The Taylor Huth Memorial Golf Tournament is an annual event that benefits Epilepsy Alliance Ohio and remembers the fun-loving spirit of Taylor Huth, who began having seizures in high school and died at an early age. In spite of being challenged with epilepsy, Taylor was a good-natured young man who would do anything for anyone and was committed to life. Please join Taylor’s family and friends in helping those who have epilepsy continue to live each moment to the fullest and celebrate Taylor’s joy for life, friends and golf!

Foursomes are still available for this golf outing June 7th at Elks Run Golf Course in Batavia, Ohio. The course is both beautiful and challenging and prizes, food and drinks throughout the course will keep everyone entertained. To register, please visit our website at www.epilepsy-ohio.org or call our office at 513-721-2905.

Live @ Polaris Summer Concert Series

For the second year in a row you can support the work of Epilepsy Alliance Ohio while enjoying a mix of free live music at Polaris Lifestyle Center. Our volunteers will be serving up some cold beer at the concerts with all proceeds benefitting our many programs and services. Bring your lawn chair and enjoy an evening for the whole family. Upcoming concerts benefitting Epilepsy Alliance Ohio include:

- June 13 - featuring the band Conspiracy
- June 20 - featuring SWAGG
- August 1 - featuring The McCartney Project
- August 8 - featuring The Reaganomics

Concerts are from 6:45 p.m. to 9:15 p.m. and are held near Barnes & Noble and The Cheesecake Factory.
Froglegs 5K

We are very excited to announce we are partnering with WEBN to host the 1st Annual Frog Legs 5K on Saturday, **August 31**st along Cincinnati’s beautiful riverfront parks. For over 40 years WEBN has hosted the world renowned fireworks show on the Sunday of Labor Day Weekend and are now going to extend the festivities by hosting this 5k the day before. Participants will receive a unique WEBN t-shirt for the race, but they will also be treated to music to rock your socks throughout the course. Additionally the top male and female runners will watch the fireworks show from WEBN’s VIP riverfront tent complete with food and drinks. This is an event that is sure to become a Cincinnati tradition and we are very fortunate that they have chosen Epilepsy Alliance Ohio to receive the proceeds!

To register go to ... rrrrrrrribbit

Columbus Clippers Baseball Game

Thanks to the generous support of Greenwich Biosciences, we are hosting an Epilepsy Awareness Day at Huntington Park on Sunday, **June 23**rd. All participants will be treated to free food and drinks in the Hall of Fame Bar & Grill and then will enjoy a ballgame against the Lehigh Valley iron Pigs. Tickets are limited so call us at 877-804-2241 to reserve yours today.

Sand Volleyball

The fun in the sun continues at Flannagan’s in Dublin as we host our annual Sand Volleyball tournament on **Saturday, July 27**th. This outstanding venue features something for everyone including free use of the pool after the tournament. The courts are filling up so please register early and get the best price at www.epilepsy-ohio.org.
Knights of Columbus again share their Time and Talents

The Knights of Columbus group from St. Francis de Sales Church in Lebanon, Ohio, again gave up a Saturday to beautify the grounds at Benton Home. Their members cut grass, weeded gardens, trimmed bushes, planted flowers and vegetables and left the home looking so much better. We are thankful for their generosity and all they shared with residents at our group home.

If you group would like to make a difference in one of our homes, simply call us at 513-721-2905.

Thank You!

Greetings!

Summer is approaching and we are gearing up for many different opportunities to provide education and awareness to a wide variety of audiences throughout Ohio and Northern Kentucky. With 1 in 26 people being diagnosed with epilepsy at some point in their life, ensuring that your daycare, school, place of employment and places you visit are “seizure safe” means being able to recognize different types of seizures and being able to administer first aid to the person experiencing the seizure. If you are interested in this training or want to recommend training at a specific location, please contact our offices and ask for Steve Hutton or Karen Brown.

Epilepsy Alliance Ohio is the only epilepsy organization in Ohio that provides the extensive in-person and online services free of charge to those living in Ohio and Northern Kentucky. We take pride in working hard to meet the multiple challenges seizures create to those living with epilepsy.

Our staff will answer your calls, meet with you whether in-person or over the phone, and help to educate people in Ohio and Northern Kentucky about epilepsy and seizures. While we provide trainings and support groups online as well, nothing replaces the human contact and the engaging dialog that ensues during face-to-face training, support groups, or counseling sessions.

With a dedicated staff of 62, we are here to help with any challenge you may face. We appreciate your continued support and as always, please feel free to contact us at any time.

Happy Summer,

Kathy Schrag
Ask an Expert: Transition from Pediatric to Adult Care
Dr. Emily Nurre - Assistant Professor
University of Cincinnati Gardner Neuroscience Institute

The transition from pediatric to adult care can be a challenging time for everyone involved: caregivers (family, aides), providers (doctors and nurses) and patients themselves. It can be especially difficult for families who often feel a sense of loss as they leave pediatric providers who have been there since the child’s diagnosis. Adolescents and young adults and their families may have fears about a new healthcare system and need time to adjust and trust new providers during transition. This transition time has additional challenges as adolescents/young adults begin to take more responsibility for their own care instead of their parents. These feelings are natural and there are steps to take to help ease this process and ensure that there is no gap in high quality epilepsy care.

Ideally, we start talking about transition several years before the transition process occurs. Current guidelines suggest that discussion can begin around age 12 but this may vary depending on condition. Discussing transition with your provider early allows for a plan prior to actual transition. For some adolescents/young adults, there may be no need to transition if the epilepsy resolves itself before adulthood. For others, transition to an adult provider is necessary and our goal is to help you develop the skills necessary to make the transition process successful. These skills include things like:

- taking medicine independently
- ordering medicine and knowing what medicines you are allergic to
- making and keeping appointments,
- discussing health issues with your providers

It is important to note that not all patients have the same goals - they are different from patient to patient depending on skill levels. Further information for transition can be found at [https://www.childneurologyfoundation.org/transitions/](https://www.childneurologyfoundation.org/transitions/)

The Epilepsy Transition Clinic is a partnership between Cincinnati Children’s Medical Center and UC Health (two of the largest providers of epilepsy care in the state of Ohio) and will begin this year. We recommend discussing transition by age 16 with your pediatric epilepsy provider and checking skills and goals yearly thereafter. At this age, it is important to start practicing seeing your provider on your own and begin a plan to transition to adult care. We have created an Epilepsy Passport that can be completed by your pediatric provider with a summary of your epilepsy history and treatments to assist in the transition to your adult provider. Adult epilepsy specialists from UC Health see patients at the new UCGNI site in Clifton, West Chester and Florence. It is important to discuss financial and legal needs prior to transition such as guardianship and insurance changes, as well as any other conditions like depression and anxiety that you will need treatment for on the adult side. Early discussion allows for a smooth transition!

Based on input from parents, adolescents, and young adults, it is important to have a friendly face to help during the transition process at the last pediatric and first adult clinic visits. We are very grateful to Epilepsy Alliance Ohio Social Workers, Doug Simmons and Patty Trotta, who have offered to be these friendly faces. We hope to decrease gaps in care by providing a path to adult providers and helping pediatric patients gain independence as much as possible.
Camping Opportunities

Epilepsy Alliance Ohio offers a variety of camping opportunities for the young and old alike. For more information on these programs and to register call our office at 877-804-2241 or email Mark Findley at mfindley@epilepsy-ohio.org

- Camp for Champs Day Camp, June 24-28 at Shane Center in Centerburg, Ohio
- Summer Overnight Camp for Kids, July 14-18 at Camp Kern in Oregonia, Ohio
- Fall Camp for Kids, September 20-22 at Camp Kern in Oregonia, Ohio
- Fall Camp for Adults, September 27-28 at Lutheran Memorial Camp in Fulton, Ohio

Live Epilepsy Educational Programs

Our two full-time community educators (Karen Brown and Steve Hutton) have been busy canvassing the state providing a variety of educational programs to schools, businesses and community organizations. These programs are uniquely tailored to meet the needs of the audience and help bring understanding to this often misunderstood condition. They have recently been to the statewide school nurse conference, EMT convention, The Museum Center, Ken Anderson Alliance, Recreation Unlimited, Stepping Stones Center, a host of schools and much, much more. If you would like to have your school or business seizure safe, please call us.

Peggy Clark, long time board member and CNP in neurology at Cincinnati Children’s Medical Center will present at the OAAPN Statewide conference on October 25th. We look forward to providing these health professionals with the latest treatments and trends in epilepsy care. Thank you Peggy for your service to the epilepsy community.

Recently Dr. Shannon Standridge and Dr. Mark Callow presented an outstanding Facebook Live event at our office that was enjoyed by all in attendance. About 1000 people have viewed the program around the country. They covered treatment options for intractable seizures. Their knowledge, expertise and experience was appreciated by all. If you were unable to watch the program live, you can still see it on our Facebook videos or click here.
We are happy to share that the Gries family in Anderson Township, Ohio, will be hosting a unique fundraiser at their home to benefit our children’s camps on Sunday, **June 30** from 5:00 p.m. to 9:00 p.m. Their home has beautiful grounds that will play host to three live bands, various food trucks, games and much more. This is an event the whole family can enjoy! Bring your lawn chair and blanket and enjoy a fun evening of entertainment. Tickets are $20 each with children admitted free. Parking is available at Mt. Zion Lutheran Church (1175 Birney Lane, 45230) with shuttles taking you to and from the Gries’ home.

**Moms!**

Our Mom’s group is for ALL moms who have kids (young and old) with epilepsy who would like to connect with other moms to share and gain support. You are not alone!

The Mom’s Group meets next on **June 26** at our main office with guest speaker, Dr. Emily Nurre, who will be discussing the topic: “Transition from Pediatric to Adult Care”.

The Mom’s group will continue to meet every other month on the last Wednesday from 6:30 - 8:00 PM. Future dates include **August 28** venue TBD, and **October 30** venue TBD. For more information contact Doug Simmons at dsimmons@epilepsy-ohio.org or call 513-721-2905.

Also, [HERE](#) is a link to a closed Facebook page, Epilepsy Alliance Ohio Mom’s Group, where Moms can share experiences and help parents navigate the epilepsy world.

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**Job Opportunities: Direct Care Workers**

We currently have openings for **2nd Shift Full and Part Time** to work with the residents in our group homes located in the **Batavia and Williamsburg** areas. These positions involve assisting in providing for the resident’s basic needs and following each client’s Individual Habilitation Plan to encourage them to reach their maximum level of independence. Must have a positive attitude and the desire to make a difference in the lives of disabled adults

For more information and to apply go to our [website](#) or call us at 513-744-4543.
**Calendar of Events**

**June 5, 2019 6:00-8:00 PM**
Columbus Adult Support Group: Dempsey Family Education and Resource Center (Silver Tower area of Riverside Methodist Hospital, 3535 Olentangy River Road, Columbus, Ohio 43214) *First Wednesday

**June 12, 2019 5:30-7:00 PM**
Warren County Support Group: Kidd Coffee (653 Reading Rd., Mason, OH, 45040) *2nd Wednesday

**June 12, 2019 6:00-8:00 PM**
Columbus Young Adult Support Group: Dempsey Family Education and Resource Center (Silver Tower area of Riverside Methodist Hospital, 3535 Olentangy River Road, Columbus, Ohio 43214) *2nd Wednesday

**June 12, 2019 6:00-7:30**
Hamilton County Epilepsy Support Group: Epilepsy Alliance’s Main Office (895 Central Ave., Suite 550, Cincinnati, OH 45202) *Usually 3rd Wednesday

**June 19, 2019 6:00-8:00 PM**
Licking County Support Group: Licking Memorial Hospital (Mound View Room, 1320 West Main St., Newark, Ohio 43055) *3rd Wednesday

**June 23, 2019**
Columbus Clippers Baseball Game

**June 24-28, 2019**
Camp for Champs, Centerburg, Ohio

**June 24, 2019 6:30-8:00 PM**
Columbus Parent Support Group and Teen Support Group: Dempsey Family Education and Resource Center (Silver Tower area of Riverside Methodist Hospital, 3535 Olentangy River Road, Columbus, Ohio 43214) *Last Monday

**June 20, 2019**
Barnstock 2019

**June 26, 2019 6:30-8:00 PM**
Mom’s Group: Epilepsy Alliance’s Main Office, Cincinnati, Ohio

**July 3, 2019 6:00-8:00 PM**
Columbus Adult Support Group

**July 10, 2019 5:30-7:00 PM**
Warren County Support Group

**July 10, 2019 6:00-8:00 PM**
Columbus Young Adult Support Group

**July 14-16, 2019**
Camp Flame Catcher, Oregonia, Ohio

**July 17, 2019 6:00-7:30 PM**
Hamilton County Support Group

**July 17, 2019 , 2019 6:00-8:00 PM**
Licking County Support Group

**July 27, 2019**
Sand Volleyball, Flannagans, Dublin, OH

**July 29, 2019 6:30-8:00 PM**
Columbus Parent Support Group & Teen Support Group

**August 7, 2019 6:00-8:00 PM**
Columbus Adult Support Group

**August 14, 2019 5:30-7:00 PM**
Warren County Support Group

**August 14, 2019 6:00-8:00 PM**
Columbus Young Adult Support Group

**August 21, 2019 6:00-7:30 PM**
Hamilton County Support Group

**August 26, 2019 6:30-8:00 PM**
Columbus Parent Support Group & Teen Support Group

**August 28, 2019 6:30-8:00 PM**
Mom’s Group: Epilepsy Alliance’s Main Office, Cincinnati, Ohio

**September 4, 2018 6:00-8:00 PM**
Columbus Adult Support Group

**September 11, 2019 5:30-7:00 PM**
Warren County Support Group

**September 11, 2019 6:00-8:00 PM**
Columbus Young Adult Support Group

**September 18, 2019 6:00-7:30 PM**
Licking County Support Group

**September 20-22, 2019**
Camp Flame Catcher, Oregonia, Ohio

**September 18, 2019 6:00-8:00 PM**
Licking County Support Group

**September 27-28, 2019**
Lutheran Memorial Camp for Adults, Fulton, Ohio

**September 30, 2019 6:30-8:00 PM**
Columbus Parent Support Group & Teen Support Group

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**Executive Director:** Kathy Schrag

**Board of Directors**

**President:** Jake Freyvogel

**Vice President:** Chad Schaefer

**Secretary:** Dale Dean

**Members**

Peggy Clark, Dr. David Ficker, Craig Forrest, Dr. Emily Klatte, Dr. Diego Morita, Matt Salyers, Alyssa Whitt

The Update is a periodic newsletter published by the Epilepsy Alliance Ohio (EOA). The EAO was founded in 1953 to assist people with epilepsy and their families in meeting their multiple health and social needs. We provide direct services to optimize each person’s understanding of epilepsy and to improve their methods of coping with epilepsy in all facets of their lives.
Buckeye’s for Hope OSU Watch Party
Join us at this inaugural event at The Hub on Kenney on Saturday, **September 14**th as our Buckeyes take on the IU Hoosiers. Six TV screens throughout the venue will be broadcasting the game as participants can enjoy some great food, beer and games. All proceeds benefit our programs and services. Space is limited at this unique event, so reserve you ticket today.

**Art Therapy Programs - 2019**

Here we go again! Back by popular demand, Epilepsy Alliance Ohio is proud to offer Art Therapy in both Cincinnati and Columbus to people with epilepsy. This unique program allows participants the opportunity to explore their creativity as a means to express themselves in an open, accepting and safe group setting. Art is a natural way to communicate, relieve tension and express emotions.

Participants will work with licensed art therapists using a variety of artistic media to open up about their individual experiences in epilepsy through visual expression.

The days and times will be released shortly and registration is limited so look for those dates soon. A link for up-to-date information can be found [HERE](#).

For more information contact Doug Simmons at dsimmons@epilepsy-ohio.org or 877-804-2241.

**Mission Statement:**

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

**Epilepsy Alliance Ohio**

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