

## Continued Anticonvulsants After Resolution of Neonatal Seizures: A Patient-Centered Comparative Effectiveness Study

~ funded by Patient Centered Outcomes Research Institute (PCORI) ~

Welcome to our seventh newsletter for the **Neonatal Seizure Registry (NSR)**. As we wrap up our final follow-ups and plan our data analyses, we have exciting news to share! We have learned that the National Institutes of Health has funded our early childhood follow-up study, which we are calling “*Neonatal Seizure Registry – Developmental Functional Evaluation*” or **NSR-DEV**. This means that we will have four more years of funding to answer your important questions about early childhood outcomes after neonatal seizures.

- PARTICIPATING HOSPITALS**
- UCSF Benioff Children’s Hospital**  
Hannah Glass, MDCM, MAS  
Parent Partner: Kamil Pawlowski
- Mott Children’s Hospital**  
Renée Shellhaas, MD, MS  
Parent Partner: Libby Hill
- Lucille Packard Children’s Hospital**  
Courtney Wusthoff, MD, MS
- Children’s Hospital of Philadelphia**  
Nicholas Abend, MD, MS  
Parent Partner: Lisa Grossbauer
- Children’s National Medical Center**  
Taeun Chang, MD  
Parent Partner: Dana Annis
- Massachusetts General Hospital**  
Catherine Chu, MD, MS  
Parent Partner: Tristan Barako
- Boston Children’s Hospital**  
Janet Soul, MD  
Parent Partner: Jennifer Guerriero
- Duke University**  
Monica Lemmon, MD
- Cincinnati Children’s Hospital Medical Center**  
Cameron Thomas, MD, MS  
Parent Partner: Katie Grant
- AFFILIATE ORGANIZATIONS**
- Hand to Hold**  
Parent Partners: Claire Brown  
Casey’s Circle  
Parent Partner: Marty Barnes
- Hope for HIE**  
Parent Partner: Betsy Pilon

### NSR-DEV Details

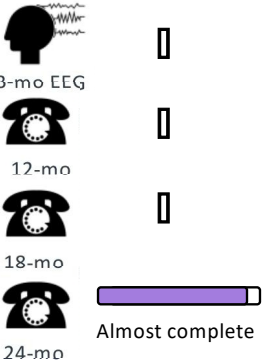
Our Parent Partners helped us identify 3 key research priorities for this study:

1. Neonatal or infant predictors of developmental and learning challenges in childhood
2. Characteristics of parent well-being that help or hinder success in childhood
3. Early, easily applied, accurate methods to predict childhood impairment

NSR-DEV will work to address these priorities by conducting 3 or 4 additional follow ups over the next four years. These will occur in person and through electronic surveys when children reach the ages of 3 to 8 years.

		NSR-DEV Follow Up Time Points				
Study Measurement	Enrollment	3 years	4 years	5.5 years	7 years	8 years
Medical history review	X	X	X	X	X	X
Parent well-being surveys	X	X	X	X	X	X
Developmental surveys	X	X	X	X	X	X
In-person assessment				X		
Teacher rating forms				X		

**Study Progress**



24-mo

Your local teams will be in contact with more information soon!



## Featured Work

At the 2019 meeting of the Child Neurology Society, NSR Investigator Monica Lemmon presented the four major themes from the analysis of the neonatal discharge survey.

*“Thank you for providing such important information about the parent experience of caring for newborns with seizures. It was a privilege to share these experiences with the child neurology community.”* – Monica Lemmon

### 1. **Sources of strength**

- Medical team consensus
- Opportunities to contribute to child’s care
- Watching child’s progress

### 2. **Uncertainty**

- Daily uncertainty of the NICU experience
- Uncertain future
- Lack of consensus between team members

### 3. **Adapting family life**

- Adjusting the family’s lifestyle
- Adjusting parenting approach and routine
- Anticipated financial and work challenges

### 4. **Emotional and physical toll**

- Parents reported worry, fear, stress, and helplessness

## Parent and Stakeholder Engagement



NSR welcomes Hope for HIE president Betsy Pilon. Hope for HIE is deeply committed to providing comprehensive, personalized support for each family's journey. We are fortunate to have Betsy on our team!

*“So many of our families in the HIE community struggle with the experience they have in the NICU, with neonatal seizures as one of the most stressful complications from HIE. This research is vital to helping our community, and those that will join in the future, get the best treatment and resources for their journey ahead.”*-Betsy Pilon



Parent Partner Lisa Grossbauer will join the NSR team in Philadelphia at the Pediatric Academic Societies annual meeting, where we will engage participants in a discussion on *“Studying what matters: How to engage parents in research.”* Lisa will join NSR investigators and representatives from PCORI and NIH for this workshop.

*“I am very proud and humbled to represent such a devoted team of family stakeholders at the Pediatric Academic Societies annual meeting in Philadelphia. As Children’s Hospital of Philadelphia’s family partner representative, it will be “extra special” to share our story with dedicated physicians, and researchers in hopes of planting a seed of thought with regards to family contributions to valued research in pediatrics.”* -Lisa Grossbauer

Our study team has remained devoted to our initial goal – to figure out the safest and most effective way to treat newborns with seizures and understand how the medical treatments for newborn seizures can impact families as their children grow. We will continue to update you as we learn more!

**For more information about the study, please visit our website:**

<https://www.pcori.org/research-results/2016/continued-anticonvulsants-after-resolution-neonatal-seizures-patient-centered>