Quality Improvement Project: Pediatric Remote Epilepsy Services

Marina Khrizman, DO <> Pediatric Neurology, Jersey Shore University Medical Center
Andrea Racioppi, M.A.T <> VP of Epilepsy, Epilepsy Services of New Jersey
Michelle Gulotta <> Epilepsy Services of New Jersey
Caroline Coffield, PhD <> Training Director, The Boggs Center on Developmental Disabilities

BACKGROUND

Children with epilepsy often have higher rates of neurodevelopmental disabilities (1) and psychosocial stressors that impact their care. Providing appropriate comprehensive resources to help a family cope with their child’s epilepsy has been identified as a potential way improve some of these outcomes and decrease caregiver stress (2). Epilepsy Services of New Jersey (ESNJ) is a non-profit organization that provides various services to help navigate the available resources available to those with epilepsy. Due to the COVID public health emergency, remote rather than in person appointments with an epilepsy services representative from this organization were deemed a good way to trial integrating community services into the epilepsy care delivery model.

METHODOLOGY

Key Driver Diagram, Plan-Do-Study-Act Cycle, IRB non-human Research approval, Meetings with ESNJ representatives

Site: Pediatric Neurology Clinic at Jersey Shore University Medical Center

Aim: Increase the proportion of families of children 0-5 years of age with epilepsy who have completed a remote meeting (audio or audio-visual) with an epilepsy services representative from 0-30% over the next one month and sustain for the next 6 months.

Method: All families of children with epilepsy 0-5 years of age will be offered a connection to an epilepsy services representative using a remote visit with audio only or audio visual technology after their most recent neurology appointment. Families will schedule the appointment themselves with scheduling link/contact information provided.

Scheduling Process:

- Online only calendar platform that is synched to calendar of ESNJ representative and will allow automatic scheduling by patients.
- Neurology nurse sends out program information including scheduling link to families via mail and email after neurology appointment
- Spanish Language Option offered

MEASURABLE OUTCOMES

Primary: Percent of children completing appointments with an epilepsy services representative out of the total eligible patient population

Secondary: Online Family Satisfaction Questionnaire

Epilepsy Services of New Jersey Program Invitation Text

Welcome to Epilepsy Services of New Jersey (ESNJ), we are a nonprofit organization dedicated to helping people with epilepsy and their loved ones across the state of New Jersey. We provide various services to help navigate the resources available to those with epilepsy and their families and improve quality of life, including:

- Information about navigating the education system with epilepsy including Individualized Education Programs (IEP), Special Education, 504 interventions, and early interventions.
- Opportunities to connect with other families affected by epilepsy all across the state so you can build a supportive community.
- A prescription assistance program so that you can get help paying for Anti-Seizure Medications.
- Connecting you or your loved one with helpful seizure alert devices.
- Providing training to educate your family, school, or daycare about recognizing various types of seizures and how to perform first aid if someone is having one.
- Providing referrals to other types of therapy to help control seizures.

Follow this link or scan the QR code below in your camera app to appointment with us to learn more about our organization:

arrangr.com/epilepsyservices

We are happy to have you as part of our ESNJ community and are here to help people with epilepsy and their families live their lives to the fullest!

RESULTS

Program invitations were sent in the first month to six children who met criteria for the project. This include three children seen in the first month and three children from previous months as a trial of the program. No appointments were made by the families of these children.

The project was re-evaluated due to low number of children meeting criteria for 0-5 years of age and low initial participation. Access to the project was expanded to families of children 0-18 years of age with epilepsy. A retrospective chart review of all eligible families in the pediatric neurology clinic over two months was conducted. An additional 18 eligible children were identified and invitations for the program were sent out.

References: