

Neonatal Seizure Registry

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Welcome to the third newsletter for the *Neonatal Seizure Registry (NSR)*. We are expanding our newsletter to include updates from all studies led by the NSR group. As a reminder, you previously participated in NSR-2 **OR** are currently participating in NSR-DEV **OR** NSR-RISE. Thank you for being a part of this important work!



NSR-DEV Research Enrollment 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. We have enrolled **181** families thus far and are continuing to work towards our goal of enrolling **241** families from across the USA. We are recruiting parents who are willing to complete the enrollment assessments for their children (*online* assessments of children’s functional development and behavior, an additional *in-person* assessment if the child is older than 5). All of our sites use strict COVID precautions for on-site assessments.

We are enrolling children of all abilities! Whether your child is in mainstream activities or receives support for special needs, the information we learn from each child will help us to counsel families like yours so that all children thrive.



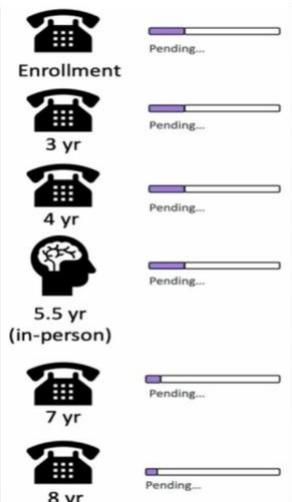
NSR-RISE Research Enrollment Update

For this study, we are evaluating the role of inflammation in infants who had seizures during the newborn period. This study will help us better understand:

1. The relationship between inflammation and seizure severity in infants
2. How inflammation and seizure severity relate to infant’s risk for developing epilepsy in early childhood



We are continuing to work towards our goal of enrolling **87** families in Neonatal Intensive Care Units at participating sites across the USA. To date, we have enrolled **49** participants.





Results of your participation

Neonatal Seizure Registry II

- + Glass HC, Soul JS, Chang T, et al. Safety of Early Discontinuation of Antiseizure Medication After Acute Symptomatic Neonatal Seizures. *JAMA Neurol.* 2021.
- + Thanks to participation of our NSR-II families, we are pleased to report that the results from our large, PCORI funded study have been published in a top journal! We learned that stopping anti-seizure medicine before a child goes home is safe. We compared newborns who took medicines only in the hospital (36 %) versus those who continued the medicines after they went home (64 %) and used a strategy called “propensity scoring” to adjust for baseline differences between the groups.
- + After two years, the two groups didn’t differ in:
 - Functional development, which included physical abilities, communication, skills like feeding and dressing, and social awareness
 - Motor ability, or how well children could walk
 - The risk of developing epilepsy
- + Based on these results, we anticipate that more babies will be discharged to home without antiseizure medication.

Parent Well-Being Research and Infographic

- + Franck LS, Shellhaas RA, Lemmon M, et al Associations between Infant and Parent Characteristics and Measures of Family Well-Being in Neonates with Seizures: A Cohort Study. *J Pediatr.* 2020
- + Lemmon M, Glass H, Shellhaas RA, et al. Parent experience of caring for neonates with seizures. *Arch Dis Child Fetal Neonatal Ed.* 2020.
- + After being discharged from the hospital, many families experienced challenges with finances, mood, coping, navigating uncertainty, and adapting family life.
- + To help support families, we developed the infographic included in this mailer, which includes resources to help parents support themselves and their families.

To access the infographic online, scan the QR code with your phone camera. This infographic was created by NSR and Hope for HIE.



Your Participation Matters!

We know the COVID-19 pandemic has impacted family life for almost everyone. Many parents just haven’t had the time or energy to think about participating in studies, even though they feel the studies are important. Our research coordinators are available to help make enrolling and completing follow-ups as easy as possible, whether that means navigating the websites or reading questions on the phone. Every participating family is important. The information we learn from each and every child is valuable to our shared long-term goal of preventing disability and epilepsy, and helping every child with neonatal seizures reach their full potential.

“Being a part of a group where we each bring something different to the table helped me feel like I’m not alone and empowered me to keep pushing and thinking outside the box. I have a sense of pride when I bring up that I’m the parent partner and that our research is being published. I see ideas from our panel calls made into research questions, which then in turn show common parent experiences. This helps us identify areas to study that one day will help make another parent’s life a little easier. I really am happy to be part of the team!”

- Katie Grant (Parent)

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