VOICE OF THE PARTICIPANT: A Father’s Perspective on Pediatric Critical Care Research and Bereavement

The Collaborative Pediatric Critical Care Research Network - Family Network Collaborative

Whit Coleman, MRA, BSN, RN
About Me:

- Husband and Father of 5
- CNA and RN
- Research Coordinator and Nurse
- Research Administration
- Nurse Educator
- Education
The Diagnosis

- Jonas diagnosed with SMA 6 weeks old
- Maggie diagnosed via Amniocentesis
No Options

- Supportive care but no treatments
- ICU frequent flyers
- Research became our hope
- Career change
Research in the ICU

Corollary to research priorities

ICU is a nightmare
  - Disruption, crisis, stress, fear, etc.

Lessons Learned:
  - Be an expert in the topic
  - Focus on benefits and risks
  - Volunteering and no change to care
My Experience of Death

➤ Jonas died at home - Hospice
  ➢ No HCP at time of death

➤ Maggie died in the hospital - ICU
  ➢ ICU providers present
  ➢ Palliative Team Consult
My Grief Experience

- No Evaluation of Grief
- Strong family, religious and friend support
- Symptoms of grief
  - Avoid songs, pictures or items
Advocate for Bereavement

- I’m Lucky. Others may not have support
- How can we support providers?
  - Training and support
- Wanting to participate
- CPCCRN, Dr. Meert and Dr. Suttle
Parent Collaboration/CPCCRN

- CPCCRN has made involving parents a priority
- Opportunity for PTG
- 1st model
- 2nd model
FNC

► Outcomes, Consenting, and Research Priorities
► Opportunity to attend Steering Meetings
► Tasks: Genetic Results, tool feedback, core outcome set, and survey comprehension
Thank you!

NICHD

CPCCRN