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

~ funded by Patient Centered Outcomes Research Institute (PCORI) ~

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Welcome to our fifth newsletter for the **Neonatal Seizure Registry (NSR)**. This time last year we welcomed the last family into the study and in April 2019 all participants will have completed their 1-year follow-up! We will continue to follow participants at 18 and 24-month time-points. While we are working toward those milestones, we are in the early stages of analyzing the data from the first time points, sharing those findings, and writing new proposals for funding to continue learning more about neonatal seizures and their effect on child development and family well-being. We will update you about what we learn as we go.

### Our Work



Pictured from left to right: Dr. Shavonne Massey (Children's Hospital of Philadelphia), Dr. Nicholas Abend (Children's Hospital of Philadelphia), Dr. Janet Soul (Boston Children's Hospital), Dr. Renée Shellhaas (Mott Children's Hospital), Dr. Hannah Glass (UCSF Benioff Children's Hospital), Dr. Taeun Chang (Children's National Medical Center), Dr. Adam Numis (UCSF Benioff Children's Hospital).

### Study Progress:



3-mo EEG



12-mo



18-mo

Pending...



24-mo

Pending...

This past October, hundreds of child neurologists and other professionals gathered in Chicago, IL for the 47<sup>th</sup> annual Child Neurology and Society (CNS) Conference. The *Neonatal Seizure Registry* team presented three abstracts: “**EEG Monitoring and Seizure Characteristics of the Neonatal Seizure Registry Cohort of Neonates with Severe Cardiopulmonary Disease**,” “**Seizure Management and Medication Efficacy in the Neonatal Seizure Registry Cohort of Neonates with Severe Cardiopulmonary Disease**” and “**Response to Anti-Seizure Medication in Neonates with Acute Symptomatic Seizures**.” Our study team is dedicated to advancing knowledge about the safety and effectiveness of treating seizures in newborns and understanding how the medical treatment impacts families.



## Data Analysis – What is it like for parents of babies who have neonatal seizures?

We are learning a lot from our first look at the data collected so far. At discharge from the hospital, parents answered questions about their views and experiences of caring for their baby and its impact on their baby and family. Four themes were identified from the 144 parents who participated in the first survey:

- **Sources of strength** (91% of parents): Families highly valued medical team consensus and opportunities to contribute to their child's care. Parents shared that bonding with their baby, and witnessing their developmental and medical progress, brought them joy and hope.
- **Uncertainty** (72% of parents): Parents described three primary types of uncertainty, all of which caused distress: 1) the daily uncertainty of the intensive care experience, 2) concerns about their child's uncertain future, and 3) lack of consensus between members of the medical team.
- **Adapting family life** (67% of parents): Parents described the many ways in which their baby's condition led to adaptations in their family life, including adjusting their family's lifestyle, parenting approach, and routine. Many parents described financial and work challenges due to caring for a child with medical complexity.
- **Emotional and physical toll** (62% of parents): Parents shared their worries, concerns, and fears. Many felt helpless in the face of their child's complex early medical course.

In conclusion, parents of babies with seizures face challenges as they adapt to and find meaning in their role as a parent of a child with medical complexity. Despite these challenges, nearly all parents identified sources of strength. Our next steps are to widely share these findings with healthcare professionals caring for babies with seizures and their families and work with them to develop and test new ways to support parents and promote resilience.



## THANK YOU

*"Program officers from our sponsor (PCORI) are very pleased with the overall progress and high retention rates of our cohort. These achievements are only possible through the willingness and participation of our families. We cannot do this work without your involvement and support. Thank you for your continued participation and for joining the NSR Family!"*

-Renée Shellhaas, MD, MS and Hannah Glass, MDCM, MAS (Co-Principal Investigators)



**For more information about the study, please visit our website:**

<https://www.pcori.org/research-results/2016/continued-anticonvulsants-after-resolution-neonatal-seizures-patient-centered>