THE PROBLEM

Despite continued progress in the treatment of epilepsy, the psychosocial outcome in adults is reported as poor, even in patients who reach seizure freedom. Rates of psychopathology are high in patients with epilepsy, ranging from 37 percent to 77 percent in children and adolescents with epilepsy. An analysis of 29 cohorts of patients with epilepsy demonstrated increased risk of suicide compared with the general population.

The primary goals of this project are to increase awareness about mental health issues in children with epilepsy; decrease the stigma surrounding mental health care; and educate families, caregivers, schools, peers and the medical community on the need to refer epileptic youths struggling with mental health problems to the appropriate level of care. The program will target children and adolescents with epilepsy in Greater Cleveland.

METHODOLOGY

Cleveland Clinic’s Neurological Institute treats more than 140,000 patients every year, making it one of the nation’s busiest centers for neurological diagnosis and treatment. The institute developed the Knowledge Program® in an effort to enhance quality of life among patients by systematically analyzing this patient volume to improve care and outcomes. This initiative allows us to consistently measure each patient’s illness severity over time and assess the effectiveness of our treatment protocols, while accelerating the collection of electronic data.

The Knowledge Program allows a patient to record a self-assessment directly into his or her electronic medical record (EMR). The EMR contains information that is traditionally gathered by physicians or nurses; however, this method makes the information readily available for future use.
The Knowledge Program will be used to screen for mental health problems in youths with epilepsy. We will develop a triage system to assess, refer and treat the mental health needs of patients with epilepsy, and we will expand our Epilepsy Support Group to improve knowledge about mental health problems in children with epilepsy.

Educational newsletters will be used to increase knowledge about mental health problems in children with epilepsy among doctors who treat this population. We will also partner with the local community to build knowledge among stakeholders and peers.

COORDINATION

We will collaborate with the Epilepsy Association of Cleveland, the Cleveland Metropolitan School District and the National Alliance on Mental Illness – Greater Cleveland (NAMI GC) to increase knowledge about mental health issues in children with epilepsy. A mental health toolkit will be developed and distributed to help improve access to and knowledge of mental health resources for children with epilepsy, and to train families, providers, schools and patients in the problems these children face and how to help them. In addition, curricula targeting the families and the children’s schools will be developed.

WE WANT TO HEAR FROM YOU

- What are some topics that you would like to learn more about?
- What types of issues is your family member with epilepsy currently facing?
- Would you be interested in coming to Cleveland Clinic if we offer educational talks about epilepsy and your child?
- How much does your pediatrician or primary care provider know about the day-to-day struggles that your child with epilepsy has? Is the provider helpful?

If you are interested in participating in Project COPE, please complete the information below and submit it by mail to:

Tatiana Falcone, MD
Cleveland Clinic
9500 Euclid Ave., P57
Cleveland, OH 44195

SPONSORED BY

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PROJECT COPE PARTICIPATION FORM

Child’s Name ______________________________________________________________________________________

Age_______ Grade_______ School ___________________________________________________________________________

Parent’s Name _____________________________________________________________________________________

Email ____________________________________________________________________________________________

Phone Number (_______________) __________________________________________________________________________

Address __________________________________________________________________________________________

City, State, Zip Code ________________________________________________________________________________

For more information and to submit your suggestions, contact Tatiana Falcone, MD, 216.444.7459.