



NEONATAL SEIZURE REGISTRY

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

Thank you for your participation in the *Neonatal Seizure Registry (NSR)*! In this newsletter, you can find updates about *NSR* studies, frequently asked questions, and other exciting updates.

NSR-GENE Enrollment Update

We are excited to share that we are now able to include families with single parents. As of this month, NSR-GENE has enrolled 121 participants, which is 57% way to our goal of enrolling more than 200 families from across the United States. With the expanded inclusion, we hope to increase accessibility for children and families who could benefit from participating in our research. The information we collect can help us gain a deeper understanding of genetic factors that contribute to epilepsy in children after acute newborn seizures.

Contact your local site to learn more and see if your family might be a good fit for this important research!



Frequently Asked Questions

If my family is already enrolled in a NSR study, how much additional time will I expect to spend on NSR-GENE?

- > You will not commit additional time as we will combine NSR-DEV/NSR-RISE and NSR-GENE medical history calls together. The information on the questionnaire is relevant to both studies.

Will the genetic analysis be shared with the family?

- > The genetic testing for this study is approved for research purposes only and results will not be shared with you. However, if new clinically important information is found, you will have the option to have the study team refer you to a clinical geneticist for further evaluation.

NSR-DEV – Your participation matters!

Thanks to the amazing dedication of families like yours, we have successfully completed all follow-ups for our 3 and 4-year-old participants!

For families with children aged 5 to 7 years: If you have not yet had your in-person visit, please reach out to your local study team now to schedule this important appointment. We understand scheduling can be challenging and we truly appreciate your ongoing efforts. As we approach September 2024, study teams will be contacting you to complete final study follow-ups. We are looking forward to share results from your participation.

NSR-RISE Study Progress

We are on our final stretch of the study! We have successfully completed the 12-month follow-ups for all participants and are well on our way to finish all 24-month follow-ups by the end of 2024. Once all follow-ups are completed, our research team will begin analyzing the data. We look forward to sharing the findings with you in a future newsletter!



Results From Your Participation: Abstracts to be presented at the 2024 meeting of the Pediatric Academic Societies

Risk factors associated with parental and family well-being for pre-school and school-aged children following acute provoked neonatal seizures.

Franck L, Lemmon M, Sturza J, McCulloch C, Grossbauer L, Moline K, Pawlowski K, Anwar T, Benedetti GM, Berl M, Chu C, Larson JG, Massey S, Rogers E, Soul J, Thomas C, Wusthoff C, Shellhaas RA, Glass HC

- > The long-term impact of neonatal seizures on parent and family's well-being after 24 months is not known.
- > In this research, we collected data from 165 parents and found 65-92% of parents have no symptoms of depression, anxiety, and post-traumatic stress when their children were between 3 to 8 years.
- > Families of children with functional and social challenges were most likely to experience poorer well-being.
- > This highlights that most families are coping very well and emphasizes the importance of early screening for child development, parent well-being and family function.



Parent partner Betsy Pilon, and Study Investigators Drs. Courtney Wusthoff, Renée Shellhaas, Shavonne Massey, Giulia Benedetti, and Adam Numis at AES 2023.

Impact of Our Work Together

The annual American Epilepsy Society (AES) conference was held last December in Orlando, Florida. Investigators and our Parent Partner Betsy Pilon proudly represented the *Neonatal Seizure Registry*. Notably, the Pediatric State of Art Symposium, co-chaired by Dr. Shellhaas, featured presentations by **five** *NSR* investigators. Dr. Benedetti delivered insights on quantitative EEG and seizure predictions. Dr. Massey presented *NSR* findings on seizures in neonates with congenital heart defects. Dr. Numis discussed genetic testing for neonates with seizure and gave a glimpse into the exciting work of *NSR*-GENE. Dr. Wusthoff introduced the new American Clinical Neurophysiology Society guidelines on neonatal EEG monitoring. Ms. Pilon discussed the impact of neonatal seizures on parents and families – again highlighting the key work of *NSR*. These presentations showcased the significant impact of *NSR* research, and this success would not be possible without the dedication of participants like you. Thank you for your continued contribution in advancing this research!

Participating Hospitals

UCSF Benioff Children's Hospital

Hannah Glass, MDCM, MAS
Parent Partner: Kamil Pawlowski

C.S. Mott Children's Hospital

Giulia Benedetti, MD
Renée Shellhaas, MD, MS
Parent Partner: Libby Hill

Lucile Packard Children's Hospital

Courtney Wusthoff, MD, MS
Parent Partner: TBA

Children's Hospital of Philadelphia

Shavonne Massey, MD, MSCE
Parent Partner: Lisa Grossbauer

Children's National Medical Center

Tayyba Anwar, MD
Tammy Tsuchida, MD, PhD
Madison Berl, PhD

Parent Partner: Dana Annis

Massachusetts General Hospital

Catherine Chu, MD, MS
Parent Partner: TBA

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 Partners: Katie and Justin Means

Affiliate Organizations

Hand to Hold

Parent Partner: Katrina Moline

Casey's Circle

Parent Partner: Marty Barnes

Hope for HIE

Parent Partner: Betsy Pilon

