

# The Update

EPILEPSY  
ALLIANCE  
OHIO

2020, Volume II

## Fundraisers in Flux???

Since the onset of the COVID Pandemic, which occurred the same week as the Emerald Miles, we have had to alter many of our events. As we await direction from our state leaders, we are hopeful we can host our upcoming fundraisers and bring in the necessary revenue to support our programs and services. Tentatively we have the following planned:

**Emerald Miles** has been changed to a virtual run/walk. Register at [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org).



**Run to Erase Epilepsy** has been changed to a virtual run/walk with a possible physical event at a place and date to be determined. Watch for updates! Thanks to Mt. Carmel Health for being the Title Sponsor of this event.

**Taylor Huth Golf Outing** is rescheduled for Friday, September 11, at 9:00 a.m. at Elks Run Golf Course in Batavia. Stay tuned for more information!!!

**Sand Volleyball** Our annual Sand Volleyball tournament will tentatively be held on Saturday, July 25th, at Flannagan's in Columbus, Ohio. This venue provides the perfect location for a fun filled event with great volleyball and a bar to relax at after the event. Thanks to OSU Wexner Medical Center for being the Title Sponsor. Confirmation as to this date or rescheduling will be made on June 1, 2020. Register at [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org).

**Buckeyes for Hope Watch Party** Join us on Saturday, September 12th, as we host our second annual OSU Watch Party. All in attendance will be able to watch the OSU/Oregon game on multiple TV's and enjoy delicious food and plentiful drinks. Gather your friends to support your Buckeyes and people living with epilepsy.



## Ask the Expert: Advanced Treatments for Epilepsy: What To Do When Treatment Isn't Working

Michael Privitera, MD. Professor of Neurology, Director Epilepsy Center, University of Cincinnati Gardner Neuroscience Institute



**If standard treatments for epilepsy haven't worked for you, you are not alone.** Only about half of people with epilepsy will have their seizures controlled with medication. Over 1 million people in the US alone are considered to have medication resistant seizures where trials of at least 2 appropriately chosen anti-seizure medications don't stop the seizures. It is the role of the Epilepsy Center to provide advanced treatment options for medication resistant seizures including making an accurate diagnosis of seizure type, then choosing among the latest medications, epilepsy surgery, stimulation devices or dietary therapy to treat seizures.

**The most important first step in treating seizures is getting an accurate diagnosis.** The inpatient Epilepsy Monitoring Unit (EMU) is the core of the Epilepsy Center. In the EMU, seizures are recorded on simultaneous video and EEG under close supervision. The EMU evaluation accurately identifies seizures that are focal (start in a particular part of the brain and then spread) vs. those that are generalized (start in the whole brain at once)—this is critical in choosing the right medication or in determining who might be a candidate for surgery or stimulation devices. Many people who come into an EMU find out that the source of the problem is not epilepsy—it may be a heart problem or a stress reaction that looks just like a seizure.

**Many new anti-seizure medications have been introduced in the past decade.** None of these medications is a cure-all for everyone, but some are better at controlling seizures, some have fewer side effects, and some treat both focal and generalized onset seizures. Even though the odds of stopping seizures completely are low after failing two anti-seizure medications, the experts at the Epilepsy Center may be able to match someone's seizures with one of the new medications and get better results.

**Two new treatments are attracting lots of attention recently.** Cannabidiol (CBD) is the component of marijuana that does not have the psychotropic effects but has been proven effective against seizures in several rigorous clinical studies. The FDA approved cannabidiol in liquid form as Epidiolex for treatment of seizures associated with two severe epilepsy syndromes: Dravet Syndrome and Lennox Gastaut Syndrome. There are also studies indicating CBD may work for many different seizure types. It is confusing that there are multiple different sources of CBD that may vary in quality. Epidiolex is FDA approved, is available through specialty pharmacies, and may be covered by insurance. State medical marijuana dispensaries also have CBD products available, but many of the products also contain THC, which is not needed for anti-seizure effect and may produce unwanted side effects. Health insurance will not cover medical marijuana from state dispensaries. CBD products can also be purchased on-line, but there is great variability among different on-line sellers based on analysis of products. Anyone wanting to try CBD should do so under the guidance of their doctor. Another new anti-seizure medication generating interest is carisbamate (trade name Xcopri). This medication was approved by the FDA recently and is expected in pharmacies in mid-2020. In clinical trials, the proportion of people who became seizure free was very high compared to similar studies of older medications. Once a larger number of people try this medication we will see if equally good results are seen.

**New advances in epilepsy surgery have made surgery more effective and safer than ever before.** Epilepsy Centers have taken advantage of improvements in brain imaging, EEG technologies, surgical techniques, and laser technology to improve surgical outcomes. Successful surgery depends on precise localization of the site of seizure onset (the "seizure focus") and precise mapping of critical brain functions like speech, movement and memory. Advanced brain imaging techniques have dramatically improved brain mapping for surgery. The newest addition is laser ablation of the seizure focus. In this procedure, a tiny hole is drilled in the skull and a thin catheter with a laser tip is placed at the seizure focus. The laser heat ablates the seizure focus and stops seizures. Laser ablation has reduced complications from surgery and may be appropriate for many people with focal seizures.

**Stimulation devices can reduce seizures for people where medications have not worked and who are not a candidate for laser or resective surgery.** Vagus Nerve Stimulation (VNS) was FDA approved in 1997 and helps control focal seizures. The Responsive Neurostimulator (RNS) is implanted on the brain area where seizures start and sends an electrical impulse when it detects a seizure beginning. The RNS requires precise localization of the seizure focus and the electrodes remain on or in the brain for years. Deep Brain Stimulation (DBS) has been used for years for Parkinson's Disease but was FDA approved more recently for focal seizures. DBS is implanted in deep brain structures that may be distant from the actual seizure focus, and unlike RNS is not triggered by seizures, but rather provides ongoing stimulation throughout the day and night.

**When surgery isn't possible, or instead of surgery for some people, trying a special diet may help control seizures.** The most common types of diets currently being used are the ketogenic diet or the modified Atkins diet. These diet treatments should be prescribed and followed by an epilepsy specialist and nutritionist. Dietary treatment is mostly used in children, but may work in some adults who don't respond to medicine. Usually people on a diet treatment continue to take anti-seizure medications.

Advanced treatments for epilepsy allow more people hope for seizure control. Find out if one or more of these treatments may help you or your loved one by contacting an Epilepsy Center. The Epilepsy Center of the University of Cincinnati Gardner Neuroscience Institute has a world class team that has been helping people with difficult to control epilepsy since 1987, and has expertise in all these options.

## *Greetings!*

Hello! I hope you all are healthy and staying safe. While it is difficult adjusting to all of the changes we are facing due to the COVID-19 pandemic, my hope is that you all are enjoying extra time with family and a more quiet change of pace.

Epilepsy and the effects of epilepsy continue on during this pandemic. The needs of our families are still there and some needs have actually increased. These are truly unprecedented times and we are doing our best to adapt to providing these increased services, while maintaining physical distance. It is definitely creating challenges for Epilepsy Alliance Ohio as we have had to cancel or postpone programs, trainings, camp and fundraising events.

Our Community Programs are fully funded by our fundraising events, individual grants and donations. We rely on our events and donations to ensure that we are able to provide the vital programs and services to those living in our communities affected by epilepsy. Due to the uncertainty of our economy, we have watched our donations drop considerably. People are having to make cuts in their own budgets due to changes in their employment and not knowing what their future holds. We completely understand. This does put a tremendous strain on our budget and cash flow. However, we are still here, providing as much help and assistance as possible to anyone in need.

Our social workers and counselors are still holding support groups through Zoom meetings. We have added some additional times to accommodate more individuals. We have also added a Dad's Support Group to our list of support groups. Please let us know if you would like to participate and we will email you the link. If you "like" us on Facebook and Twitter, you can see the posts with the dates and times of the groups.

We were so sad to cancel our Spring Camp Flame Catcher weekend camp. We know how much the campers love and depend on camp, so we held our first Zoom Camper Visit and had close to 50 campers and counselors on the call. With such a great turnout, we will continue to offer these visits so the kids can continue to have that opportunity to connect with their friends! We are coming up with ways to be able to continue to support the kids to give them what they are needing so they are not feeling so isolated.

Another area that has been very difficult for families is the transition to remote learning. With many children on 504 plans or IEP's, parents are struggling with working from home and working with their children and their special needs. Our staff is working with families, through Zoom, in assisting with school work and helping work through these issues. Additionally, our social workers are continuing to attend the IEP meetings with families. Please reach out to us if you would like us to attend these meetings with you as well.

In order to be able to continue to find innovative ways to help families and advocate for their needs, we need to be able to retain our staff. Without the staff, we can not provide the much needed services. In order to retain the staff, we have to have the revenue stream and cash flow to continue to meet payroll needs. This is becoming increasingly difficult as we have had to cancel or try to postpone events. We have our events throughout the year to help with these budget issues. The fall will continue to be very busy for us as we already have other events scheduled. We are thinking of creative ways to keep everyone involved and supporting us as we continue to support those living with epilepsy. You will find several of these ideas on the pages of this issue!

I would like to give a big shout out and THANK YOU to our dedicated Residential Managers and Direct Care staff who are working tirelessly to provide the best possible care to the individuals living in our Residential Facilities. They have worked very hard to implement the ever-changing guidelines being issued by the state, while being very sensitive to the needs of staff and residents. This has been very hard on the residents as they may not quite understand why they can not visit with family or go out into the community. So, please, if you come in contact with people who work in residential group homes, be sure to thank them for their dedication and hard work!!

Please know how much we appreciate you and thank You for your continued support!

*Kathy Schrag*

Executive Director - Epilepsy Alliance Ohio



**COVID-19 Healthy at Home TOP 10 Self-Care Tips** - Steve Hutton, Director of Community Education

COVID-19 has caused us to move away from the old normal and to create a new normal. To help us and our families handle this new change, we have to focus on our own Self-Care. One thought to begin your Self-Care journey is that you need to give yourself credit for the days that you made it through when you thought you couldn't.

While doing research on the topic of Self-Care during COVID-19, I found some tips from psychologist Margie Donlon. Her tips for Self-Care are some of the very best that I found. To help us thrive during the COVID-19, Epilepsy Alliance Ohio presents the following TOP 10 Self-Care tips for our community.

Find something you can control, and control the heck out of it. In moments of big uncertainty and overwhelming emotions, control your little corner of the world. Organize your bookshelf, purge your closet, put together that furniture, group your toys. It helps to anchor and ground us when the bigger things are chaotic.

Limit social media and COVID conversation, especially around children. One can find tons of information on COVID-19 to consume, and it changes minute to minute. The information is often sensationalized, negatively skewed, and alarmist. Find a few trusted sources that you can check in with consistently, limit it to a few times a day, and set a time limit for yourself on how much you consume (again 30 minutes tops, 2-3 times daily). Keep news and alarming conversations out of earshot from children—they see and hear everything, and can become very frightened by what they hear.

Help others. Find ways, big and small, to give back to others. Support restaurants, offer to grocery shop, check in with elderly neighbors, write psychological wellness tips for others—helping others gives us a sense of agency when things seem out of control.

Find a long-term project to dive into. Now is the time to learn how to play the keyboard, put together a huge jigsaw puzzle, start a 15 hour game of Risk, paint a picture, read the Harry Potter series, binge watch an 8-season show, crochet a blanket, solve a Rubix cube, or develop a new town in Animal Crossing. Find something that will keep you busy, distracted, and engaged to take breaks from what is going on in the outside world.

Engage in repetitive movements and left-right movements. Research has shown that repetitive movement (knitting, coloring, painting, clay sculpting, jump roping etc) especially left-right movement (running, drumming, skating, hopping) can be effective at self-soothing and maintaining self-regulation in moments of distress.

Find an expressive art and go for it. Our emotional brain is very receptive to the creative arts, and it is a direct portal for the release of feelings. Find something that is creative (sculpting, drawing, dancing, music, singing, playing) and give it your all. See how relieved you can feel. It is a very effective way of helping kids to emote and communicate as well!

Find lightness and humor in each day. There is a lot to be worried about, and with good reason. Counterbalance this heaviness with something funny each day: cat videos on YouTube, a stand-up show on Netflix, a funny movie—we all need a little comedic relief in our day, every day.

“Chunk” your quarantine, take it moment by moment. We have no road map for this. We don't know what this will look like in 1 day, 1 week, or 1 month from now. Often, when I work with patients who have anxiety around overwhelming issues, I suggest that they engage in a strategy called “chunking”—focusing on whatever bite-sized piece of a challenge that feels manageable. Whether that be 5 minutes, a day, or a week at a time—find what feels doable for you, and set a time stamp for how far ahead in the future you will let yourself worry. Take each chunk one at a time, and move through stress in pieces.

(continued)

Remind yourself daily that this is temporary. It seems in the midst of this quarantine that it will never end. It is terrifying to think of the road stretching ahead of us. Please take time to remind yourself that although this is very scary and difficult, and will go on for an undetermined amount of time, it is a season of life and it will pass. We will return to feeling free, safe, busy, and connected in the days ahead.

Find the lesson. This whole COVID-19 experience can seem sad, senseless, and at times, avoidable. When psychologists work with trauma, a key feature to helping someone work through said trauma is to help them find their agency, the potential positive outcomes they can effect, the meaning and construction that can come out of destruction. What can each of us learn here, in big and small ways, from this experience? What needs to change in ourselves, our homes, our communities, our nation, and our world?

Here's one extra Self-Care tip that you may want to incorporate into your daily routine. Each night before your children go to bed, remind them that today was rough. We will try again tomorrow. Remind your children of your endless love for them, and give your heart a rest because not everyday can be easy. We will have days that wear on us. Be gentle to yourself. Be gentle to your children, and just try again tomorrow.

Remember, before we can take care of everybody else, we have to take care of ourselves first. Additional Self-Care tips can be found on the following Epilepsy Alliance Ohio social media platforms or Facebook, Epilepsy Alliance Ohio Mom's Group, LinkedIn, Twitter, and Instagram. If Epilepsy Alliance Ohio can be of support to you, please reach out to our office at 513-721-2905.



# Camp Corner

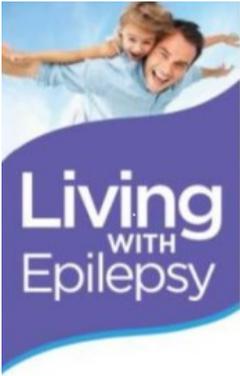
Presently we have the following camps scheduled. Please check our website for status updates.

**Camp for Champs Day Camp** to take place the week of June 29 – July 3 at Shane Center in Centerburg, Ohio. This five-day camp runs from 9:00 a.m. to noon daily and offers instruction in horseback riding and other activities centered around the farm. Registration is limited to only 10 campers and there are only a few slots left. Call today at 877-804-2241 to reserve your spot.

**Camp Flame Catcher Summer Camp** to take place the week of July 12-16 at Camp Kern. Campers will spend the night and take part in a host of activities ranging from canoeing and swimming to horseback riding, crafts, games and so much more. To register call 877-804-2241.

**Fall Kids Weekend Camp** will take place the weekend of September 25-27 at Camp Kern. The fall is a perfect time to camp and during this weekend the kids will be hiking, canoeing, horseback riding and much more. Don't delay in registering!

**Fall Adult Weekend Camp** The weekend of October 23-25 we will gather at Lutheran Memorial Camp north of Columbus for a great time in the outdoors. Limited to only 10 adults this camp is filled with crafts, games, hiking and much more. It is a great time to relax, make friends and rekindle old friendships. Call our office at 614-725-1031 to register.



## Living with Epilepsy Conferences

This fall we will be offering two Living with Epilepsy Conferences across the state to educate and inform on the latest topics related to epilepsy.

**Dayton:** Join us on Friday September 18th from 8:00 am to 2:30pm for this informative conference for professionals, caregivers, and anyone interested in learning more about living with epilepsy! Presented in partnership with Premier Health. This conference will be held at Miami Valley Hospital in the Berry Building Auditorium located at 1 Wyoming Street, Dayton, Ohio. CME's available.

**Columbus:** On Saturday, October 3rd we will be hosting our annual Living Well with Epilepsy Conference in Columbus at Riverside Methodist Hospital. The brochure for this event is still being developed and will be put on our website once it is ready. Expect great presentations from doctors at OSU, OhioHealth, Mt. Carmel Health and Nationwide Children's.

### Support Groups

One of the biggest challenges to attending support groups has always been the ability to physically get there, especially for those affected by epilepsy who may not be able to drive themselves. Covid-19 has presented us with an opportunity to expand our ability to offer support groups to a wider geographic area than ever before. Through the use of Zoom, people in all parts of our service area and beyond are welcome to join whichever group works best for you. The dates and times are all listed on the next page. Zoom allows you to connect with other people with similar challenges and successes, and find, share and offer support where needed. We look forward to reconnecting in-person at our various locations but will also be continuing a number of Zoom Support Groups to fulfill the needs of those we serve. Until then, we invite you to take part in a group in front of your smart phone, computer, or simply call in by voice-only. Be sure to check Facebook or call our office for up to date times and the link or call-in informations.

**Please note: ALL upcoming support groups will be via Zoom only until Covid-19 restrictions are lifted.**

**Epilepsy Alliance Ohio proudly recognizes two employees who have each reached their 25 years of service in 2020!!  
Thank you for your 25 years of dedicated service!!**



**Patty Trotta**

**Director of Counseling and Professional Education**



**Trina Umberg**

**Residential Activities Director**

# Calendar of Events

**Please note: ALL upcoming support groups will be via Zoom only until Covid-19 restrictions are lifted.**

**May 4, 2020 6:00-7:30 PM**

Dayton Adult Support Group  
\*1st Monday

**May 6, 2020 6:00-8:00 PM**

Columbus Adult Support Group  
1st Wednesday

**May 13, 2020 5:30-7:00 PM**

Warren County Support Group  
\*2nd Wednesday

**May 13, 2020 6:00-8:00 PM**

Columbus Young Adult Support Group  
2nd Wednesday

**May 14, 2020 2:00-3:30 \*\*NEW\*\***

All Epilepsy Support Group  
\*2nd Thursday

**March 15, 2020**

**Emerald Miles 5K Run/Walk - Virtual**

**May 18, 2020 6:30-8:00 PM**

**\*\*NOTE DATE CHANGE\*\***

Parent Support Group  
\*Last Monday

**May 20, 2020 6:00-7:30**

Hamilton County Epilepsy Support  
Group \*3rd Wednesday

**May 28, 2020 7:00-8:30 \*\*NEW\*\***

Dad's Epilepsy Support Group  
\*Last Thursday

**June 1, 2020 6:00-7:30 PM**

Dayton Adult Support Group

**June 3, 2020 6:00-8:00 PM**

Columbus Adult Support Group

**June 10, 2020 5:30-7:00 PM**

Warren County Support Group

**June 10, 2020 6:00-8:00 PM**

Columbus Young Adult Support Group

**June 11, 2020 2:00-3:30**

All Epilepsy Support Group

**June 17, 2020 6:00-7:30**

Hamilton County Epilepsy Support

**June 25, 2020 7:00-8:30**

Dad's Epilepsy Support Group

**June 27, 2020**

**Run to Erase Epilepsy - Columbus, Ohio**

**June 29, 2020 6:30-8:00 PM**

Parent Support Group

**July 1, 2020 6:00-8:00 PM**

Columbus Adult Support Group

**July 6, 2020 6:00-7:30 PM**

Dayton Adult Support Group

**July 8, 2020 5:30-7:00 PM**

Warren County Support Group

**July 8, 2020 6:00-8:00 PM**

Columbus Young Adult Support Group

**July 9, 2020 2:00-3:30**

All Epilepsy Support Group

**July 15, 2020 6:00-7:30**

Hamilton County Epilepsy Support

**July 25, 2020**

**Sand Volleyball - Columbus, Ohio**

**July 27, 2020 6:30-8:00 PM**

Parent Support Group

**July 30, 2020 7:00-8:30**

Dad's Epilepsy Support Group

**August 3, 2020 6:00-7:30 PM**

Dayton Adult Support Group

**August 5, 2020 6:00-8:00 PM**

Columbus Adult Support Group

**August 12, 2020 5:30-7:00 PM**

Warren County Support Group

**August 12, 2020 6:00-8:00 PM**

Columbus Young Adult Support Group

**August 13, 2020 2:00-3:30**

All Epilepsy Support Group

**August 19, 2020 6:00-7:30**

Hamilton County Epilepsy Support

**August 27, 2020 7:00-8:30**

Dad's Epilepsy Support Group

**August 31, 2020 6:30-8:00 PM**

Parent Support Group

  
*Executive Director:* Kathy Schrag

Board of Directors

*President:* Jack Freyvogel

*Vice President:* Alyssa Whitt

*Secretary:* Dale Dean

*Treasurer:* John Wood

*Member at Large:* Chad Schaefer

Members

Peggy Clark, Dr. David Ficker,  
Craig Forrest, Michael Loewenstein,  
Darcy Perry

  
The Update is a periodic newsletter published by the Epilepsy Alliance Ohio (EAO). 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.



We would like to extend our sincere **Thank You** to the following people and companies for the generosity shown to our agency during these unprecedented times. They have helped the frontline workers who care for our clients in our group homes remain healthy and safe in our time of need.



**-Totes Isotoner Corporation** and **Ben Miller** for donating 150 ponchos to serve as protective gowns.

**-Saturday Knight LTD** and **Ron Hood** for donating 50 masks

**-3M** and **Mike Chatlos** for donating 8 N-95 masks

**-Matthew Ministries** for donating 50 disposable masks, 3 boxes of hand sanitizer, a case of AA batteries and 3 boxes of disinfecting wipes.

**-Melanie Clark, Peggy Clark, and Tracy Clark** for donating homemade masks.

**-Richell Mcevoy** for donating 37 masks.

### 2020 Scholarship Recipients

We are happy to announce that three young adults with epilepsy have been chosen to receive our Taylor Huth Memorial Scholarship to assist them in college this fall.

**Ellie Hall** is graduating this spring from Badin High School and is looking to pursue a degree in Education, hoping to teach children with special needs

**Samuel Howard** is graduating this spring from Bishop Brossard High School in Northern Kentucky and focusing on a degree in Mechanical Engineering

**Logan Schlachter** is graduating this spring from Ayersville Local Schools in Defiance, Ohio. He has been an honor student and involved in many extra-curricular activities.

We congratulate these three young adults on winning this award and wish them the best as they head off to college.

We would like to thank the family and friends of Taylor Huth and the many players and sponsors at our annual golf outing that make this award possible.

### **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, OH 45202 ◇ Phone: (513) 721-2905 / (877) 804-2241 ◇ Fax: (513) 721-0799

E-mail: [eao@epilepsy-ohio.org](mailto:eao@epilepsy-ohio.org) ◇ Web address: [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org)