NEONATAL SEIZURE REGISTRY

Fall 2023

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

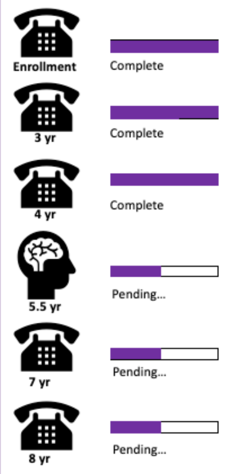
Thank you for your participation in the Neonatal Seizure Registry (NSR). In this newsletter, you can find updates about NSR studies and upcoming events!

NSR-GENE – Enrollment continues!

Children who have brain injury and seizures during infancy may develop epilepsy. While researchers have learned a lot about which babies are most likely to have epilepsy later in childhood, there are still lots of questions that need answers. NSR-GENE will collect samples – a cheek swab from the child and a small saliva sample from both biological parents – to look for genetic (inherited) risk factors that may increase the risk of epilepsy. Collecting the samples is easy and can be completed during a scheduled clinic visit or in the comfort of your own home. Participation in this study can help doctors understand how some children have a higher risk for epilepsy than others. The information collected will help guide the design of new approaches to treating epilepsy after neonatal seizures. *If your family is interested or you believe you may be eligible, please reach out to learn more.*

NSR-DEV in-person visit – A parent's perspective

As a part of the study follow-up, families with children between 5 and 6 years old are asked to complete an in-person visit at the local participating hospital. This visit lasts about 1-3 hours and the data collected from the assessments given at the visit are some of the most important measures in this study. We greatly appreciate everyone who has already participated. Families who have completed the in-person visit have shared with us their joy in seeing their child grow throughout the study. Your involvement during the final follow-up stages remains an important part of the study's progress! *If you haven't had your in-person visit yet, please contact your local team to schedule.*



> ***"The in-person visit was easy to complete, and UCSF provided accommodations to help make the visit more doable for our family. It was a very pleasant experience. It really opened my eyes to how much my daughter can do!"***
>
> *~ Parent of a child participating in NSR-DEV*

NSR-RISE Study Progress

Our study teams are actively following up with participating families. We expect to finish the 12-month follow-ups by the end of 2023 and completing all 24-month follow-ups by the end of 2024. We have also started testing the blood samples for inflammatory protein levels. We anticipate having early results to share soon! *If your family is also eligible or interested in learning more about the NSR-GENE study, please reach out to your local team.*

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
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 Partner: 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

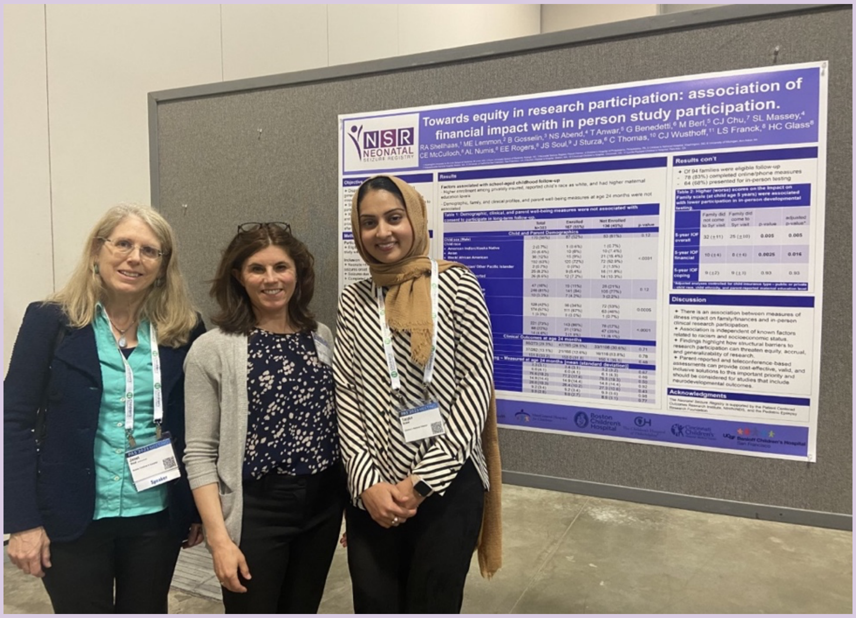
Your Participation Matters!

The Neonatal Seizure Registry is extremely fortunate and proud to collaborate with a dedicated group of Parent Partners who work with us to make sure that all our research focuses on questions that are important to children and their families. The feedback we get from our Parent Partners has been key to making sure the research is accessible, conducted in a respectful way, and that results are shared in ways that are easily understandable for families and communities. Here is a quote from one of our Parent Partners about why she supports this research:

> *"Life brings us special gifts. It is my duty to share my gift with the research community to move knowledge and understanding forward, which ultimately improves the quality of life of other children and families."*
>
> *~ Lisa Grossbauer*

Upcoming Conferences

Neurologists, researchers, and academics from across the USA and Canada will be attending the Child Neurology Society (CNS) annual meeting in Vancouver this October. Investigators and Parent Partners from the *Neonatal Seizure Registry* team will be in attendance to discuss future directions of the *NSR*. Our study team is excited to continue this impactful work and could not do it without the participation from dedicated families like yours – thank you!



Study Investigators Drs. Janet Soul (Boston Children's Hospital), Hannah Glass (UCSF), and Tayyba Anwar (DC Children's National) present a poster at the 2023 Pediatric Academic Societies' annual meeting in Washington DC.

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

Contact us: neuroglasscrc@ucsf.edu