

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

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



Welcome to our third newsletter for the **Neonatal Seizure Registry (NSR)**. We are pleased to announce that we have met and exceeded our recruitment target and have 305 babies and their families enrolled in the study! We will continue to follow participants to the 24-month time-point and are in the preliminary stages of baseline data analysis. We will continue to update you as our analyses uncover new findings.

Our Work

There is not enough high quality research to tell doctors the best way to treat seizures in babies. Different doctors have different approaches. Our goal is to figure out the safest and most effective way to treat newborns with seizures. We also want to understand how the medical treatments for newborn seizures can impact families as their children grow. We are working with the Patient Centered Outcomes Research Institute (PCORI) to carry out a large, multi-site observational study to better understand how to treat seizures in newborns. Our nine participating hospital sites and Parent Partners span from coast to coast:

PARTICIPATING HOSPITALS

UCSF Benioff Children's Hospital

Hannah Glass, MD, MS

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

Parent Partner: Gwen Ma

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

Parent Partner: Terri Long

Cincinnati Children's Hospital Medical Center

Cameron Thomas, MD, MS

Parent Partner: Katie Grant

AFFILIATE ORGANIZATIONS

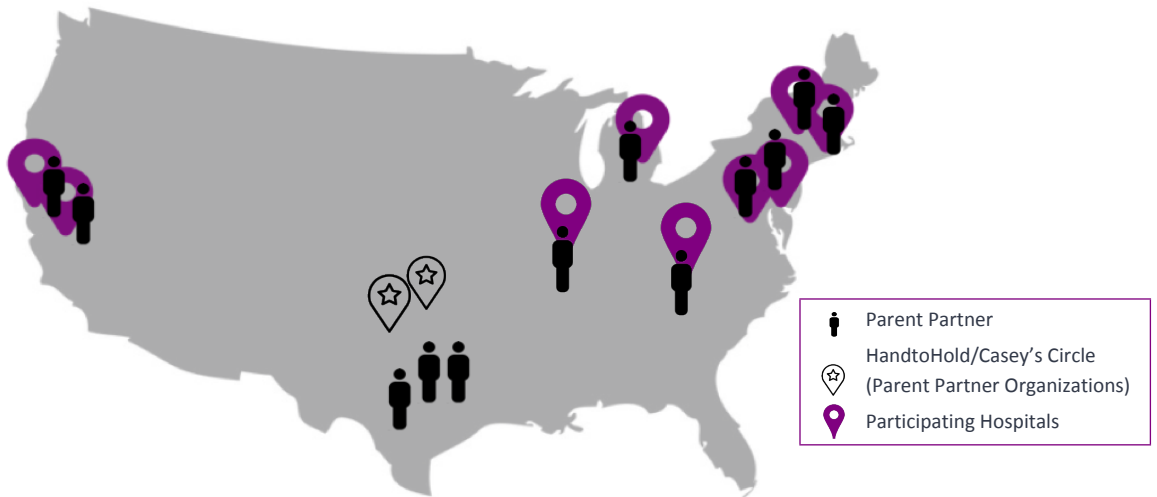
Hand to Hold

Parent Partners: Claire Brown

Parent Partner: Karla Contreras

Casey Circle

Parent Partner: Marty Barnes



MOVING?

Don't forget to contact your local study coordinator to update your contact information.



What happens in the study:

At 3 months: A clinic visit for children to receive an EEG and parents to complete a survey.

At 12, 18, and 24 months: parents complete a telephone survey.



3-mo EEG



12-mo



18-mo



24-mo

Your Participation Matters



"It is a privilege being a part of this multi-site study in which we are able to communicate so directly with our parent partners. What we learn is so much more useful when we keep the patient and family perspective front and center. It is exciting to already be seeing results and we look forward to learning even more as the data continues to be gathered and analyzed. What we have learned so far will be shared at national meetings in the coming months and is certain to generate a lot of excitement and discussion in this field. Among our study investigators, we are already discussing the impact of what we are learning and how this can provide the best and most accurate information to families and guide future research. We appreciate the patience and consistency that our families show in their continued participation with the study over time. We are hopeful that we can continue to learn from the wonderful patients and families enrolled in this study as this phase is completed and for many years to come."

– Cameron Thomas, MD, MS (Cincinnati Children’s Hospital Medical Center)



"When our newborn daughter, Tosca, had a stroke followed by seizures, my wife and I were stunned, scared, and totally bewildered. Having access to the resources being developed by the Neonatal Seizure Registry would have made an enormous difference, which is why I’m thrilled to be a member of its Parent Stakeholder Advisory Panel. Being involved with the NSR has also shown me the critical importance of collecting longitudinal data, as well as the great value of regular communication between clinical researchers and the parents of children suffering from seizures."

– Tristan Barako (Massachusetts General Hospital NSR Parent Partner)



Next Phase

A Message From the Lead Investigators:

"As we follow these infants and their families through the first two years of their lives, we will learn about how the neonatal seizures and their treatment influence child development, later seizures, and family well-being. We hope the results of this work will help doctors and families of newborns with seizures as they make treatment decisions and will provide clear information about what to expect for the future."

– Renée Shellhaas, MD, MS and Hannah Glass, MD, MS (Co-Principal Investigators)

Future Applications:

We are in the process of writing grant applications to receive funding to extend the follow up period within this cohort. Parents have told us they are keenly interested in identifying predictors for early school age development outcomes at 4-6 years old. We are excited to partner with you to answer these questions and will keep you updated in the coming months!

Contact for Future Research: This research is only possible because of the willingness of our families. We are grateful for your ongoing participation and hope that you continue with the same enthusiasm moving forward.

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>