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

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



Welcome to our fourth newsletter for the **Neonatal Seizure Registry (NSR)**. As many of you already know, we exceeded our enrollment target in March and have now completed all 3-month EEGs! We will continue to follow participants at 12, 18, and 24-month time-points and are in the preliminary stages of baseline data analysis. We will update you as our analyses uncover new findings.

Our Work

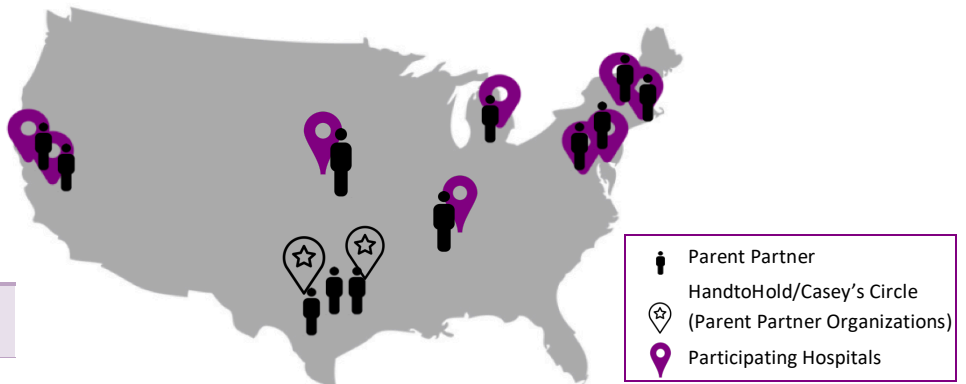
What is a comparative effectiveness study?

Comparative effectiveness studies are research projects designed to tell us whether one treatment is better than another. 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.

What types of data are being analyzed?

- Demographics (age, sex, race, mother's education, etc.)
- Imaging (EEGs and MRIs)
- Treatment of seizures (past and/or current medications and how long they were given)
- Cause of seizures (hypoxic-ischemic encephalopathy, stroke, hemorrhage, infection, etc.)
- Parent mental health (depression and anxiety scores)

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's Circle

Parent Partner: Marty Barnes

Partnering Site	Number of Participating Families
UCSF Benioff Children's Hospital	41
University of Michigan C.S. Mott Children's Hospital	54
Lucille Packard Children's Hospital	28
Children's Hospital of Philadelphia	20
Children's National Medical Center	48
Massachusetts General Hospital	25
Boston Children's Hospital	55
Duke University	18
Cincinnati Children's Hospital Medical Center	16

Study Timeline:

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



"Family well-being is necessary for children to grow and thrive. That is why it is so important to learn more about parent and family well-being during the early years after a child has had neonatal seizures."

– Linda Franck, RN, PhD, FAAN (UCSF Core Study Team)



"As a parent of a child who had a fetal maternal hemorrhage and had a stroke and related seizures, it was very scary and difficult to think about having another child. My husband and I feel so blessed to announce the birth of our new baby, who is loved so much by the older sibling. I am honored to play a role as an NSR parent partner, and I hope other families going through what we went through can benefit from our experience."

–Jennifer Guerrriero, PhD (Boston Children’s Hospital Parent Partner)



Upcoming Conferences

The *Neonatal Seizure Registry* team will be presenting two abstracts at the Child Neurology Society annual meeting in Chicago this October. The first presentation will be about our research findings showing that children who continue anti-seizure medication (like phenobarbital) after they go home from the newborn stay receive higher doses of medication and may have slightly longer hospital stays. The second presentation will highlight our findings that many newborns continue to have seizures after the first dose of anti-seizure medication unrelated to whether the baby is born early or not, or type of medication. However, we did find that children who receive cooling therapy and have low seizure burden may be more likely to respond to the first dose of medicine. These are very exciting preliminary results and we are pleased to share them with other child neurology specialists at the conference. We hope to have more results that will improve young children’s anti-seizure treatment as the study continues – and we will share those findings with you.

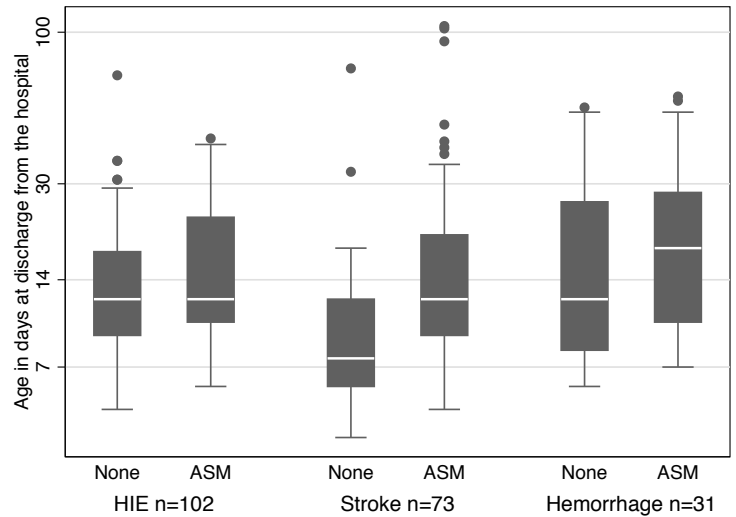


Figure: Newborns who stay on anti-seizure medication (ASM) after the newborn stay may be more likely to have a longer length of stay.

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>