



# Participant Newsletter

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

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

## NSR-DEV: Study Visits Are Done!

A big thank you to all the families who participated. Together, we have reached our research goals. As you may remember, NSR-DEV started in 2020 during the peak of the COVID-19 pandemic. Despite many challenges, we successfully enrolled 188 participants across the U.S. and completed 113 in-person visits.

The information we learn from your participation can help improve care and support for future families facing similar challenges. Stay tuned for more updates as we continue to analyze the data in the coming months. Thank you for being a part of this journey with us!

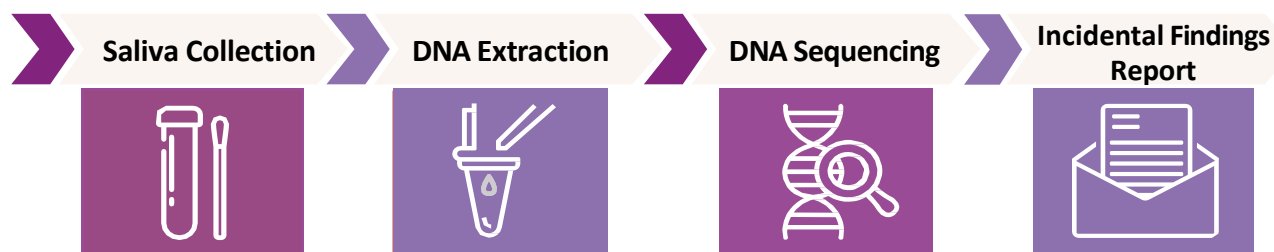
## NSR-RISE: Preliminary Findings

We are excited to share that we have found five biomarkers that have a strong link with epilepsy. While these are early findings, they are promising. In the coming months, we will be looking more closely at these biomarkers to better understand their role in the development of epilepsy and possible future treatments for children with neonatal seizures.

We want to express our heartfelt thank you to all participating families. We couldn't have made these discoveries without your support. We look forward to keeping you updated as we continue our analysis.



## NSR-GENE: Where Are My Genetic Samples?



If you and your child provided saliva samples, they are being processed at our UCSF lab for DNA extraction and at the Broad Institute for DNA sequencing. Over the next few months, our research team will carefully analyze the data from these samples. If we find any important results and you have opted to be informed of incidental findings, your family will receive a report from your local team.

**Please note that the genetic testing is for approved research purposes only.** If you or your child receives a positive test result, you may need follow up with your clinical team for further testing. We recommend discussing any findings with your healthcare provider.

### Send Your Samples In!

Just a friendly reminder to send your saliva samples back to us. Getting these samples in helps us advance our research. Your contribution is a vital part of this process!

## Results From Your Participation: Selected Publications

### Life after neonatal seizures: Characterizing the longitudinal parent experience

Field NK, Franck LS, Shellhaas RA, Glass HC, Young KA, Dhar S, Hamlett A, Pilon B, Means K, Soul JS, Massey SL, Wusthoff CJ, Chu CJ, Thomas C, Rogers E, Berl M, Anwar T, Benedetti GM, and Lemmon ME, for the Neonatal Seizure Registry

- > Parents of children with neonatal seizures can experience ongoing symptoms of anxiety, depression, and post-traumatic stress.
- > Some parents described fears about their child's seizures recurring and worries about their child's future development.
- > Nearly all parents shared the joy they found in caregiving.
- > Many parents shared the pride they felt watching their child grow and develop their own unique personality.
- > These findings show the need for resources and support for parents that go beyond the neonatal period. It also shows the importance of positive coping and building strong parent-child relationships.

### Question Prompt List for parents of neonates with seizure

Field NK, Glass HC, Franck LS, Shellhaas RA, Means J, Lemmon ME, for the Neonatal Seizure Registry

- > Parents of neonates with seizures may be unsure about what questions to ask the healthcare team. Studies show that sharing a list of possible questions with parents can help make it easier to start conversations with members of the care team.
- > The NSR created a Question Prompt List (QPL) with common questions that parents have found useful during the neonatal period.
- > The questions are divided into five categories: 1) Understanding my baby's seizure diagnosis, 2) Antiseizure medication, 3) Expectations for the baby's future, 4) What to do in case of seizures after discharge, and 5) Finding information and support.
- > To find our QPL, scan the QR code:



## Hear From Our Team

"Growing up with epilepsy, I saw the ways in which seizures impacted not only my own health and wellbeing, but those closest to me. I am proud to contribute to research with the Neonatal Seizure Registry which makes it a priority to keep patients, families, and their stories at the heart of all that they do, and I am grateful for all the families who have shared their experiences to make this work possible."



**Natalie Field**  
Second Year Duke Medical Student

### Participating Hospitals

<b>UCSF Benioff Children's Hospital</b> Hannah Glass, MDCM, MAS Parent Partner: Kamil Pawlowski	<b>Children's National Medical Center</b> Tayyba Anwar, MD Tammy Tsuchida, MD, PhD Madison Berl, PhD Parent Partner: Dana Annis
<b>C.S. Mott Children's Hospital</b> Giulia Benedetti, MD Parent Partner: Libby Hill	<b>Boston Children's Hospital</b> Janet Soul, MD Parent Partner: Jennifer Guerriero
<b>Lucile Packard Children's Hospital</b> Courtney Wusthoff, MD, MS Parent Partner: TBA	<b>Duke University</b> Monica Lemmon, MD Parent Partner: Ashley Hamlett
<b>Washington University in St. Louis</b> Renée Shellhaas, MD, MS	<b>Cincinnati Children's Hospital Medical Center</b> Cameron Thomas, MD, MS Parent Partners: Katie & Justin Means
<b>Children's Hospital of Philadelphia</b> Shavonne Massey, MD, MSCE Parent Partner: Lisa Grossbauer	
<b>Massachusetts General Hospital</b> Catherine Chu, MD, MS Parent Partner: TBA	

### Affiliate Organizations

<b>Hand to Hold</b> Parent Partner: Katrina Moline & Taneisha Stamps
<b>Casey's Circle</b> Parent Partner: Marty Barnes
<b>Hope for HIE</b> Parent Partner: Betsy Pilon