

The Update



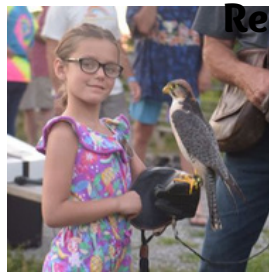
March 2023



Please join us Saturday, March 11, for the 2023 Emerald Miles 5K Run/Walk. Your participation in this event helps Epilepsy Alliance Ohio provide valuable services to our community including: counseling, support groups, community education, group homes, Camp Flame Catcher for youth with epilepsy, an Adult Day Activity Program and much more!

Support people with epilepsy by either running or walking the 5K scenic course that starts at the Purple People Bridge, crosses over the Ohio River, loops through Sawyer Point into Cincinnati and then returns via the Purple People Bridge.

Register [HERE](#).



Camp Flame Catcher Fun

Taylor Huth Memorial Scholarship Program

A college scholarship fund set up by the family and friends of Benjamin "Taylor" Huth to remember and celebrate Taylor's zeal and love for life.

A 1 year, \$2,000 Scholarship honoring local, outstanding students who have:

Overcome or are working to overcome the challenges of epilepsy
Been successful in school

Done well in activities outside the classroom or in the community
Shown a desire to make the most out of college or graduate school



For consideration applications must be postmarked by March 31, 2023.

Self-Disclosure Patterns Among Children and Youth with Epilepsy: Impact of Perceived-Stigma

Lisa M Clifford , Shannon L Brothers, Amy Lang

Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital
Medical Center, Cincinnati, OH, USA

Perceived stigma (i.e., feeling judged or feeling different than others) is common in youth with epilepsy (children, teens, and young adults). For some people with epilepsy, perceived stigma is one of the hardest parts of their illness. To get a better understanding of how perceived stigma impacts youth with epilepsy, we conducted a systematic review of the research in this area.

We found that perceived stigma is more common in youth with epilepsy compared to youth with other chronic illnesses and is associated with lower self-esteem, more difficulty coping with epilepsy, and is a common barrier to youth disclosing (i.e., telling others) their epilepsy. Youth who were reluctant to disclose their epilepsy were also more likely to report loneliness, anxiety about having a seizure in public, feeling different from their peers, less involvement in social activities, and lower quality of life. Barriers to disclosing epilepsy included other's avoiding or discouraging epilepsy-related conversations, youth having insufficient knowledge and understanding of their epilepsy, lack of public awareness about epilepsy, worry about being treated differently by others, and worry about being viewed negatively.

While concealment contributes to perceived stigma and may decrease access to important supports and resources for youth with epilepsy, disclosure, on the other hand, was often associated with greater peer acceptance and support, more positive family communication about epilepsy, more confidence in daily life, more engagement in social activities, higher quality of life and lower perceived stigma.

Large health organizations, like World Health Organization (WHO) and International League Against Epilepsy (ILAE) have highlighted the importance of prioritizing social policy focused on decreasing epilepsy-related stigma, however, progress has been slow and much work remains.

Here is what you can do to help break down stigma and stigma-related barriers! 1) support epilepsy public awareness campaigns including initiatives to mandate epilepsy education in schools; 2) empower youth to learn, ask questions, and educate others about their epilepsy; 3) engage patients in care plan discussions at clinic visits; 4) help youth build their social network through epilepsy-related camps, support groups, and advocacy programs; and 5) emphasize youth's strengths, keep them engaged in developmentally normative activities, and support their efforts to build new strengths and skills.

The entire article can be read here: [Adolescent Health, Medicine and Therapeutics](#)

Save the Dates

March 11 - Emerald Miles 5K Run/Walk

March 24-26 - Camp Flame Catcher

March 31 - Taylor Huth Memorial Scholarship Applications Due

June 23 - Taylor Huth Golf

July 29 - Sand Volleyball

Mission Statement:

Epilepsy Alliance Ohio is dedicated to supporting those in our communities impacted by epilepsy by confronting the spectrum of challenges created by seizures.

Epilepsy Alliance Ohio

895 Central Ave., Suite 550 Cincinnati, Ohio 45202

(513) 721-2905 / (877) 804-2241 / Fax (877) 721-0799

EAO@epilepsy-ohio.org www.epilepsy-ohio.org