

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

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

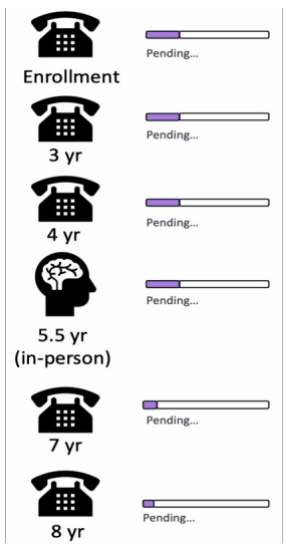
Welcome to the first newsletter for the “*Neonatal Seizure Registry – Developmental functional Evaluation*” (NSR-DEV) study. We are up and running with enrollment starting across our sites! We are excited for the opportunity to continue this work with you!

NSR-DEV Enrollment Update

Our goal is to enroll **280** families from across the USA. Parents have been keen to participate in the enrollment assessments (*online* assessments of functional development and behavior for children who are now 3 and 4 years old). The Children’s National Medical Center has initiated *in-person* assessments at the age 5.5 year visit (with COVID precautions in place, of course!). All of our sites will eventually offer these in person assessments.

Site	Informed Consent
UCSF Benioff Children’s Hospital	19
C.S. Mott Children’s Hospital	8
Lucile Packard Children’s Hospital	5
Children’s Hospital of Philadelphia	In progress
Children’s National Medical Center	19
Massachusetts General Hospital	7
Boston Children’s Hospital	12
Duke University	1
Cincinnati Children’s Hospital Medical Center	In progress
Total Completed	71

- 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: TBA
- Cincinnati Children’s Hospital Medical Center**
Cameron Thomas, MD, MS
Parent Partner: Katie Grant
- AFFILIATE ORGANIZATIONS**
- Hand to Hold**
Parent Partner: TBA
- Casey’s Circle**
Parent Partner: Marty Barnes
- Hope for HIE**
Parent Partner: Betsy Pilon





Recent NSR Presentations and Upcoming Conferences

Treatment Duration and 2-Year Outcome in Neonates with Acute Symptomatic Seizures

- + Presented at Pediatric Academic Society (PAS) and Child Neurology Society (CNS) meetings
- + To view for free, visit: <https://2020.pas-meeting.org/webinar-events-calendar/> . Under Week 5, select “Recording” for [Neonatal Neurology: Clinical I](#).
- + **NSR-II primary results showing safety of discontinuing anti-seizure medications after the seizures resolve and before discharge from the neonatal seizure admission.**

Early-life epilepsy after acute symptomatic neonatal seizures – a prospective multicenter study

- + Presented at American Epilepsy Society (AES) annual meeting
- + **13% of children with neonatal seizures developed epilepsy by age 24 months (about 1/4 were treatment-resistant meaning they had seizures in spite of 2 or more medications).**



Education Corner

Tips for parents during COVID, from the World Health Organization and our Parent Advisory Panel In times of stress, it is common for children to seek more of your attention. What you can do:

- Maintain familiar routines as much as possible, or create new ones, especially if you must stay at home
- Discuss the coronavirus with your children in an honest way, using ability-appropriate language.
- Support children of all abilities with at-home learning and make sure time is set aside for play.
- Help children find positive ways to express feelings such as fear and sadness. Sometimes engaging in a creative activity, such as playing or drawing, can help with this process.
- Facilitate staying in contact with friends and family through telephone and online channels.
- Make sure that your children have time away from screens every day and spend time doing off-line activities together. Try something creative: draw a picture, read a book together, sing or dance, or play in your garden, if you have one.
- Check out these ideas from our partner organizations Casey’s Circle and Hope for HIE:
 - Craft DIY: <https://caseyscircle.org/surviving-covid-19/>
 - Activity ideas: <https://youtu.be/Hs8sEQLM2K8>
 - Low-cost adaptive equipment such as the EasyHold can be useful to include children across all developmental levels to do things like art projects, bake, etc.
 - Find off-peak hours for popular places like zoos, aquariums, nature centers with accessible paths, etc.

Don’t forget to contact your providers to inquire about telehealth options – many routine visits and therapies can be conducted by telehealth.



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