

Neonatal Seizure Registry

Fall 2022

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Hand to Hold

Parent Partner: Katrina

Moline

Casey’s Circle

Parent Partner: Marty Barnes

Hope for HIE

Parent Partner: Betsy Pilon

NSR-DEV Study Progress



Enrollment



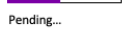
3 yr



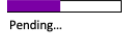
4 yr



5.5 yr



7 yr



8 yr



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

Welcome to the newsletter for the *Neonatal Seizure Registry (NSR)*, which includes updates on all studies led by the NSR group. Thank you for being a part of this important work!

In Loving Memory of Dr. Taeun Chang (1971-2022)

The *Neonatal Seizure Registry* shares in the sadness of the neurology and neonatal communities at the passing of *NSR* investigator Dr. Taeun Chang due to complications from cancer. Dr. Chang was our site investigator at Children’s National Medical Center. She was involved in the *NSR* since its inception in 2012, and her leadership helped bring multiple *NSR* publications, presentations, and grants to fruition. We express our deepest condolences to the family, friends, patients, colleagues, and mentees of Dr. Chang. With gratitude, we remember her tireless efforts to improve the lives of newborns with neurological conditions and the families that care for them. Dr. Tayyba Anwar and Dr. Madison Berl will be taking over as site investigators for Children’s National Medical Center.



NSR-GENE recruitment has started—your family may be eligible!

Children who experience brain injury and seizures as newborns can develop more seizures weeks, months, or even years later, which is a condition called epilepsy. Researchers have identified some reasons why children may develop epilepsy – like severity of the newborn seizures or brain injury – but there are gaps in our knowledge. This new study will collect samples from both biological parents and the child to look for genetic (inherited) risk factors for epilepsy. Samples are easy to collect – a cheek swab for kids and saliva specimen for parents – and can be done during a regularly scheduled clinic visit or in the privacy of your own home. *Even if your child has not experienced seizures since the newborn period, your participation is important!* You may help doctors understand the risk factors for epilepsy, better diagnose and treat children with early life seizure, and develop new treatments to prevent epilepsy. *Local study coordinators will reach out to eligible and interested families soon.*



NSR-DEV – Importance of the In Person Visit!

We have enrolled **189** families and have completed **67** in-person visits. The in-person visit takes place when your child is between 5-6 years old and takes about 1-3 hours. During this visit, a healthcare professional administers two neurodevelopmental assessments at your local participating hospital. After the study visit, you will receive a report that explains the results. **These assessments are key to helping researchers understand the range of strengths and weaknesses of the school age children who had newborn seizures.** To better counsel families, we need to follow as many children as possible! *Please contact your local team to schedule the in person visit. We will do our best to accommodate your schedule and special needs so that your child can participate.*



NSR-RISE Research Study Update

Inflammation is the immune system’s response to injury or infection. The role of inflammation in infants who had seizures during the newborn period is not well understood. Because of this, researchers are studying the relationship between inflammation and seizure severity in infants. This is important because it may help us to better understand whether inflammation and newborn seizure severity affect an infant’s risk for developing epilepsy later in life. We have enrolled **79** participants in Neonatal Intensive Care Units at participating sites across the USA. *If your family is also eligible for our new NSR-GENE study, local study coordinators will reach out soon.*



Results of your participation: Selected Publications



Feeding and Developmental Outcomes After Neonatal Seizures

+ Roberts, K.H, Barks, J.D.E., Glass, H.C., Soul, J.S., Chang, T., Wusthoff, C.J., Chu, C.J., Massey, S.L., Abend, N.S., Lemmon, M.E., Thomas, C., Guillet, R., Rogers, E.E., Franck, L.S., McCaffery, H., Li, Y., McCulloch, C.E., Shellhaas, R.A. *Annals of the Child Neurology Society.*

+ This study assessed the relationship between newborn feeding and development at 2 years of age.

+ Newborns who were not able to take full feeds by mouth by the time they went home from the hospital were at high risk of abnormal development when they reached 2 years of age.

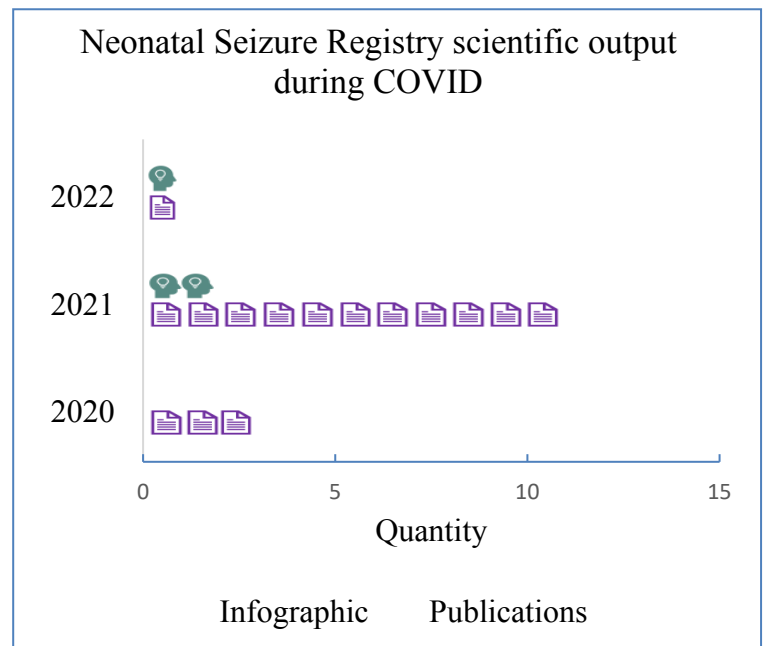
+ At least half of babies who needed tube feeds at discharge were on oral feeds at the 2-year follow-up, which means that many babies taking tube feeds when they leave the hospital do learn to feed orally at home.

+If babies aren’t able to feed by mouth after they go home from the hospital, parents should ask their providers whether an occupational therapy (OT) referral is needed.



Impact of our work together during COVID-19

The past 2-1/2 years of COVID-19 have been challenging for families with young children. Even so, NSR participants continued to contribute to this important work. Because of your time and effort, we have gained insights about how to best treat neonatal seizures and support families. This work has been shared with parents and the health care community through 3 infographics and 15 publications in top medical journals. NSR Investigators presented this work at national conferences such as the Child Neurology Society, American Epilepsy Society and Pediatric Academic Societies. ***Your participation has had a real impact on the care of babies and families affected by neonatal seizures.*** This success would not be possible without your time and effort. We are so grateful and look forward to our future work together.



To learn more about our infographics:



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

Contact us: neuroglasscrc@ucsf.edu

