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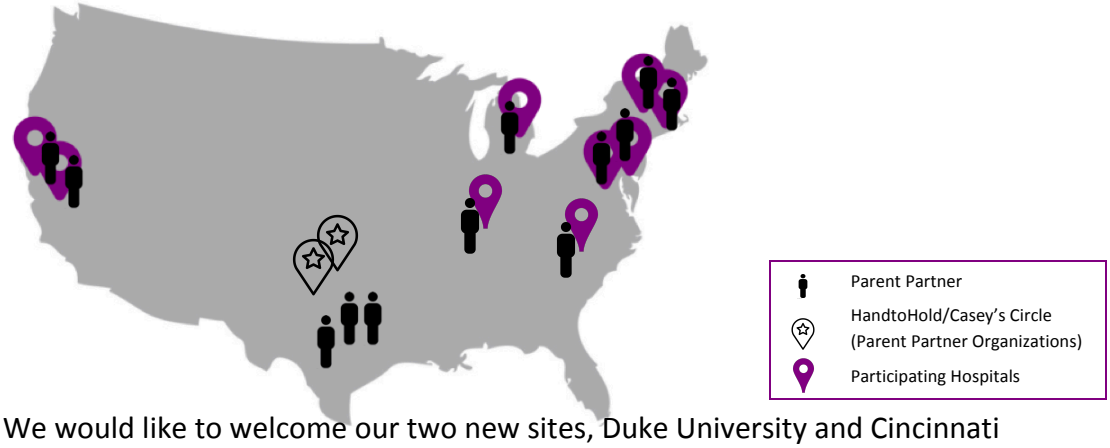
Continued Anticonvulsants After Resolution of Neonatal Seizures: A Patient-Centered Comparative Effectiveness Study

- *funded by Patient Centered Outcomes Research Insititute (PCORI)* -

Welcome to our second newsletter for the ***Neonatal Seizure Registry (NSR)***. We have recruited 217 families and are on target to enroll 300 babies and their families in this study by March 2018.

Our Work

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:



We would like to welcome our two new sites, Duke University and Cincinnati Children's Hospital Medical Center!

PARTICIPATING HOSPITALS

UCSF Benioff Children's Hospital
Hannah Glass, MD, MS
Mott Children's Hospital
Renée Shellhaas, MD, MS
Lucille Packard Children's Hospital
Courtney Wusthoff, MD, MS
Children's Hospital of Philadelphia
Nicholas Abend, MD, MS
Children's National Medical Center
Taeun Chang, MD
Massachusetts General Hospital
Catherine Chu, MD, MS
Boston Children's Hospital
Janet Soul, MD
Duke University
Monica Lemmon, MD
Cincinnati Children's Hospital Medical Center
Cameron Thomas. MD

There is not enough high quality research to tell doctors the best way to treat seizure 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.

Families are invited to participate if:

- Their baby is born at or transferred to one of our 9 study centers
- Their baby's seizures began less than 4 weeks after the baby's full term due date and needed medication to treat the seizures
- The family speaks and reads English or Spanish

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.

Meet Our Parent Partners and New Site Investigators

"Understanding how long to continue seizure medications after neonatal seizures, and how neonatal seizures and their treatments impact parent well-being, are pressing questions for our field. We are delighted to join as a site for this important study, and look forward to working with all of you."

–Monica Lemmon, MD (Duke University)

"As a parent of an adult son suffering from an uncontrolled seizure disorder, I feel blessed to be given the opportunity to support neonatal seizure research which will help guide younger parents as they begin caring for their child. As Always for My Christopher…"

–Lisa Grossbauer (Children's Hospital of Philadelphia NSR Parent Partner)

Education Corner

Epilepsy and Infantile Spasms after Neonatal Seizures

Most children with neonatal seizures will never have another seizure. Studies estimate that 75% (3 in 4 children) do not develop epilepsy. Unfortunately, we don't know how to accurately tell which babies will go on to have more seizures. This is why more research is needed.

Epilepsy is tendency toward "out of the blue" (unprovoked), recurrent seizures. These seizures usually begin months or years after the initial newborn seizures subside. Epilepsy may be diagnosed via an EEG test, descriptions of the seizures, or videos of the episodes.

Infantile Spasms is a rare type of epilepsy that occurs in less than 10% (1 out of 10) of children with neonatal seizures. Spasms usually have their onset before 1 year of age (average age is 4 months, range 1 month to 2 years). Spasms can have a subtle appearance (for example head drops or body "crunches" that occur in clusters), so it may be difficult for parents to recognize that it is a serious problem. Spasms are sometimes mistaken for startle reflex, colic or reflux. It is very important to recognize that a child has infantile spasms as soon as they begin because specific medications can control the spasms and the longer the spasms last before they are controlled, the higher the chance of developmental disability. An EEG is always used to help diagnose infantile spasms. Most children with spasms will have a very abnormal EEG pattern called hypsarhythmia. Infantile spasms may come before other types of seizures or may come after a child has other seizures.

References: *http://www.childneurologyfoundation.org/disorders/epilepsy/* ***and*** *http://www.childneurologyfoundation.org/disorders/infantile-spasms/*

Funding update! The *Neonatal Seizure Registry* recently received funding from the Pediatric Epilepsy Research Foundation (PERF) to study risk factors for infantile spasms in children who had neonatal seizures. We hope to predict which children are at highest risk so that we can diagnose and treat spasms rapidly and eventually start trials of new medications to prevent this type of epilepsy.