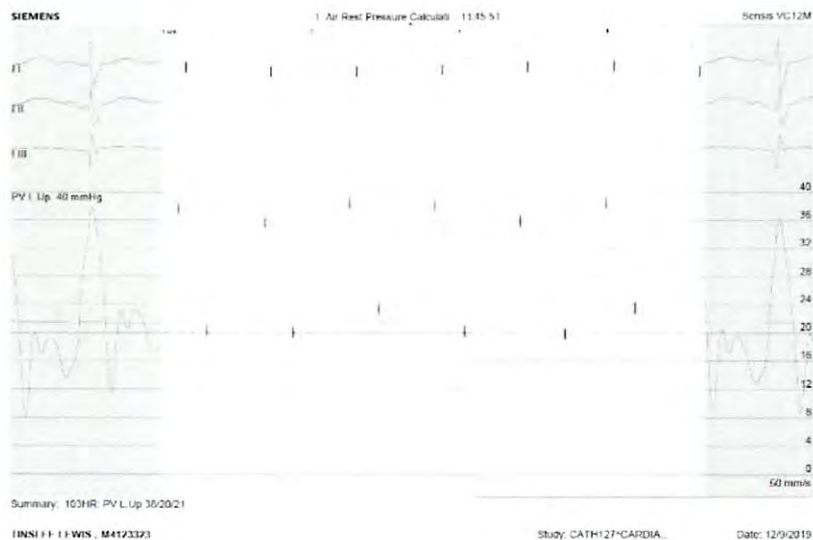
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



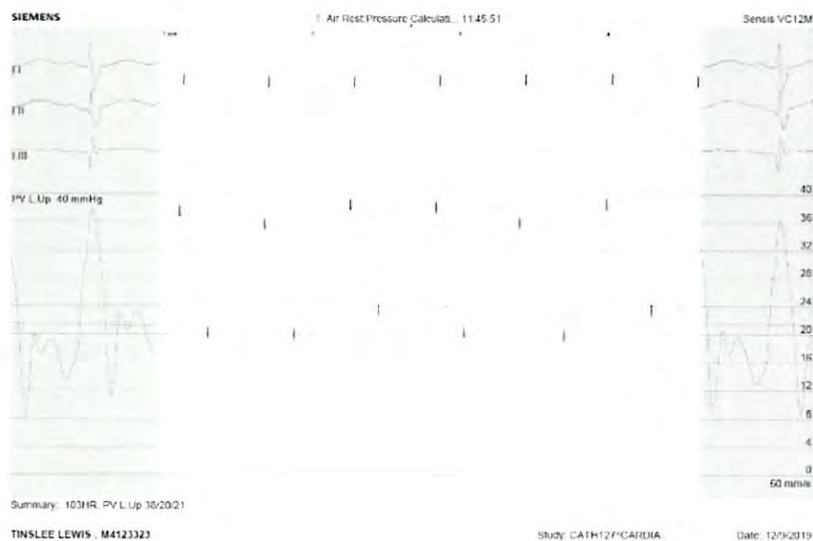
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



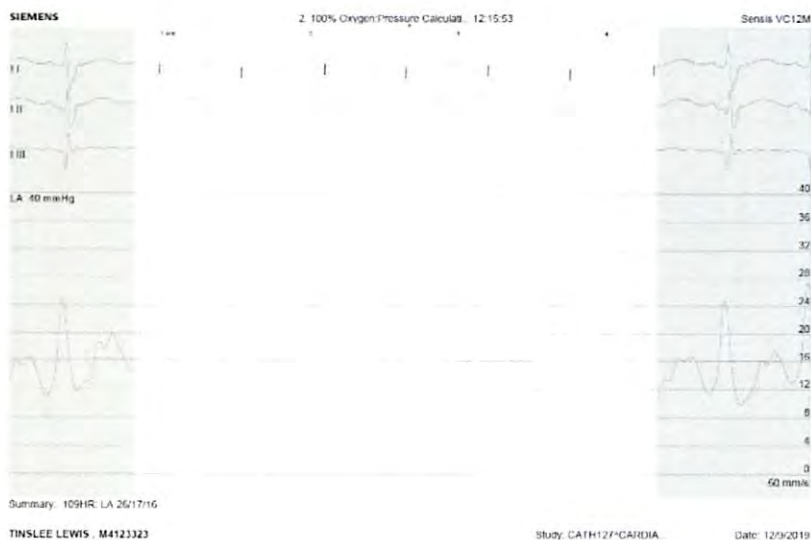
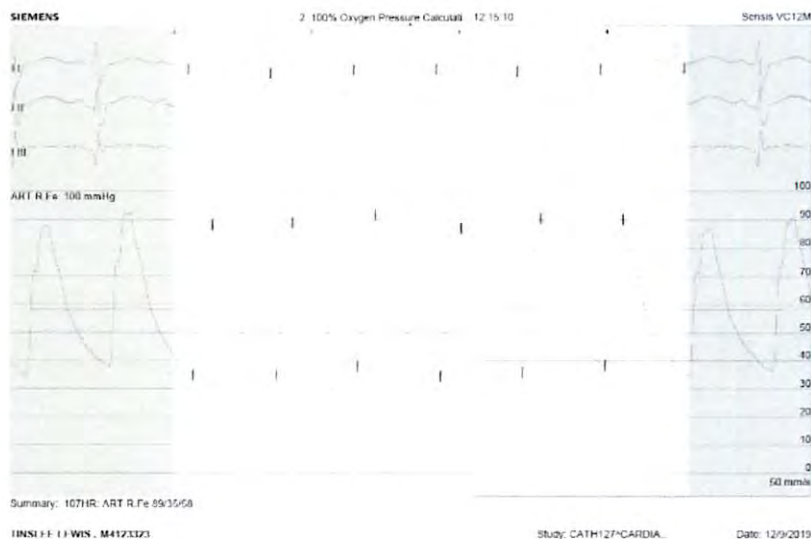
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



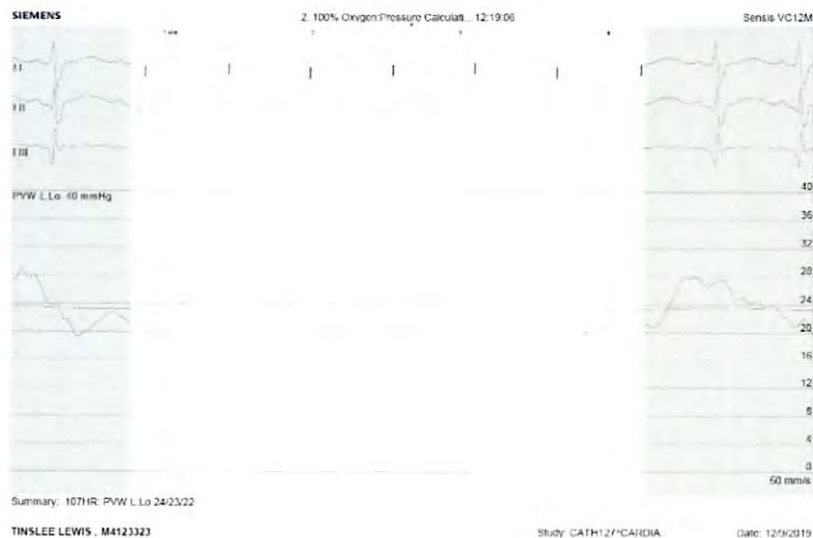
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



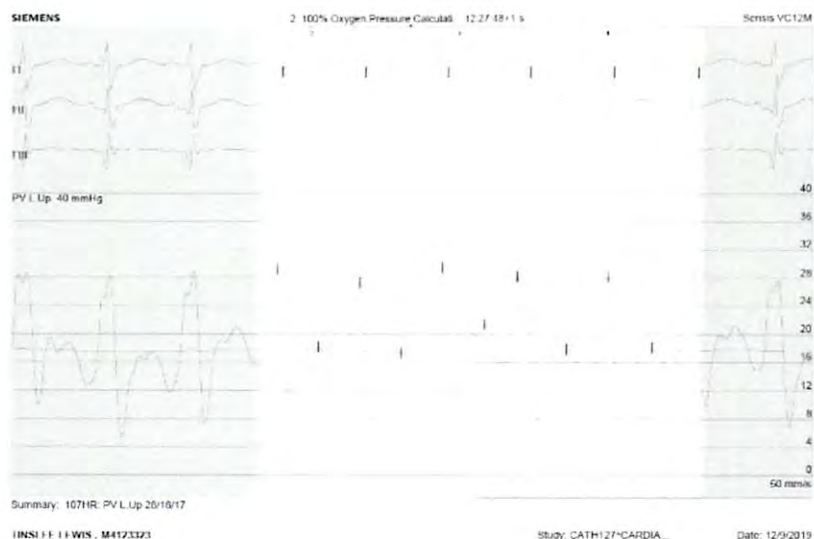
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



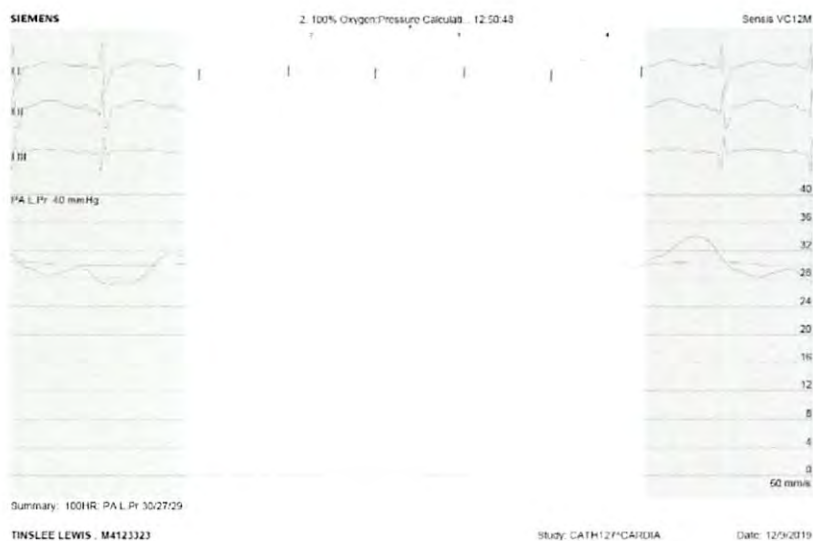
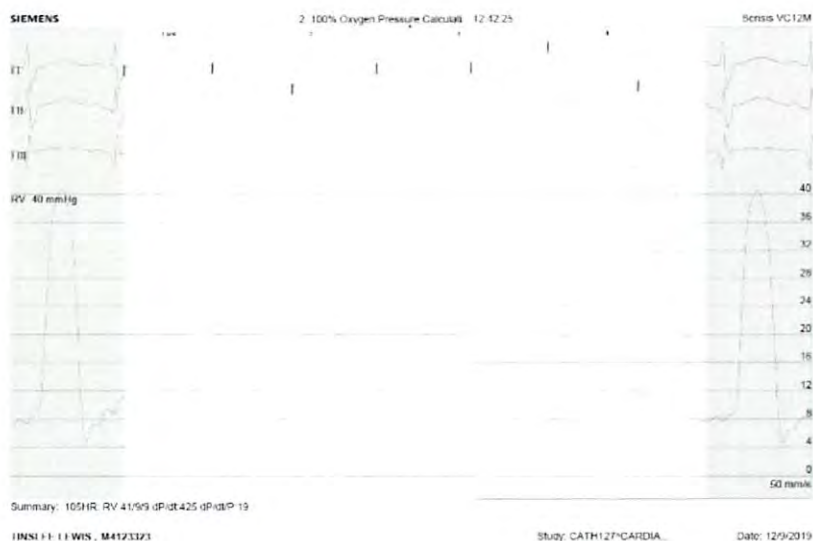
Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²



Order-Level Documents: (continued)

Name: LEWIS, TINSLEE	Patient ID: M4123323
Height: 68 cm Weight: 11.1 kg	BSA: 0.42 m ²





COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Order-Level Documents: (continued)

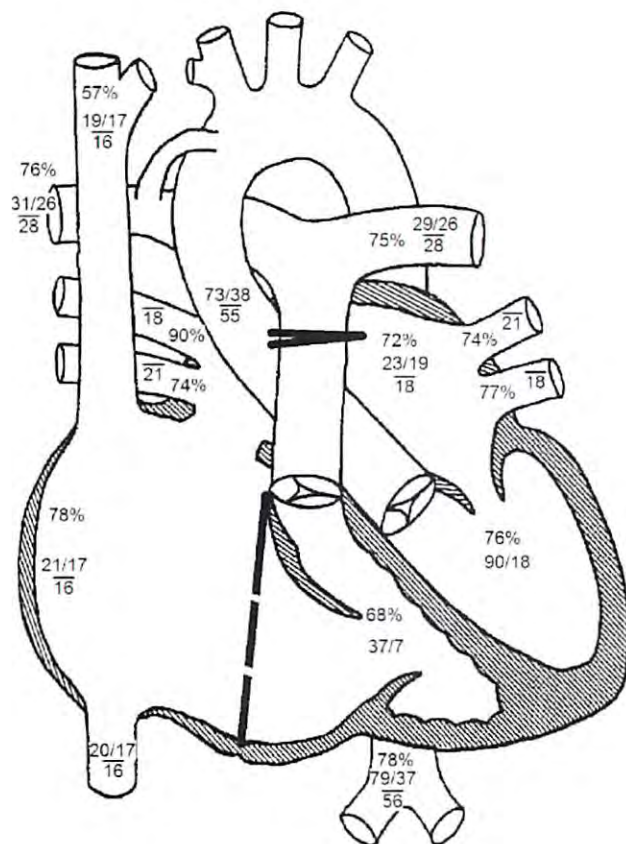
Ped Cath - Scan on 12/9/2019 3:52 PM (below)

Order-Level Documents: (continued)



Cook Children's Medical Center

Fort Worth, Texas
Pediatric Cardiology
Cardiac Catheterization Laboratory



Arrows indicate catheter course.

Diagnoses / Procedures

370. Ebstein's anomaly

Comments

10 month old ex-32 week premie with lung disease and Ebstein anomaly s/p Starnes procedure with atrial septectomy, 3 mm RMBTS, pulmonary valvotomy, and reduction right atrial plasty (2/13/19 - Tam), s/p mediastinal exploration with clip placed to isolate MPA from RV due to PI (2/14/19 - Tam), s/p delayed sternal closure 2/22/19. Proximal RPA angioplasty on 5/17/19. Cardiac arrest requiring VA ECMO 7/9/19. Upsizing of BTS to 5 mm with successful ECMO decannulation (7/14/19 - Tam). Persistent cyanosis. Balloon angioplasty of innominate artery and proximal RPA (8/14/19). Subsequently underwent BTS takedown and conversion to 5 mm central shunt with innominate artery repair (8/16/19 - Tam).

Lewis, Tinslee Breun

MRN: M4123323 Acct. #: 1015678564
Birth Date: 02/01/2019
Cath Date: 12/09/2019
Cath #: 19-586 Acc. #: OT251005-19
Age at cath: 10 months
Gender: Female

Attending: James A. Kuo MD
Fellow:
Referring:

Height: 68.0 cm Weight: 11.1 kg
BSA = 0.43 m2
Fluoro: 57.14 min Contrast: 38.00 mL
Radiation Dose: 95.60 mGy 656.59 cGy-cm2
Vein: Left femoral 4fr
Artery: Right femoral 4fr

Air Rest

Qp = 7.46 L/min (17.36 L/min/m2)
Qs = 2.07 L/min (4.82 L/min/m2)
Rp = 1.34 units (0.58 units x m2)
Rs = 19.29 units (8.30 units x m2)
Qp/Qs = 3.60 : 1 | Rp/Rs = 0.07

100% Oxygen

Qp = 6.22 L/min (14.47 L/min/m2)
Qs = 2.07 L/min (4.82 L/min/m2)
Rp = 1.77 units (0.76 units x m2)
Rs = 19.29 units (8.30 units x m2)
Qp/Qs = 3.00 : 1 | Rp/Rs = 0.09



COOK CHILDRENS
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Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Order-Level Documents: (continued)

Coding Queries

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Lori Lee Nesslein, MD		Procedure Note	02/01/2019 2110	Response Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Lori Lee Nesslein, MD		Procedure Note	02/01/2019 2111	Response Received			

Query Message

--- Doc Query Message ---

From: Lori Lee Nesslein, MD
Sent: 2/4/2019 10:19 AM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Lori Lee Nesslein, MD : 02/04/2019 - 10:19 AM

Sender	Recipient	Type	Subject	Created	Status	Outcome	Responding Provider	Response Note
Hb, Background	Rekha Balla Hamilton, MD		Procedure Note	02/09/2019 1745	Response Received			

Query Message

--- Doc Query Message ---

From: Rekha Balla Hamilton, MD
Sent: 2/9/2019 9:46 PM CST
Subject: Procedure Note

This is an auto-generated reply.

The following user has specified that this query has been addressed:
Rekha Balla Hamilton, MD : 02/09/2019 - 09:46 PM



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733

Lewis, Tinslee Breaun
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Coding Queries (continued)

END OF REPORT



COOK CHILDRENS
MEDICAL CENTER
801 7TH AVE
FORT WORTH TX 76104-
2733
Amb Encounter Report

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Nursing Note - Encounter Notes (continued)

Nursing Note by Callie F Parrish, RN (continued)

10/10/2019 5:00 PM

Electronically Signed by Callie F Parrish, RN on 10/10/2019 6:32 PM

Nursing Note by Katharine E Carvalho, RN

10/5/2019 10:00 PM

Author: Katharine E Carvalho, RN
Filed: 10/5/2019 11:42 PM
Status: Signed

Service: Nursing
Date of Service: 10/5/2019 10:00 PM
Editor: Katharine E Carvalho, RN (Registered Nurse)

Author Type: Registered Nurse

Creation Time: 10/5/2019 11:41 PM

Patient's mom requested to speak with this RN in the patient's room. Mom and Dad were both in the room at the time of conversation. Mom stated she is requesting a written statement from Texas Children's Hospital stating there is not more they can do for Tinslee than what Cook Children's is providing from a medical standpoint. This RN stated she would let the doctor know Mom's wish for written documentation from Texas Children's, and the doctors could then inquire with Texas Children's Hospital on Monday. Mom and Dad agreed. Mom then stated she is frustrated she did not receive a call from Texas Children's Hospital herself. Mom stated she was told the day before that the patient's paperwork had not been sent to Texas Children's Hospital yet. This RN apologized for the confusion and acknowledged Mom and Dad's frustration, but as stated by the provider earlier, Texas Children's Hospital said they could not do any more than what Cook Children's is currently providing. Mom asked if there was a reason why the patient's information was not sent to Dallas. This RN stated she did not know why and stated she was not there for the conversation but would ask the doctor for more information. Mom and Dad agreed.

Mom then proceeded to state there must be something that can be done to fix her (Tinslee), and there is a drug or a surgery that can help her (the patient) get better. Mom then stated, "I do not want to talk to the doctors anymore." This RN asked Mom to clarify what she means and explain why she feels this way. Mom stated she is upset when she sees other sick patients get better and be able to leave the Cardiac ICU while they (the patient) is still here. This RN acknowledged the family's frustration and stated as a unit we are giving Tinslee the best care and wanting the best for her. Mom then stated, "I just feel like the doctor's don't care about Tinslee anymore." This RN re-directed the previous statement by Mom stating the doctors and the whole ICU care very strongly for Tinslee and are providing the best care possible. Mom did not respond to this statement. This RN then stated she would talk to the doctor regarding a written statement from Texas Children's Hospital and notify physician Mom and Dad request of a written statement from all other hospitals where they were seeking another opinion. This RN also stated she would inquire with the physician about why the patient's information was not sent to Dallas as Mom reported to this RN during this conversation she requested Tinslee's information be sent to Dallas.

Katharine E Carvalho, RN

Electronically Signed by Katharine E Carvalho, RN on 10/5/2019 11:42 PM

Social Work - Encounter Notes

Social Work by Amy M Thomas, LBSW

10/29/2019 4:09 PM

Generated on 11/14/19 9:57 PM



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COOK CHILDRENS
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801 7TH AVE
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Amb Encounter Report

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Nursing Note: Social - Encounter Notes

Nursing Note: Social by Gennifer Gerard, RN

10/9/2019 9:00 PM

Author: Gennifer Gerard, RN
Filed: 10/9/2019 11:37 PM
Status: Signed

Service: Nursing
Date of Service: 10/9/2019 9:00 PM
Editor: Gennifer Gerard, RN (Registered Nurse)

Author Type: Registered Nurse

Creation Time: 10/9/2019 9:59 PM

This RN discussed Tinslee's POC with Mom at the bedside including Mom's expectations and goals for Tinslee. We also reviewed Tinslee's most recent x-ray together and discussed the difference between Tinslee's and a 'normal' x-ray. In reference to goals for Tinslee, Trinity stated, "I don't know the answer to that". Trinity stated that she doesn't want to speak to any of the doctors about Tinslee because they always say the same thing. This RN asked 'what about their conversations bother you?' and she reported, "they just say she is going to die, if God were going to take her, he would have taken her already. I just feel like there is some other medication or something someone can do for her lungs". This RN explained that it was, "my understanding that we have tried medications we have not used before including Bosentan, Tolvaptan, and Zaroxylin" in order to provide more diverse care for her. Trinity stated that she is confused because "someone told me to call Houston and other hospitals then the doctor's start her back on all these medications". This RN allowed Trinity to express her frustrations about the conversations that have been had between Trinity and the CICU intensivists regarding Tinslee. Trinity stated that she sat down with Dr. Duncan, Dr. Davis, and Dr. Chemelli and "the doctors said that her problem was the fluid she was retaining and why she was having problems on the ventilator". Trinity then stated that "Dr. Duncan said that he didn't think she was gonna make it" and that "they told me what it would be like if she were to come off of the ventilator and she would just be suffocating and I can't do that." This RN stated that she understood why she felt that way. Trinity then stated, "They took her cousin off of the ventilator but he was brain dead, if Tinslee were brain dead I would say take her off of the ventilator". Trinity asked what would happen if Tinslee were to come off the ventilator, "what would she do". This RN explained that it would all depend on Tinslee considering she is on a lot of support right now. This RN stated that the intensivists would have a more concrete answer and Trinity stated that "she didn't want to talk to them". This RN helped Trinity explore the option of a DNR d/t her previous statement about "God taking her" in order to allow a natural death for Tinslee. Trinity stated that, "I don't know what that looks like to do compressions, so I don't know". This RN then stated that, "if something were to happen and we did need to code her but you [Trinity] were not here, the code could take a long time, taking a toll on Tinslee's body" and explained that Tinslee is not an ECMO candidate. Trinity verbalized that she understood Tinslee is not an ECMO candidate.

Electronically Signed by Gennifer Gerard, RN on 10/9/2019 11:37 PM

Nursing Note: Change in Status/Significant Event - Encounter Notes

Nursing Note: Change in Status/Significant Event by Leny S Demafles, RN

10/29/2019 4:35 AM

Author: Leny S Demafles, RN
Filed: 10/29/2019 6:20 AM

Service: —
Date of Service: 10/29/2019 4:35
AM

Author Type: Registered Nurse
Creation Time: 10/29/2019 6:18 AM

Status: Signed

Editor: Leny S Demafles, RN (Registered Nurse)

Pt. Desaturated to low 60's, bagged patient and prn Vecuronium and Morphine given, patient has saturation as low as in the mid 20's, recovers post prn given.



COOK CHILDRENS
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Amb Encounter Report

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes - Encounter Notes (continued)

Progress Notes by Ryan Ray Meyer, MD (continued)

10/30/2019 7:18 AM

Endocrine: No hydrocortisone.

Lines:

Reason for Central Venous Line: Difficult Access

Reason for Foley: Not Applicable (No Foley)

Parents: Mother visits mostly at night. She often desires to not speak to the physician despite multiple attempts to communicate with her.

Other Issues: Bio ethics committee meeting again.

Communication: Plan discussed with multidisciplinary team.

Billing Time: I have personally seen and examined this patient and spent 70 minutes of critical care time on this patient's behalf.

Electronically Signed by Ryan Ray Meyer, MD on 10/30/2019 8:28 AM

Progress Notes by Olga L Rodriguez, PharmD

10/29/2019 2:09 PM

Author: Olga L Rodriguez, PharmD
Filed: 10/29/2019 2:10 PM

Service: Pharmacy
Date of Service: 10/29/2019 2:09 PM

Author Type: Pharmacist
Creation Time: 10/29/2019 2:09 PM

Status: Signed

Editor: Olga L Rodriguez, PharmD (Pharmacist)

TPN CONSULT

Diagnosis: Ebstein's anomaly of tricuspid valve

Current Nutrition Status: TPN

Feed Order: NPO

Reviewed Labs From: 10/29

TPN Status: Goal TPN

Trace Elements: standard

Lipid Status: Goal INTRALipids

Electronically Signed by Olga L Rodriguez, PharmD on 10/29/2019 2:10 PM

Progress Notes by Susan Lynn Davis, MD

10/29/2019 10:33 AM

Author: Susan Lynn Davis, MD
Filed: 10/29/2019 10:49 AM

Service: Critical Care
Date of Service: 10/29/2019 10:33 AM

Author Type: Physician
Creation Time: 10/29/2019 10:33 AM

Status: Signed

Editor: Susan Lynn Davis, MD (Physician)



COOK CHILDRENS
MEDICAL CENTER
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Amb Encounter Report

Lewis, Tinslee Breau
MRN: M4123323, DOB: 2/1/2019, Sex: F
Adm: 2/1/2019, D/C: —

Progress Notes - Encounter Notes (continued)

Progress Notes by Susan Lynn Davis, MD (continued)

10/29/2019 10:33 AM

Mother has not had communication with Texas Children's Hospital regarding their denial of Tinslee earlier this month per CICU team. I was asked to follow up with TCH.

When they called me and denied the transfer (approximately October 3, 2019), they stated they would call Trinity. A plan was made if that fell through, that Tinslee's mother could call transfer center there, and they would put her in contact with the physician with whom I spoke. I conveyed that to mother earlier this month when she expressed frustration over them not calling her.

I called transfer center today and asked for something in writing to give to mother. The transfer director stated that they could not put anything in writing per their legal department regarding the denial. I asked that the cardiology team there put something in writing denying the transfer and they stated that they did not know if that could be done. They had mother's number in their records and it was re-confirmed. They state they will try to call her and they will get back to me regarding possibility of anything in writing.

Susan Davis, MD

Electronically Signed by Susan Lynn Davis, MD on 10/29/2019 10:49 AM

Progress Notes by Sami K. W. Hadeed, MD

10/29/2019 7:59 AM

Author: Sami K. W. Hadeed, MD
Filed: 10/30/2019 12:16 PM

Service: Pulmonology
Date of Service: 10/29/2019 7:59 AM

Author Type: Physician
Creation Time: 10/29/2019 7:59 AM

Status: Signed

Editor: Sami K. W. Hadeed, MD (Physician)

PULMONARY INPATIENT PROGRESS NOTE

Patient Name: Tinslee Breau Lewis

Medical Record Number: M4123323

Date of Service: 10/29/2019

Date of Admission: 2/1/2019 , LOS: 270

Chief Complaint: CDH, chronic hypoxic respiratory failure, CLD, pHTN

Problem List:

Patient Active Problem List

Diagnosis

- Ebstein's anomaly of tricuspid valve
- Atrial flutter (CMS/HCC)
- SVT (supraventricular tachycardia) (CMS/HCC)
- Acute respiratory failure with hypoxia and hypercarbia (CMS/HCC)
- Electrolyte and fluid disorder
- Acute systolic heart failure (CMS/HCC)
- Chronic lung disease in neonate