



# Continued Anticonvulsants After Resolution of Neonatal Seizures: A Patient-Centered Comparative Effectiveness Study

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Welcome to our eighth newsletter for the **Neonatal Seizure Registry (NSR)**. This is the final newsletter for the “Continued anticonvulsants After Resolution of Neonatal Seizures: A Patient-Centered Comparative Effectiveness Study” (NSR-II). We are excited to share the preliminary NSR-II study results with you!

We are grateful for your participation in this study and look forward to working with you on our follow-up study “Neonatal Seizure Registry – Developmental Functional Evaluation” (NSR-DEV).



## Main Findings about Treatment Duration (preliminary)

1. Anti-Seizure medications (usually phenobarbital) were stopped during the hospital stay after about 6 days for 36% of children (“short duration”) and continued for about 4 months in 64% of children (“long duration”).
2. Newborns who had a lot of seizures, complex clinical course, and abnormal neurological exam at hospital discharge were more likely to receive long duration phenobarbital.
3. The risk for abnormal development or epilepsy was the same in the short and long treatment duration groups. *This suggests that short treatment duration is safe.*

**Based on these findings, we will encourage all centers to adopt a “short duration” approach for most newborns with acute neonatal seizures.**

**Want to know more?** Register now to see these results presented by video link to the 2020 Pediatric Academic Societies annual meeting on July 28, 2020: <https://2020.pas-meeting.org/webinar-events-calendar/>

**View** the talk, which will be posted online at the same website after the live presentation.

**Other opportunities:** All study investigators plan to present the work at their local centers during the upcoming academic year.

- PARTICIPATING HOSPITALS**
- UCSF Benioff Children’s Hospital  
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  - C.S. Mott Children’s Hospital  
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- AFFILIATE ORGANIZATIONS**
- Hand to Hold  
Parent Partner: Claire Brown
  - Casey’s Circle  
Parent Partner: Marty Barnes
  - Hope for HIE

### Study Progress



3-mo EEG



12-mo



18-mo



24-mo





## Findings about Parent Well-Being

1. *Parent and family well-being can suffer when newborns have seizures:* Symptoms of anxiety and depression are common and several parent and infant characteristics are associated with poorer parental quality of life and family well-being. *These findings are a call to action to improve mental health screening and services for parents of infants with neonatal seizures.*
2. *Parent experience of caring for neonates with seizures:* Parents shared key challenges at the time of NICU discharge, including navigating uncertainty, adapting family life, and the processing the emotional and physical toll of the NICU experience. Parents also emphasized sources of strength, including agreement among team members, developing a parent-child bond, and participating in their child’s medical care.
3. *Advice for clinicians:* Parents offered advice for members of the health care team in 3 key areas: 1) Understand and validate the parent experience, 2) Communicate information effectively, and 3) Provide support and resources.

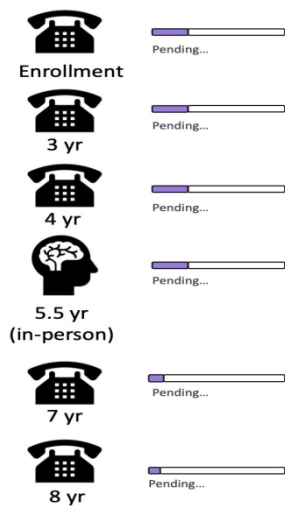
**Next Steps:** Working with our Parent Partner Advisory Panel, we are looking at how parent and family well-being changed over the 2-year study period. We will report those results soon, and then propose new interventions to support parents and families.



## NSR-DEV: Let’s now work together to learn more about longer term outcomes

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 help or hinder success in childhood
3. Early, easily applied and accurate methods to predict childhood impairment after neonatal seizures



Study Measurement	NSR-DEV Follow Up Time Points					
	Enrollment	3 year s	4 year s	5.5 year s	7 year s	8 year s
Medical history review	X	X	X	X	X	X
Parent well-being surveys	X	X	X	X	X	X
Online neurodevelopmental assessments	X	X	X	X	X	X
In-person neurodevelopmental assessments				X		

*Your local team will be in contact with more information soon!*



## NSR-DEV Enrollment begins

Families are already enrolling in NSR-DEV! **Join us today**

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