



Participant Newsletter

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

Thank you for your participation in the Neonatal Seizure Registry (NSR)!

NSR-GENE Update

Thank you to all the families who have sent their saliva samples! Our research team has begun processing the DNA from the samples. This work will bring us closer to finding potential genetic markers that could improve treatment and care for children with neonatal seizures. We look forward to sharing what we learn with you in the coming months.



Have questions or need help with your saliva kits? We are here for you! Please contact your local research team if you need a replacement kit or assistance with FedEx returns. Every sample is vital to this research!

Check Out Our New Infographics!

We have learned so much from parents about the joys and challenges of parenting a child who experienced seizures as a newborn. To better support families, we collaborated with the NSR Parent Panel to create two new infographics: the **Question Prompt List** for parents of newborns with seizures, and the **Long-Term Experience After Neonatal Seizures**. Created by parents, for parents, these resources are designed to offer guidance and support to help families feel more prepared and empowered as they care for their children after neonatal seizures.

Scan the QR codes below to view and download these infographics. They are also available in Spanish and Arabic on our website.



NSR Facts

- > Since 2012, over 500 families from 9 different hospitals have contributed to our research on neonatal seizures.
- > We are so appreciative of your ongoing participation. Thanks to your support, NSR has published over 30 manuscripts... with more on the way!
- > Findings from our research have been presented at leading conferences, including the Child Neurology Society, Pediatric Academic Societies, and American Epilepsy Society.



Findings From Your Participation: Selected Abstracts

Risk and Morbidity of Post-Neonatal Epilepsy through Childhood Among Survivors of Acute Provoked Neonatal Seizures

AL Numis, HC Glass, CJ Wusthoff, JS Soul, ML Lemmon, GM Benedetti, N McNamara, MM Berl, C Thomas, C Chu, S Massey, T Anwar, J Sturza, L Franck, CE McCulloch, RS Shellhaas

- > Among 282 NSR participants, 47 (17%) developed epilepsy (recurrent unprovoked seizures) by age 8.
- > Children born preterm were more likely to develop epilepsy later than children who were born at full term.
- > Many of the children who developed epilepsy required hospitalization for seizure management during the follow-up period, emphasizing the complexity of epilepsy in NSR.
- > These findings highlight the importance of ongoing follow-up and early interventions for children with neonatal seizures. Identifying at-risk children sooner helps guide treatment strategies and connect families with essential support resources.



Stephanie Rau, Renée Shellhaas, Catherine Chu, Adam Numis, and Giulia Benedetti at the American Epilepsy Society Meeting in Los Angeles

Sleep Disorders Among 5-Year-Old Survivors of Acute Provoked Neonatal Seizures

RS Shellhaas, LS Franck, B Pilon, CJ Wusthoff, SL Massey, CJ Chu, JS Soul, ME Lemmon, AL Numis, JS Sturza, C Thomas, GM Benedetti, S Rau, T Anwar, MM Berl, CE McCulloch, HC Glass

- > Sleep challenges are a common concern in children who had seizures as newborns. About two-thirds of parents reported their child experienced sleep problems by early school age.
- > Children diagnosed with epilepsy or cerebral palsy showed higher rates of sleep problems. However, sleep problems were also very common for children who did not have epilepsy or cerebral palsy.
- > Parents of children with sleep problems were more likely to experience symptoms of anxiety or depression, highlighting the broader impact of childhood sleep challenges on families.
- > Early screening and interventions can improve long-term outcomes for children and support family well-being after neonatal seizures.



Participating Hospitals

UCSF Benioff Children's Hospital
Hannah Glass, MDCM, MAS
Parent Partner: Kamil Pawlowski

C.S. Mott Children's Hospital
Giulia Benedetti, MD
Parent Partner: Libby Hill

Lucile Packard Children's Hospital
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Duke University
Monica Lemmon, MD
Parent Partner: Ashley Hamlett

Cincinnati Children's Hospital Medical Center
Cameron Thomas, MD, MS
Parent Partners: Katie and Justin Means

Affiliate Organizations

Hand to Hold
Parent Partner: Taneisha Stamps

Casey's Circle
Parent Partner: Marty Barnes

Hope for HIE
Parent Partner: Betsy Pilon and Gina Abraham

For more information and updates, please visit <https://neonatalepilepsyregistry.ucsf.edu/>