

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

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

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Hand to Hold

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Casey's Circle

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Welcome to our sixth newsletter for the **Neonatal Seizure Registry (NSR)**. We have now completed all 12 and 18-month follow up! While we continue to follow participants to the final 24-month time-point, we are analyzing data and applying for grant funding to continue learning more about neonatal seizures and their effect on child development and family well-being. We are grateful for our team of investigators, parents, and families that have made this work possible and are excited for the future of this project.

Our Work



Pictured from left to right: Dr. Cameron Thomas (Cincinnati Children's Hospital Medical Center), Dr. Hannah Glass (UCSF Benioff Children's Hospital), Dr. Linda Franck (UCSF Benioff Children's Hospital), Dr. Taeun Chang (Children's National Medical Center), Dr. Adam Numis (UCSF Benioff Children's Hospital), Dr. Monica Lemmon (Duke University), Dr. Janet Soul (Boston Children's Hospital), Dr. Nicholas Abend (Children's Hospital of Philadelphia), Dr. Renée Shellhaas (Mott Children's Hospital), Dr. Shavonne Massey (Children's Hospital of Philadelphia).

Study Progress:


3-mo EEG




12-mo




18-mo




24-mo



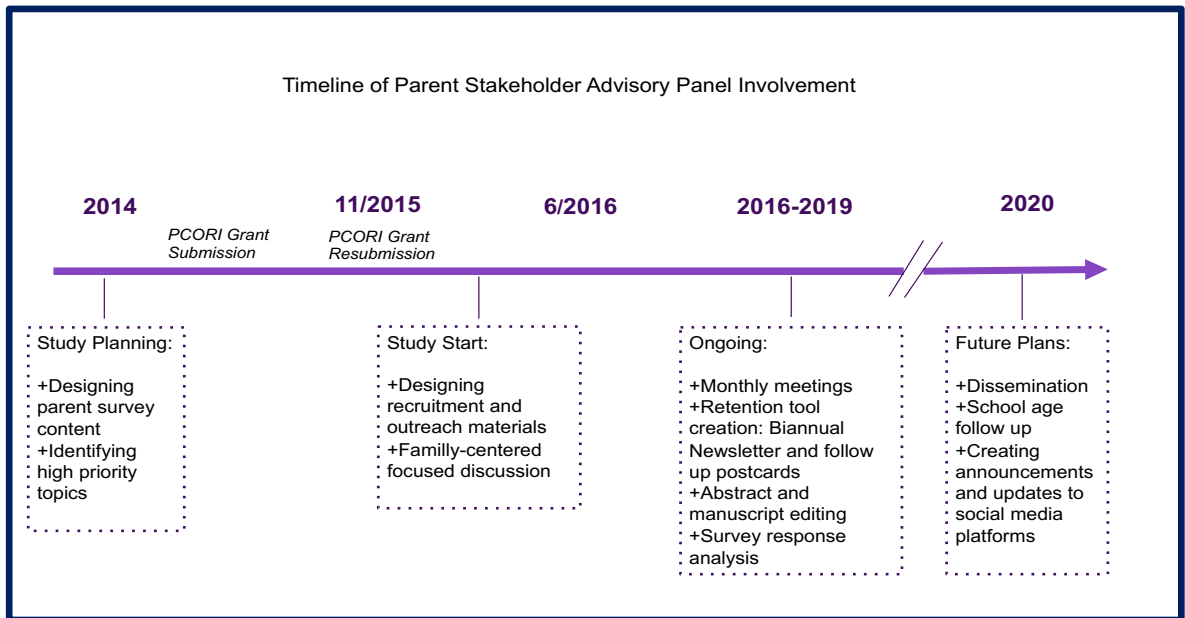
Pending...

In April of 2019, the annual Pediatric Academic Societies Meeting (PAS) meeting in Baltimore MD united thousands of pediatricians, researchers, and academics from across the USA and abroad in a shared mission to enhance childhood health. Ten investigators from the *Neonatal Seizure Registry* met for a working dinner to discuss preliminary results, ancillary studies, and grant proposals.



Parent and Stakeholder Involvement

Our Parent Partner Panel has been a unique and invaluable component of our team since the study's inception. Each of our eleven parent advisors has personally experienced caring for a child with neonatal seizures. Their authentic input keeps us focused on family priorities and helps us relate and communicate with participants. Parent Partners work with us to share our findings with families and care providers. As the study evolves, Parent Partners are actively involved in data analysis and interpretation of parent survey responses. As a result of their important contribution, members from the Panel will present a poster detailing their engagement and how this involvement has contributed to the success of the study at our sponsor's (PCORI) Annual Meeting in Washington DC in September 2019. With the help of the Parent Panel, the overall retention rate has been 86% or higher throughout the study.



Upcoming Conferences and NSR Presentations

Child Neurology Society (CNS)

Charlotte, NC – October 2019

- + Parent Experience of Caring for Neonates with Seizures
- + Characteristics of Neonatal Seizures Related to Intracranial Hemorrhage in Term Neonates: A Study of the *Neonatal Seizure Registry*

American Epilepsy Society (AES)

Baltimore, MD - December 2019

- + Seizure characteristics of neonates with severe cardiopulmonary diseases in the *Neonatal Seizure Registry*
- + Neonatal EEG Monitoring Strategy is Associated with Better Seizure Control
- + A New Risk Prediction Tool for Infantile Spasms after Acute Symptomatic Neonatal Seizures

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>