

# 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

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# About Me:

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





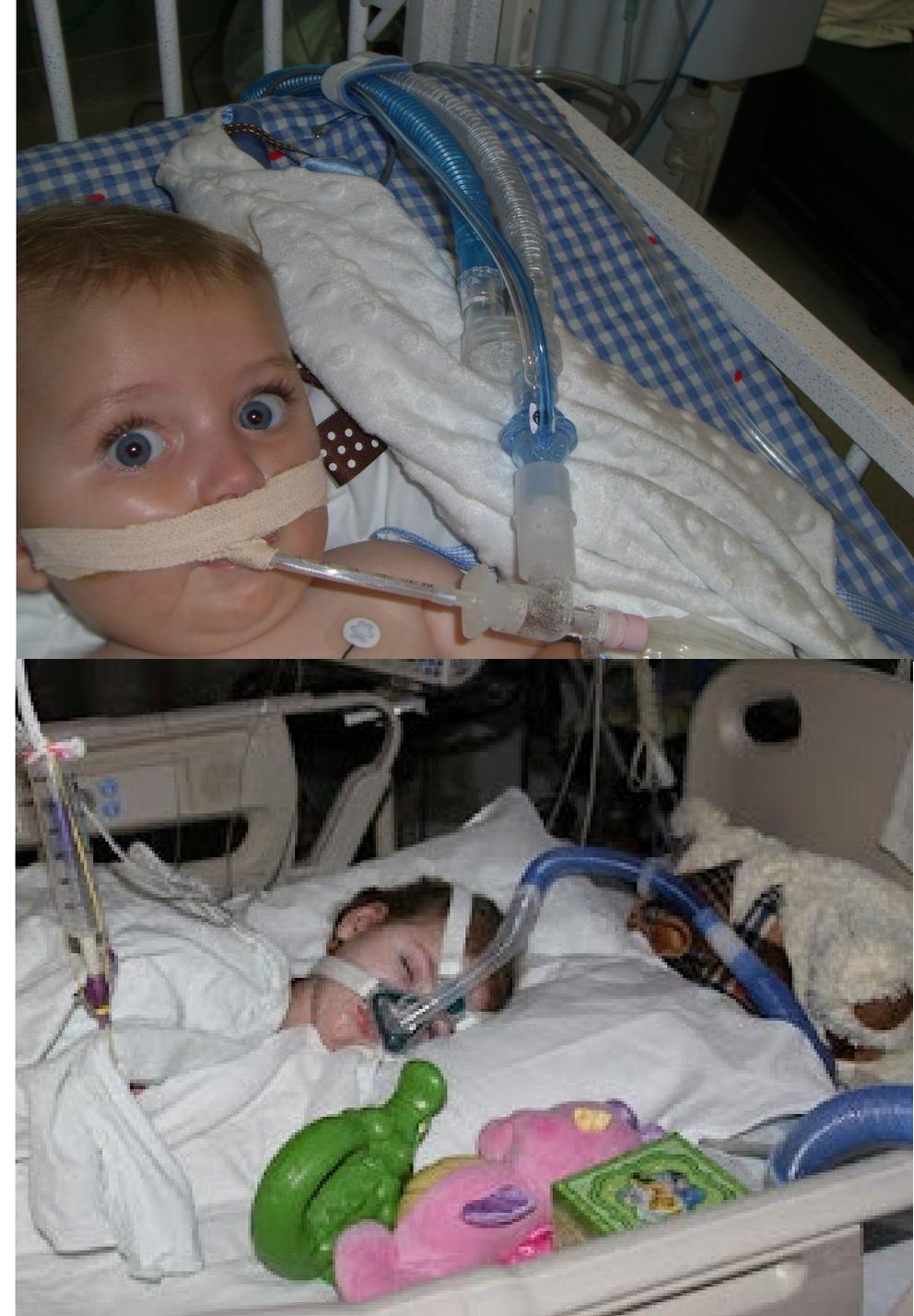
# The Diagnosis

- ▶ 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
- ▶ 1<sup>st</sup> model
- ▶ 2<sup>nd</sup> 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

