THE SOUTH FLORIDA PEDIATRIC BIOETHICS CONSORTIUM

Amanda Alladin, MD

University of Miami / Holtz Children's Hospital

University of Miami Institute for Bioethics and Health Policy

Holtz Children's Hospital

UM/JACKSON MEMORIAL MEDICAL CENTER

UNIVERSITY OF MIAMI

THE SOUTH FLORIDA PEDIATRIC BIOETHICS CONSORTIUM

Ronald Ford MD MBA

Chief Medical Officer

Joe DiMaggio Children's Hospital

Eileen Johnson MS

Bioethics Program

Nicklaus Children's Hospital

2007

Three children's hospitals decide to discuss their individual Death by Neurologic Criteria policies

Holtz Children's Hospital

Nicklaus Children's Hospital

Baptist Children's Hospital

The three hospitals decide to harmonize their policies

The Tri-BEC comes into existence

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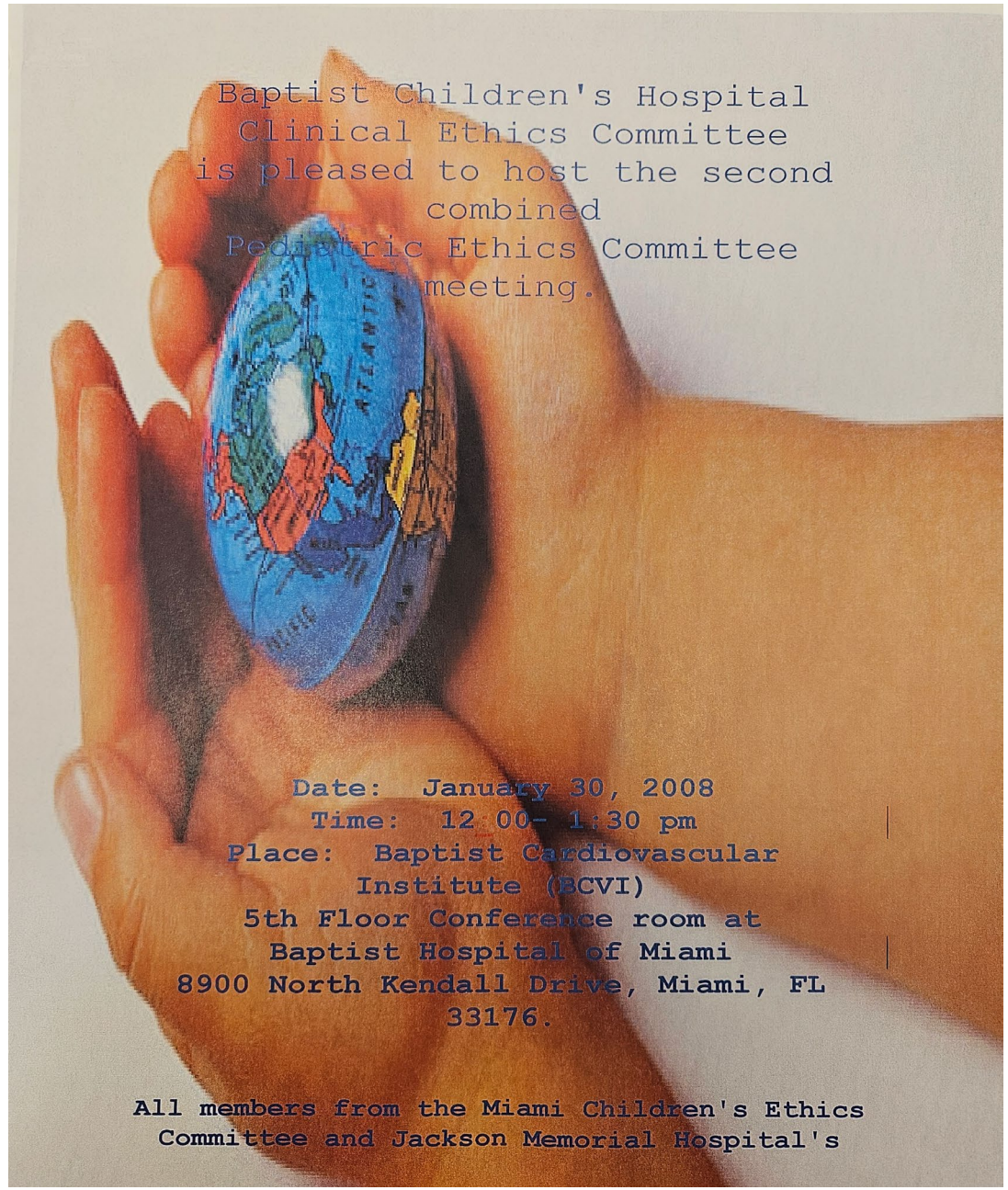
Baptist Children's Hospital
Clinical Ethics Committee
is pleased to host the second
combined
Pediatric Ethics Committee
meeting.
Date: January 30, 2008
Time: 12 00- 1:30 pm
Place: Baptist Cardiovascular
Institute (BCVI)
5th Floor Conference room at
Baptist Hospital of Miami
8900 North Kendall Drive, Miami, FL
33176.
All members from the Miami Children's Ethics
Committee and Jackson Memorial Hospital's

Tri-BEC

COMPARISON OF THE END OF LIFE POLICIES BETWEEN **BCH**, **JMH** and **MCH**

TITLE–SUBJECT OF THE POLICY

BCH: Allowing Natural Death/Levels of Care, Withdrawing of Life-Prolonging Procedures

JMH: Withholding, Withdrawing, and Forgoing of Life –Sustaining Treatment

MCH: Accept Natural Death for Minor Patients (Previously DNR)

Comment: The MCH policy is mostly about withholding cardio-pulmonary resuscitation in case of cardiopulmonary arrest. It does not deal with withholding other care or withdrawal of life support.

DEFINITIONS

BCH: It defines attending physician, designee, CPR, life prolonging procedure, parent/legal decision maker, patient, terminal condition, end stage condition and persistent vegetative state.

JMH: Does not include definitions.

MCH: It defines designee, accept natural death, life prolonging procedure, parents/guardian, patient, physician, cardiopulmonary resuscitation,

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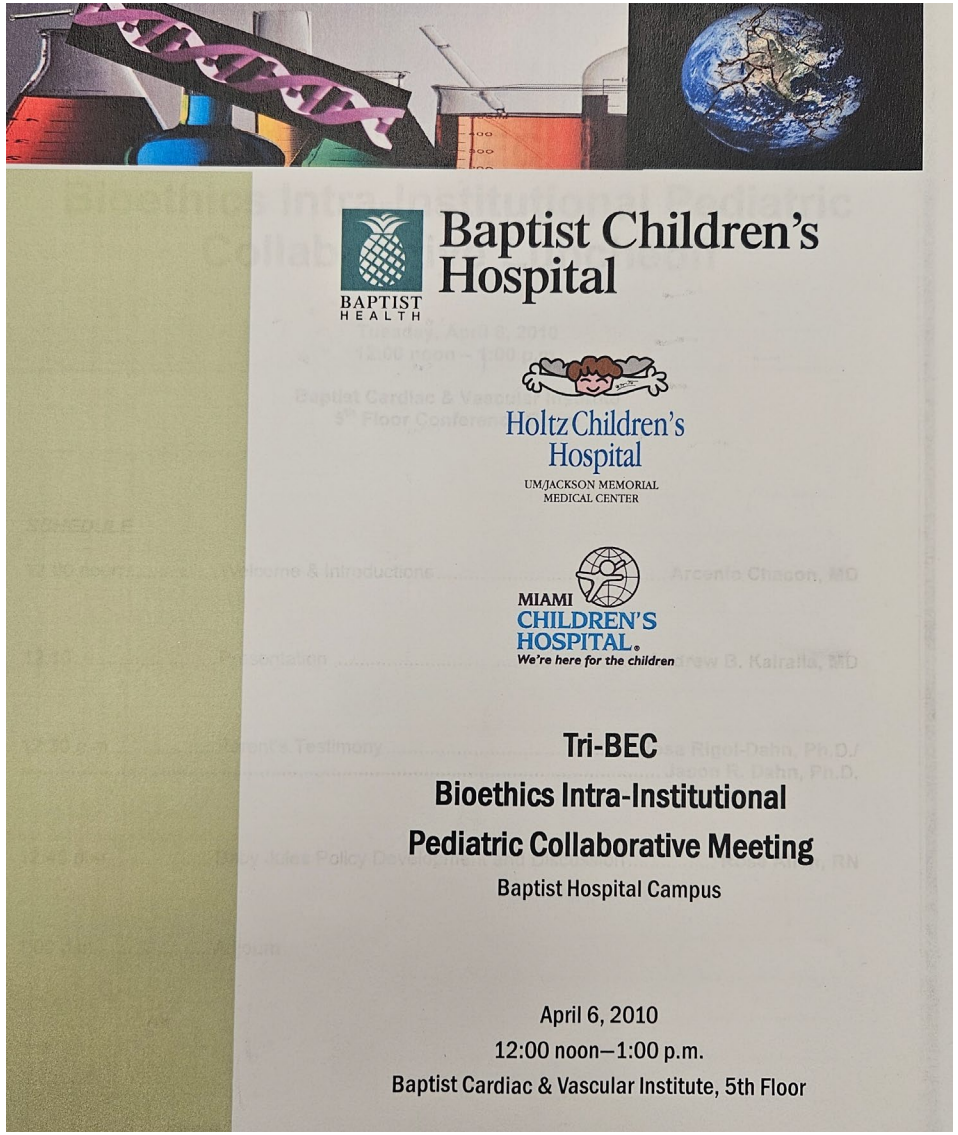
Tri-BEC



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Pediatric Bioethics Evolution

1979 - American Academy of Pediatrics formed its first Ad Hoc Bioethics Committee with three members

1985 - Official AAP Bioethics Committee convened

1998 – AAP Section on Bioethics formed

Laventhal N, Leutner S. "The Growth and Evolution of Pediatric Bioethics: Embracing the Moral Complexity of Caring for Children". AAP News. October 2023. https://publications.aap.org/pediatrics/resources/26571/The-Growth-and-Evolution-of-Pediatric-Bioethics

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Solomon MZ, Sellers DE, Heller KS, et al. New and lingering controversies in pediatric end-of-life care. *Pediatrics.* 2005;116(4):872-883

Lang CW, Smith PJ, Ross LF. Ethics and professionalism in the pediatric curriculum: a survey of pediatric program directors. Pediatrics. 2009;124(4):1143-1151

Kesselheim JC, Johnson J, Joffe S. Ethics consultation in children's hospitals: results from a survey of pediatric clinical ethicists. Pediatrics. 2010;125(4):742-746

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Pediatric Palliative Care Evolution

2000- AAP issues landmark statement on “Palliative Care for Children”

2006 – American Board of Medical Specialties recognizes Hospice and Palliative Medicine.

AAP Section on Hospice and Palliative Medicine formed

2011 – Feudtner and colleagues publish prospective study of palliative care efforts at 6 children’s hospitals

Feudtner C, Kang TI, Hexem KR, et al. Pediatric palliative care patients: a prospective multicenter cohort study. *Pediatrics*. 2011;127(6):1094-1101. doi:10.1542/peds.2010-3225

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SFPBEC Evolution

Changes in clinical landscape

Changes in member hospitals and community landscape

Supported by the experience and leadership of the Florida Bioethics Network

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Current Members

- Holtz Children's Hospital
- Nicklaus Children's Hospital
- Joe DiMaggio Children's Hospital
- Salah Foundation Children's Hospital
- Palm Beach Children's Hospital

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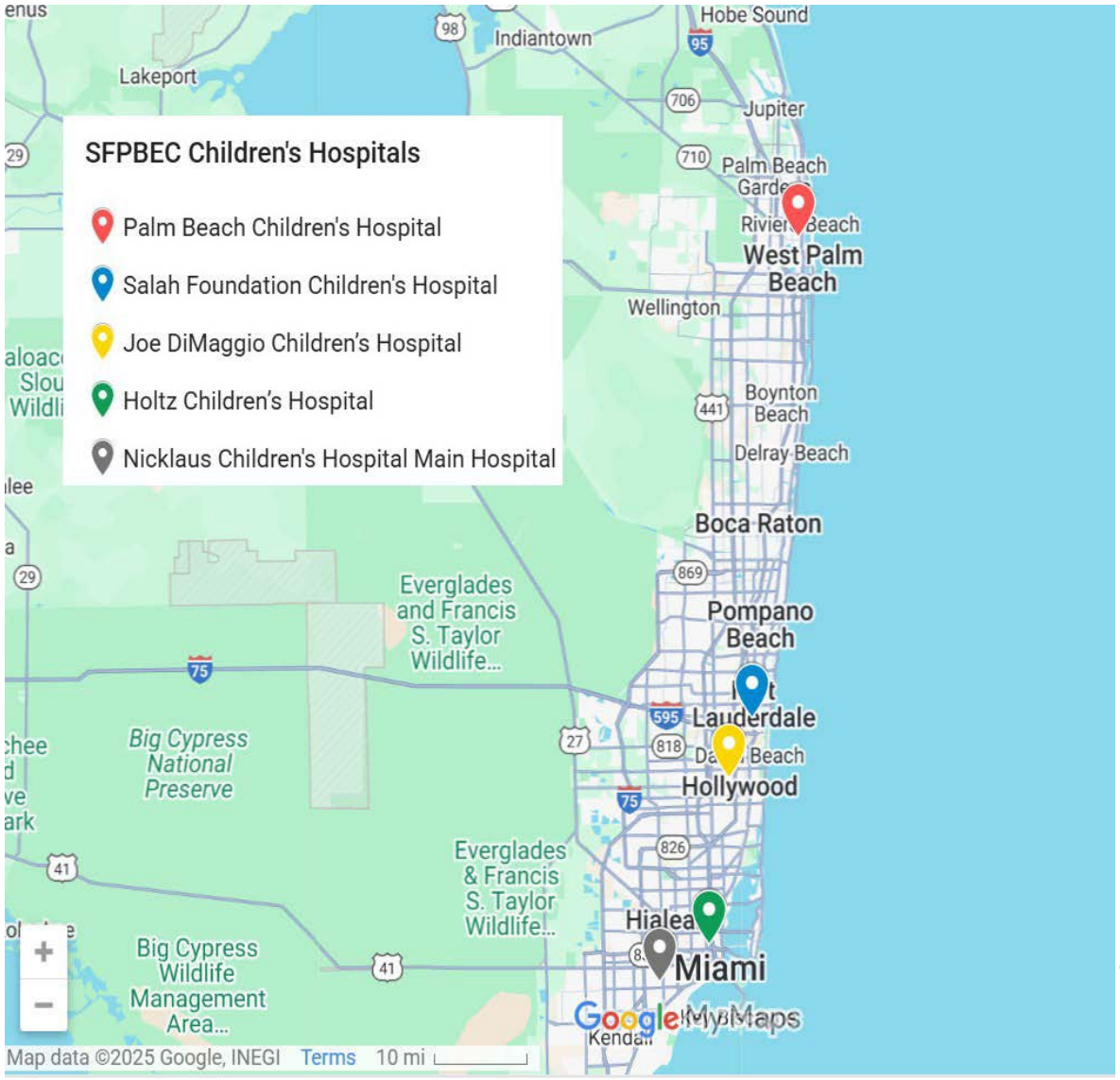
SFPBEC Member Hospitals



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Quarterly Meetings

Rotate between each of the hospitals every 3-4 months

In person meetings halted during COVID-19 pandemic

Open to all member hospitals bioethics committees as well as other interested hospital employees, medical students and trainees

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Policies

Death by Neurologic Criteria Policy

Non-Beneficial Treatment Policy

Parental Refusal of Blood Products Policy

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Cases and Topics

- NICU – Extreme prematurity and sequelae
- Thresholds for referral to DCF and state intervention
- Withholding of artificial nutrition and hydration
- Withdrawal of technologic support and end-of-life
- Transplant Ethics

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Benefits and Disadvantages of Model

Patients and Families

Medical teams

Hospital and Community

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References

Feudtner C, Kang TI, Hexem KR, et al. Pediatric palliative care patients: a prospective multicenter cohort study. *Pediatrics*. 2011;127(6):1094-1101. doi:10.1542/peds.2010-3225

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Schmitt S, Humphrey L, Sahler OJ, Linebarger J. "Pediatrics and Palliative Care – 75 years of optimizing health care delivery". April 2023. AAP Section Retrospectives. Section on Hospice and Palliative Medicine. https://publications.aap.org/pediatrics/resources/24238/Pediatrics-and-Palliative-Care-75-Years

Solomon MZ, Sellers DE, Heller KS, et al. New and lingering controversies in pediatric end-of-life care. *Pediatrics.* 2005;116(4):872-883

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THANK YOU

Joe DiMaggio Children's Hospital
AT MEMORIAL

Nicklaus Children's Hospital

Salah Foundation Children's Hospital

PALM BEACH CHILDREN'S HOSPITAL
PALM BEACH HEALTH NETWORK

Holtz Children's Hospital
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Joe DiMaggio Children's Hospital®

CASE PRESENTATION

SFPBEC CONSULTATION

Ron Ford, MD, MBA

Chief Medical Officer
Joe DiMaggio Children's Hospital
Hollywood, FL

CASE SUMMARY

- 13-year-old male born with complex congenital heart disease.
- Staged palliation surgery was done at Nicklaus Children's Hospital.
- Referred to JDCH for cardiac transplant evaluation in late 2021.
- Had a cardiac arrest just prior to VAD placement and was supported on VA ECMO before being transitioned to a VAD.
- Complications from ECMO run included dialysis-dependent renal failure, and respiratory failure requiring a tracheostomy.
- Referred to Shands in 2022 for possible heart-kidney transplant.
- Non-elibigle for transplant, but no longer dialysis dependent.

RECENT CHALLENGES

- Patient de-listed because of significant non-adherence on the part of the parents.
- Multiple readmissions (and prolonged admissions) because of fluid overload.
- Attempts at re-education of parents have been unsuccessful and patient continues to violate fluid restrictions.
- Patient's deterioration has hastened recently including cognitive decline.

ETHICAL CONTEXT

AUTONOMY

The patient previously expressed wishes against heroic interventions, but these are no longer honored due to cognitive decline and parental override.

BENEFICIENCE

The care team is focused on maximizing the patient's comfort and minimizing suffering. Multiple services have worked together to support the patient and family, despite non-adherence.

NON-MALEFICIENCE

Bringing in DCF or a healthcare surrogate could disrupt the relationship between the patient and his father, which the team considers to be of great value to the patient.

JUSTICE

Patient will not be a transplant candidate at any point due to clinical decline, irrespective of the non-adherence.

JDCH BIOETHICS SERVICE

C O N S U L T A T I O N

Recommendations:

- Supported the decision to focus on comfort and palliative care and not escalate.
- Reiterate to the family that patient is not, and will never be, a transplant candidate.
- Be somewhat permissive of the family's decision making as long as it does not cause the patient to suffer.

SFPBEC

C O N S U L T A T I O N

- Endorsed the recommendations made by JDCH.
- Provided the clinical team with abundant reassurance to chart a new path forward with the family and align the entire clinical team on goals and limits of care.
- Felt parents might be more receptive, especially with representation from NCH, since much of his care had occurred there.
- Parents often seek out other children's hospitals for care when they are presented with EOL decisions. Future consultations are anticipated when this occurs.

SFPBEC

B E N E F I T S

- Alignment on definitions: non-beneficial care.
- Diverse perspectives and cross-institutional learning.
- Standardization of language “end-stage” – “terminal”
- Policy harmonization reduces “hospital shopping”
- Validation to support first-line teams and alleviate moral distress

Thank You.

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BEST CHILDREN'S HOSPITALS U.S.News & WORLD REPORT NEONATOLOGY 2024-2025

BEST CHILDREN'S HOSPITALS U.S.News & WORLD REPORT ORTHOPEDICS 2024-2025

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CASE PRESENTATION

OF SFPBEC CONSULTATION

Eileen Johnson, MS.

Bioethicist, Bioethics Program Manager

Nicklaus Children's Hospital, Miami, FL

Contact: Eileen.johnson@nicklaushealth.org | (305)-786-2088

May 9th, 2025 | Florida Bioethics Conference

PRESENTATION OVERVIEW

- Ethics Consultation for a NICU Patient admitted at Nicklaus Children's Hospital (NCHS)
- Case Evaluation and Recommendation from NCHS Bioethics Service
- Reasoning for Consulting the SF Pediatric Bioethics Consortium
- SF Pediatric Bioethics Consortium Analysis and Recommendation
- Consortium Impact at NCHS

NICU CASE SUMMARY

- L.C. is a 7-month-old male, born at 42 weeks via emergency C-section with no respiratory effort at birth, requiring intubation.
- He has failed multiple extubation attempts.
- Transferred to NCH with severe HIE and respiratory failure for a second opinion on tracheostomy.
- Intubated and ventilated for several months without a secure airway.
- Clinical team recommends tracheostomy for long-term airway stability and potential NICU discharge.
- Parents refuse tracheostomy; father explicitly opposes compassionate withdrawal.
- Parents request trial extubation, but due to high risk of failure and inability to reintubate—and no withdrawal as a goal—this has not been pursued.

Conflicts Present:

- The current course of Treatment for the patient is untenable – L.C. cannot remain intubated/ventilated in the NICU indefinitely.
- The Medical team has determined 2 viable treatment plan options – Tracheostomy or compassionate extubation.
- Parents request a 3rd treatment plan that is determined to be non-beneficial and potentially harmful.
- Parents do not wish to consent to either treatment plan options offered.

Ethical Considerations:

This situation raises ethical issues **surrounding the balance between parental rights to make decisions for their child, the medical team's duty** to act in the best interest of the patient, and the potential long-term impacts on the child's quality of life and health outcomes.

NCHS BIOETHICS SERVICE

Required Consultation with the entire Bioethics Committee

Committee Recommendation:

It was concluded that the parents' refusal of treatment and their continued inaction vis a vis tracheostomy placement or compassionate withdrawal is not only untenable, but has reached the threshold of harm to approach the state for intervention.

THE NEED FOR THE SFPBEC

Overriding parental rights to make decisions for their child requires a high burden of proof of harm and is the last resort.

As the parents are not acting maliciously and with the medical team's recommendation that a compassionate extubation is the most appropriate course of action- NCHS wished to consult with the SFPBEC to ensure we have made an appropriate recommendation and if not, what other consideration need to be taken into account

SFPBEC CONSULT

- Over 20 members of the SFBBEC from our local pediatric institutions convened to discuss and review the case.
- We discussed the case details, parental goals of care, our institutions shared policy on Non-Beneficial care, and appropriate course of action.
- The consortium unanimously agreed that the most appropriate course of treatment-and in the best interest of the child- is to seek intervention by the court with the recommendation of a compassionate withdrawal or the placement of a guardian ad litem.

SFPBEC IMPACT

- Cases such as these are incredibly difficult on all the members of the care team.
- The decision to approach the courts to supersede parental rights in a potential end-of-life case is complex and toilsome.
- Being able to reach out to our neighboring institutions for advice and consultation lifts an incredible weight off the shoulders of all those involved.
- Having new eyes on an issue helps ensure we are not acting with blinders on.

SFPBC provides a forum that supports physicians and care teams when facing medicines most complex and difficult cases.

THANK YOU