

## Neonatal Seizure Registry - Developmental functional Evaluation Study (NSR-DEV)

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

Welcome to the second newsletter for the *Neonatal Seizure Registry – Developmental functional Evaluation (NSR-DEV)* study. We are excited to continue this work with you in 2021!



### NSR-DEV Enrollment Update

We are continuing to work towards our goal of enrolling **241** families from across the USA. We are recruiting parents who are eager 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). More of our sites (4 out of 9 to date) have initiated *in-person* assessments at the child's age 5.5 year visit. All of our sites will eventually offer in-person assessments, with COVID precautions in place.



### COVID Considerations

It is our highest priority that parents feel comfortable as they participate in our study. As a result, our team has creatively adjusted the in-person study visit to the new realities of COVID. Here are precautions and accommodations we've implemented across our study sites:

- Each study site adheres to their institution's COVID policy, as well as their regional public health policy.
- Parents have the option to postpone the in-person study visit if they are not comfortable coming on site.
- All study personnel and research participants are screened for COVID prior to the in-person study visit.
- All study personnel and research participants wear face coverings and follow physical distancing guidelines during the in-person visit.
- We recognize that each parent has unique circumstances and are happy to accommodate our participants as needed.



#### PARTICIPATING HOSPITALS

**UCSF Benioff Children's Hospital**

Hannah Glass, MDCM, MAS

Parent Partner: Kamil Pawlowski

**C.S. Mott Children's Hospital**

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**

Taeun Chang, MD

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 Grant

#### AFFILIATE ORGANIZATIONS

**Hand to Hold**

Parent Partner:

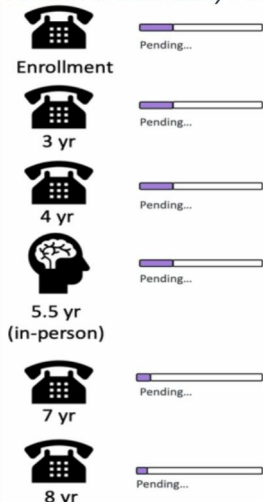
Katrina Moline

**Casey's Circle**

Parent Partner: Marty Barnes

**Hope for HIE**

Parent Partner: Betsy Pilon





## Recent Publications

### ***Neonatal Seizure Registry: Spasms Predictions After Asymptomatic Neonatal Seizures (NSR-SPASMS)***

+ Glass, H. C., Grinspan, Z. M., Li, Y., McNamara, N. A., Chang, T., Chu, C. J., Massey, S. L., Abend N. S., Lemmon, M. E., Thomas, C., McCulloch, C. E., Shellhaas, R. A. (2020). Risk for infantile spasms after acute symptomatic neonatal seizures. *Epilepsia*. To view for free, visit: <https://pubmed.ncbi.nlm.nih.gov/33188528/>.

+ Survivors of neonatal seizures are at risk for infantile spasms. Predicting infantile spasms risk for each baby could improve time to diagnosis and treatment.

+ Three risk factors predicted infantile spasms for babies in the *Neonatal Seizure Registry*: (1) severely abnormal EEG or  $\geq 3$  days with seizures recorded on EEG, (2) deep gray or brainstem injury on MRI, and (3) abnormal tone on discharge exam.

+ More than half of babies with all three risk factors developed infantile spasms, but none of the babies who did not have these risk factors had infantile spasms.

+ Based on these findings, investigators and parent partners collaborated to create infographics for Infantile Spasms Awareness Week in early December.

This infographic was created by Hope for HIE with adaptations from the Infantile Spasms Action Network and the Child Neurology Foundation.



## Your Participation Matters



*"We are so excited to start this next phase of the Neonatal Seizure Registry. For years, parents have been asking about what to expect for their child at early school age. The NSR-DEV study will provide rich information for families of children with neonatal seizures and will help providers to develop interventions to help optimize long-term development"*

- Hannah Glass and Renée Shellhaas (NSR co-PI's)



*"As both the mom of a little boy who battles seizures as well as the COO of Hand to Hold, a nonprofit supporting families with a NICU stay, I am doubly rewarded by my work with the NSR-DEV Parent Panel. I appreciate the opportunity to stay informed and involved while also being able to contribute to the well-being of other families facing the challenges of a seizure disorder."*

- Katrina Moline (Parent Partner, COO of Hand to Hold)

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

