

The Update

**EPILEPSY
ALLIANCE**
OHIO

2020, Volume I

Stroll for Epilepsy

A Family Friendly Walk

Please join us on Saturday, **January 25th** in Columbus, Ohio at Polaris Fashion Place for our annual Stroll for Epilepsy. This unique event gives participants the opportunity to stroll throughout the mall to visit various treasure stops to learn about epilepsy and get a chance to win prizes. All participants receive a t-shirt and food, drinks and music are available after the walk. There is also a silent auction and a photo booth. This event is fun for the whole family.

We encourage you to set up a team on our event website at epilepsy-ohio.org/events/stroll-for-epilepsy . From there you can invite family and friends to join you in the walk or donate to support our cause. Together we can make this our best year ever for the Stroll for Epilepsy.

Saturday, March 14, 2020

Emerald Miles 5K Run/Walk at Newport on the Levee.

This annual event is a great way to support people living with epilepsy. Gather your family and friends to start a team/fundraiser for a great cause and have fun walking or running in this event. Simply click on the [registration link](#) to register and set up a team. All participants will receive a t-shirt, can enjoy music, food and drinks after the event. This beautiful course is along the Ohio River!



**Emerald
MILES**
5K RUN/WALK
IN LOVING MEMORY OF DENNIS STEMLER



Ask the Expert: Comprehensive Epilepsy Center of Dayton at Premier Health

Barbara Phillips, MD

Medical Director: Comprehensive Epilepsy Program of Dayton, Clinical Neuroscience Institute, Wright State University / Premier Physician Network



The Comprehensive Epilepsy Center of Dayton at Premier Health is the only NAEC accredited for adults in Dayton. As a Level 3 Adult Epilepsy Center, we provide specialized comprehensive care for patients with epilepsy. A multidisciplinary group of fellowship trained epileptologists, functional neurosurgeon, neuropsychologist, neuroradiologist, advanced practice providers, nurses, and electroneurodiagnostic technologists collaborate to provide specialized care for patients with epilepsy.

Our fellowship trained epileptologists specialize in the care of patients with refractory epilepsy including those who may need surgery for epilepsy as well as special populations including women with epilepsy and seizure patients with traumatic brain injury. Individualized treatment options may include medication management, nutrition therapies, and referrals to additional support services. In some patients, surgical treatment options may be considered. Advanced diagnostics with admission to the Epilepsy Monitoring Unit (EMU) at Miami Valley Hospital (MVH) may be utilized to assist in making an accurate diagnosis and determine the best treatment options for individual patients. There is an epilepsy support group hosted by Epilepsy Alliance Ohio at Miami Valley Hospital monthly.

In patients who are being evaluated for consideration of surgery, a thorough diagnostic evaluation is performed including advanced neuroimaging, EMU evaluation, and brain mapping/neurocognitive assessment at the Brain Mapping Center. All patients being considered for surgical intervention are discussed in a multidisciplinary case conference to review results of testing and provide individualized recommendations. Surgical treatment options offered include:

- Placement of Vagus nerve stimulator (VNS), which can be used as a tool to prevent or decrease seizures by sending pulses of electric energy to the vagus nerve.

- Minimally invasive laser ablation to seizure focus in brain using the MRI guided technology, Visualase TM.

- Open surgery to remove the portion of the brain to remove the seizure focus.

- Surgical placement of short term intracranial EEG leads may be recommended during evaluation to identify precise seizure focus and assist with additional surgical planning.

We have five epileptologists who see patients at Clinical Neuroscience Intitute locations in Dayton, Englewood, Middletown, and Troy.

For more information about the Comprehensive Epilepsy Center of Dayton at Premier Health and to schedule an appointment call (937) 208-4200.

Greetings!

This year has gone extremely fast! With Epilepsy Awareness Month coming to an end, and the Holidays upon us, is so important to be thankful for our blessings. Over the course of the past year, we have triumphed with many and have cried with some. Epilepsy is hard. It is unpredictable and can be scary. However, through it all we have seen such resilience in children, teens and adults living with epilepsy. I just finished reading a powerful book written by Kurt Eikenwald called "A Mind Unraveled." Kurt is a writer for the Washington Post who is living with epilepsy. This book tells his story of the difficult, sometimes horrific journey of being diagnosed and treated for epilepsy. It tells the perspectives of his friend, parents, sibling, wife and physicians. If you have not read it and would like a free copy of the book, please contact us at 513-721-2905. This book truly show and further reiterates the need for raising awareness, education and advocacy on all levels.

As we enter in to 2020, lets all work together to raise awareness and help us reach more people. "[Like](#)" us on Facebook. Follow us on Instagram and Twitter. Share us and our posts with your friends and family. If you have a story to tell be sure to reach out to us so we can share. We are in the world of epilepsy together. Lets raise awareness to a new level in 2020.

Wishing you all a very Happy Holiday Season!

Kathy Schrag



Sand Volleyball



Barnstock 2019

Christmas Party



Seize Hope Gala

Taylor Huth Memorial



FACEBOOK Live – Check out our website at www.epilepsy-ohio.org for archived Facebook educational programs we have hosted in the past year. They are filled with valuable information that sheds light on issues surrounding epilepsy. These include Dr. Freedman's talk on CBD, Dr. Nurre and Dr. Modi's talk on Transitional Services and much more. You can enjoy these talks in the comfort of your home while being educated by some of the top doctors in the field.



Taylor Huth Scholarship Fund

The Taylor Huth Scholarship Fund was established by the family and friends of Benjamin "Taylor" Huth to remember and celebrate Taylor's zeal and love of life. This is a one year, \$1,500 scholarship honoring local college-bound students or students already in college who have epilepsy. Go to our website at www.epilepsy-ohio.org to find information and to apply. Be sure to include ALL the requested information. Every year someone misses out on this scholarship because of a lack of documentation.



Applications for the 2020 scholarship are due
Friday, February 21, 2020.

Scholarship awards to be announced at Emerald Miles March 14th.

UCB will offer 30 scholarships of up to \$5,000 and 3 scholarships of up to \$10,000 to people living with epilepsy, their family members and caregivers pursuing higher education.

Thirty applicants who demonstrate academic and personal achievement will receive scholarships of up to \$5,000 each. Two applicants will receive Epilepsy Leader Scholarships of up to \$10,000 each, and one applicant will receive the Joe D'Souza Memorial Scholarship of up to \$10,000. This scholarship was created in 2019 in memory of UCB's Global Medical Director.

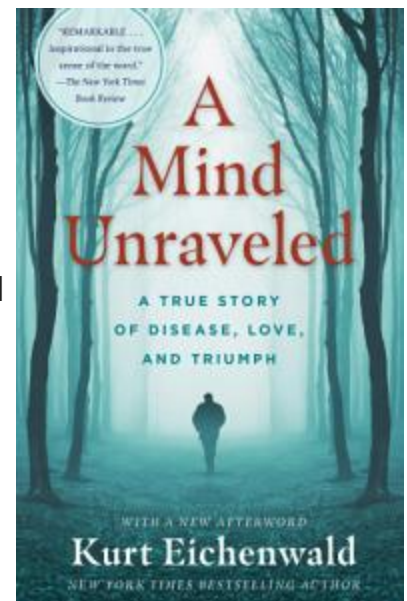
For more information check out the [program details](#) and [FAQs](#).

Applications for the 2020 scholarship are due
Wednesday, February 5, 2020.



[A Mind Unraveled](#) - Through a partnership with Epilepsy Alliance America and SK Life Science we are offering a free of copy of the book, A Mind Unraveled. This true story by New York Times bestselling author Kurt Eichenwald is a book that everyone in the epilepsy community needs to read. The story of a young man confronted by a debilitating brain disorder, who, through personal resilience and the support of loved ones, overcame medical incompetence and institutional discrimination to achieve once unthinkable success. Once you start this book, you will not want to put it down.

To receive your free copy, simply stop in one of our offices at 895 Central Ave., Suite 550, Cincinnati, Ohio 45202 OR 3857 North High St., Columbus, Ohio 43214.



Camp Corner

Camp 2020 - Epilepsy Alliance Ohio has been happy to offer a camp program for close to 25 years. During this time campers have had the chance to enjoy the beautiful outdoors while learning that they are not alone in living with epilepsy. The friendships formed at camp have been instrumental in helping people overcome the challenges which seizures present and have formed lasting bonds. Our camps range from overnight camps for kids to a day camp that specializes in horseback riding to a weekend camp for adults. Because of the generous support of our donors, we have never had to turn anyone away from camp because they cannot pay. To take part in our camps in 2020, simply call our office at (513) 721-2905 or email mfindley@epilepsy-ohio.org.

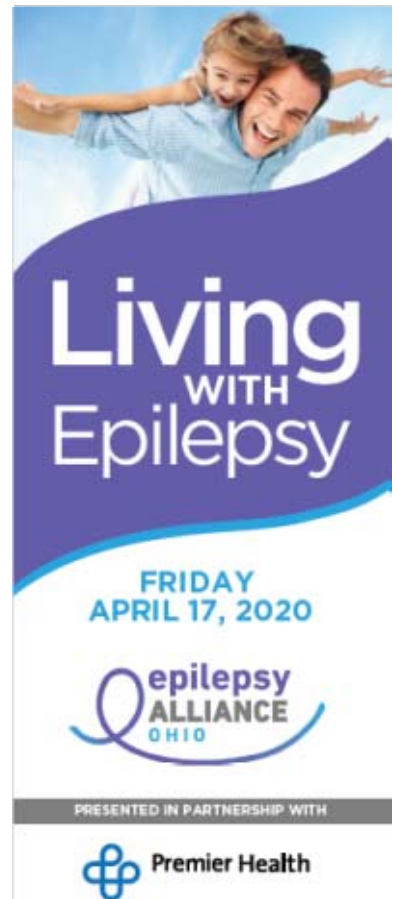
Spring Camp for Kids - March 27-29, 2020

Day Camp in Northern Columbus - June 22-26, 2020

Residential Summer Camp - July 12-16, 2020

Fall Camp for Kids - TBD

Fall Camp for Adult - September



Living with Epilepsy Conference coming to Dayton, Ohio this spring!!!

Mark your calendar for **Friday April 17th** as Epilepsy Alliance Ohio and Premier Health host a seminar that will educate participants on the latest treatments and trends in epilepsy. This conference will be geared to the person living with epilepsy, parents and caregivers and professionals in the field. CME's will be offered.

Stay tuned for more details...



Let's all stand together around these numbers!

We all know the significance of 1 in 26. Many of us live with it daily and deal with the ever present impact of seizures, side effects and the unpredictability of when the next seizure may occur. To show that we are standing with you, we are hosting a special family event on **Sunday, January 26, 2020**, (1/26 clever, right?) at [Rotolo Bowling Alley at Newport on the Levee](#). This event will feature bowling, a delicious buffet and plenty of time for fellowship and fun with others who share the diagnosis of epilepsy. The event is **free** thanks to our friends at [Greenwich Biosciences](#); however we ask that you RSVP to 513-721-2905 so we can plan accordingly.

Please call our office at 513-721-2905 to reserve your spot and, as mentioned above, family members are welcome. The event will go from Noon to 3 at Rotolo, 1 Levee Way, Newport, KY.

ATTENTION YOUNG ADULTS

Recently our Young Adult Group in Cincinnati has begun to meet on a regular basis. They met for pizza at Mellow Mushroom and a trip to the Festival of Lights at the Zoo. If you are 16 and over and would like to meet others who have epilepsy, please call our office at (513) 721-2905.

We would be happy to have you join us for our next adventure!

Moms – We are happy to share that a Mom's Group has been meeting on a regular basis in both Cincinnati and Columbus. They gather for food, fellowship and sometimes a unique activity such as wreath making, ax throwing or pottery painting. If you would like to join wither one of these groups or be a part of their private Facebook page, please call our office at (513) 721-2905.



Job Opportunities: Direct Care Workers

We currently have **2nd and 3rd shift opportunities, with full and part time** positions available to work with 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 513-721-2905.

Calendar of Events

January 6, 2020 6:00-7:30 PM

Dayton Adult Support Group: Miami Valley Hospital, Northwest Conference Room 6NW3 (30 East Apple Street, Dayton, Ohio 45109) * Normally First Monday

January 8, 2020 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) * Normally First Wednesday

January 8, 2020 5:30-7:00 PM

Warren County Support Group: Kidd Coffee (653 Reading Rd., Mason, OH, 45040) *Normally 2nd Wednesday

January 15, 2020 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) *Normally 2nd Wednesday

January 15, 2020 6:00-7:30

Hamilton County Epilepsy Support Group: Epilepsy Alliance's Main Office (895 Central Ave., Suite 550, Cincinnati, OH 45202) *Normally 3rd Wednesday

January 25, 2020

Stroll for Epilepsy - Columbus, Ohio

January 25, 2020

Taylor Huth Memorial Scholarship Deadline

January 26, 2020

1 in 26 - Rotolo - Newport, Kentucky

January 27, 2020 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

February 3, 2020 6:00-7:30 PM

Dayton Adult Support Group

February 5, 2020 6:00-8:00 PM

Columbus Adult Support Group

February 12, 2020 5:30-7:00 PM

Warren County Support Group

February 12, 2020 6:00-8:00 PM

Columbus Young Adult Support Group

February 19, 2020 6:00-7:30

Hamilton County Epilepsy Support

February 24, 2020 6:30-8:00 PM

Columbus Parent Support Group & Teen Support Group

March 2, 2020 6:00-7:30 PM

Dayton Adult Support Group

March 4, 2020 6:00-8:00 PM

Columbus Adult Support Group

March 11, 2020 5:30-7:00 PM

Warren County Support Group

March 11, 2020 6:00-8:00 PM

Columbus Young Adult Support Group

March 14, 2020

Emerald Miles 5K Run/Walk

March 18, 2020 6:00-7:30

Hamilton County Epilepsy Support

March 30 2020 6:30-8:00 PM

Columbus Parent Support Group & Teen Support Group

April 1, 2020 6:00-8:00 PM

Columbus Adult Support Group

April 6, 2020 6:00-7:30 PM

Dayton Adult Support Group

April 8, 2020 5:30-7:00 PM

Warren County Support Group

April 8, 2020 6:00-8:00 PM

Columbus Young Adult Support Group

April 15, 2020 6:00-7:30

Hamilton County Epilepsy Support

April 17, 2020

Living with Epilepsy Conference
Dayton, Ohio

April 18, 2020

Run to Erase Epilepsy - Columbus, Ohio

April 27, 2020 6:30-8:00 PM

Columbus Parent Support Group & Teen Support Group

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,
Michael Loewenstein, Darcy Perry,
Alyssa Whitt, John Wood

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.



Thank You

We would like to extend our warmest thanks to the following foundations for their generous support by awarding Epilepsy Alliance Ohio grants for our many services. Thanks to their generosity we are able to continue to serve those with epilepsy and their families. The 2019 Grants that were received and the programs to which they were designated include:

Camp:

Greater Cincinnati Foundation Summertime Kids....\$1,000

Community Education Program:

Fifth Third Bank-Charles Moerlein Foundation....\$25,000

The Wohlgemuth Herschede Foundation...\$5,000

Robert A. & Marian K. Kennedy Charitable Trust....\$1,000

PhRMA\$1,000

Chemed Foundation....\$500

Counseling Program:

The Daniel & Susan Pfau Foundation....\$20,000

The Spaulding Foundation....\$17,500

Charles H. Dater Foundation....\$10,000

PNC Charitable Trusts- Jack J. Smith Jr Charitable Trust....\$5,000

The Harry C. Moores Foundation (Columbus)....\$10,000

The Columbus Foundation-Robert Lewis Rosenstiel Fund (Columbus)....\$5,000

Anonymous (Columbus)....\$10,000

ArtsWave....Art Therapy....\$2,500

Taylor Huth Scholarship Fund:

Enterprise Holdings Foundation....\$1,000

Mission statement:

To serve people living with epilepsy and their families in overcoming the challenges created by epilepsy and in meeting their multiple health and social needs.

Epilepsy Alliance Ohio

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E-mail: eao@epilepsy-ohio.org ◇ Web address: www.epilepsy-ohio.org