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Neonatal Seizure Registry

~ funded by the National Institutes of Health (NIH) ~

Welcome to the fourth newsletter for the *Neonatal Seizure Registry (NSR),* which includes updates from all studies led by the NSR group. Thank you for being a part of this important work!

NEW: NSR receives funding for NSR-GENE. Your family may be eligible!

We are thrilled to announce that we have received funding for the Neonatal Seizure Registry- GEnetics of post-NEonatal epilepsy (NSR-GENE) study. This study will evaluate the genetic risk factors for epilepsy in children who experienced a brain injury as a newborn. Results from this study will help medical providers talk with families in the future about their child's risk of epilepsy. This study may also help researchers to better diagnose and treat children with early life seizures. Study findings could lead to development of new treatments to prevent epilepsy. *We will reach out to eligible and interested families later this year.*

NSR-DEV Research Study Update

Our Parent Partner Advisory Panel helped us identify 3 key priorities for this study: (1) Early predictors of developmental and learning challenges in childhood, (2) Features of parent well-being that impact success in childhood and (3) Early, easily applied and accurate methods to predict childhood impact after neonatal seizures. To date, we have enrolled **188** families and have completed **53** in-person visits. The in-person visit is typically 1-3 hours long and takes place when your child is between 5-6 years old. During this visit, a qualified healthcare professional administers two neurodevelopmental assessments at your local participating hospital. These assessments are the main outcome for our study, and will help researchers better understand the development of children who had newborn seizures.

NSR-RISE Research Study Update

For this study, we are evaluating the role of inflammation in infants who had seizures during the newborn period to better understand (1) The relationship between inflammation and seizure severity in infants and (2) How inflammation and seizure severity relate to infant's risk for developing epilepsy in early childhood. We are continuing work towards our goal of enrolling **87** families in Neonatal Intensive Care Units at participating sites across the USA. To date, we have enrolled **53** participants.

PARTICIPATING HOSPITALS
UCSF Benioff Children's Hospital
Hannah Glass, MDCM, MAS
Parent Partner: Kamil Pawlowski
C.S. Mott Children's Hospital
Renée Shellhaas, MD, MS
Parent Partner: Libby Hill
Lucile Packard Children's Hospital
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Parent Partner: TBA
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Shavonne Massey, MD, MSCE
Parent Partner: Lisa Grossbauer
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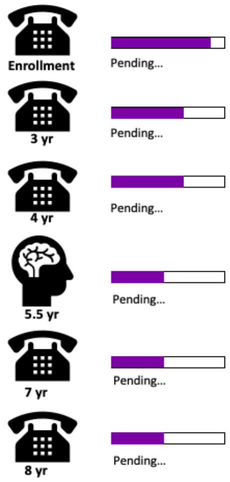
Parent Partner: Dana Annis
Massachusetts General Hospital
Catherine Chu, MD, MS Parent Partner: Brian Gosselin
Boston Children's Hospital
Janet Soul, MD
Parent Partner: Jennifer Guerriero
Duke University
Monica Lemmon, MD
Parent Partner: Ashley Hamlett
Cincinnati Children's Hospital Medical Center
Cameron Thomas, MD, MS
Parent Partner: Katie Grant

AFFILIATE ORGANIZATIONS
Hand to Hold
Parent Partner: Katrina Moline
Casey's Circle
Parent Partner: Marty Barnes
Hope for HIE
Parent Partner: Betsy Pilon
NSR-DEV Study Progress



Results of your participation: selected publications

Neonatal Seizure Registry Shows that Services were Disrupted during COVID Shutdowns

+ In this study, we asked parents about disruption to their child's developmental services during the COVID-19 pandemic for children enrolled in the *Neonatal Seizure Registry*. Nine out of 10 children experienced a disruption in developmental services (e.g., PT, OT, Feeding Therapy) due to the pandemic. For 3 out of 4, that in-person services were no longer available.
+ As services resume post-pandemic, developmental therapies may need to be tailored to make up for the loss of services for children with newborn seizures.

Peyton C, Girvan O, Shellhaas RA, Lemmon ME, Rogers EE, Soul JS, Chang T, Hamlett A, Wusthoff CJ, Chu CJ, Massey SL, Thomas C, Guillet R, Franck LS, Glass HC, on behalf of the Neonatal Seizure Registry, Impact of COVID-19 Pandemic on Developmental Service Delivery in Children with a History of Neonatal Seizures, Pediatric Neurology (2022). https://doi.org/10.1016/j.pediatrneurol.2022.01.004.

Parent Well-Being Improves Over Time in Parents of Children with Neonatal Seizures

+ In this study, we aimed to better understand parent mental health and family coping over the first two years after their infant's seizures.
+ At the two-year timepoint, one in three parents reported symptoms of anxiety and more than one in ten reported symptoms depression. About one in five reported symptoms of post-traumatic stress. Despite ongoing anxiety and depression, symptoms were lower than at the time of hospital discharge and parents also reported a moderately *high quality of life* and *positive personal change* over time despite ongoing challenges to family coping.
+ Parents and health providers should be aware of lasting risks to parent mental health and family coping for families of children with newborn seizures.

Franck LS, Shellhaas RA, Lemmon ME, Sturza J, Barnes M, Brogi T, Hill E, Moline K, Soul JS, Chang T, Wusthoff CJ, Chu CJ, Massey SL, Abend NS, Thomas C, Rogers EE, McCulloch CE, Glass HC. Parent Mental Health and Family Coping over Two Years after the Birth of a Child with Acute Neonatal Seizures. Children (Basel). 2021 Dec 22;9(1):2. https://doi.org/10.3390/ children9010002.

+ Check out our previous Parent Well-Being research, and stay tuned for more:

Impact of our work together

*"We physicians likely overestimate our own effectiveness in communicating with families of critically ill children. Gaining a better sense of what parents need and value is a good place to start improving***.** ***Parent Advice to Clinicians should be required reading for everyone who sets foot into a NICU or PICU!"***

-E. Steve Roach, MD
Former Editor-in-Chief of Pediatric Neurology
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Austin, Texas

For more information about the study, please visit our website: http://neonatalseizureregistry.ucsf.edu

Contact us: neuroglasscrc@ucsf.edu