

# The Update

**EPILEPSY  
ALLIANCE**  
OHIO

**2021, Volume I**

## Hats Off to Our Group Home Staff for Weathering the Storm

We have all seen people rise above and beyond through this Covid crisis but in our agency, none has reached higher than the staff who work in our group homes. Since March, our residents have been quarantined in the homes, unable to go to work, go on outings, etc. Through all this our direct care staff and managers in the homes have provided a safe, upbeat, and joy-filled environment for our 32 residents. They have done crafts, played games, helped the residents facetime their family members and generally provided a safe haven for the residents. We are eternally grateful for their

dedication and hard work. They are the backbone of our residential program!



Thank you!!

**Rock  
STARS**  
FOR EPILEPSY

featuring the live band  
NAKED KARATE GIRLS

epilepsy  
ALLIANCE  
OHIO

**FEB. 6  
7-9PM**

You are invited to an  
**EVENING FOR EPILEPSY  
VIRTUAL PARTY**

A promotional banner for a virtual party. The background is black with red stars and musical notes. On the left, there is a red banner with the text 'Rock STARS FOR EPILEPSY' and 'featuring the live band NAKED KARATE GIRLS'. In the center, there is a photograph of five people in costumes (gold, silver, and black) posing together. On the right, there is a white banner with the text 'FEB. 6 7-9PM' and 'You are invited to an EVENING FOR EPILEPSY VIRTUAL PARTY'. The Epilepsy Alliance Ohio logo is also present.

## Fundraisers in 2021

As you are aware, Covid has had a huge impact on in-person fundraisers in 2020. Although we would have loved to gather with our faithful supporters, we did not want to risk anyone getting Covid from a large group gathering. Although vaccines are beginning to make an impact in our community, we do not see being able to host any in-person events through the spring of 2021. However once summer hits we would love to open the door to these events beginning with sand volleyball, then our golf tournament, Buckeyes for Hope OSU Watch Party, Seize Hope and much more. Please stay tuned to our website and Facebook page for updates on when we will begin offering these events. Until then, thanks for your continued support and stay safe!!

## Fall Educational Programs

This past fall we were able to offer 11 virtual educational programs that reached people across the country. Doctors from Cincinnati Children's, UC Health, OhioHealth, OSU Wexner Medical Center and Nationwide Children's Hospital presented on a variety of topics that were of interest to many. Using Facebook Live viewers were able to ask questions of the presenters during the presentations. All programs have now been archived and are available for viewing through our [website](#) and through the videos link on our [Facebook page](#) so that people can still benefit from the wealth of knowledge that was shared.

This went over so well that we plan to offer these Facebook Live programs throughout the year.

Thank you to our presenters and the following companies who sponsored this series:



## Kroger Community Rewards

Use your **Kroger Plus** card to support Epilepsy Alliance Ohio at no cost to you!

*You must re-enroll every 12 months to continue participation.*

[CLICK HERE FOR DETAILS](#)

## *Greetings!*

Finally, 2021! The start to a brand new year! Reflecting on 2020 did not bring ALL bad experiences. For me personally, it was nice to slow down a bit. It was nice having more family time and less sporting activities in the evenings and on weekends. There was more time for family hikes and enjoying nature.

For Epilepsy Alliance Ohio, it was a year of switching gears from everything we knew. For our Community Programs, it meant creating new ways to meet the needs of those we serve. For our Residential Programs, it meant developing new protocols and policies to keep all the clients and staff safe, healthy and happy.

With regard to COVID-19 and how the vaccine may effect those living with epilepsy, we are hosting a Facebook Live event, "Epilepsy and COVID-19 Vaccine" on Thursday, February 11th at 3:00 PM. Dr. Maturu, from OSU will be presenting on this important topic. This presentation will be recorded, and also live, so if you cannot tune in at 3:00 PM, you can still access it on our Facebook page to view it at a time that works best for you.

As our fundraising efforts came to a halt, we had to get creative and find different opportunities, such as grants, to raise funds necessary to keep our programs running. We had the wonderful opportunity to meet and learn about the Elsa Heisel Sule Foundation through Ruth Klette. We were also introduced to the Deacones Foundation through Tony Woods. Both are wonderful Foundations who have chosen to support those living and impacted by seizures.

We are very happy to announce that we have opened our Epilepsy Alliance Ohio Apparel Store. We have some really great and comfortable items that show support for our epilepsy cause. Be sure to check out our store on our website at [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org).

I hope everyone's 2021 is off to a great start! My hope is that everyone stays healthy and safe.

*Kathy Schrag*

FACEBOOK Live – Check out our Facebook page at [www.facebook.com/EpilepsyOhio](http://www.facebook.com/EpilepsyOhio) or our website at [www.epilepsy-ohio.org](http://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.

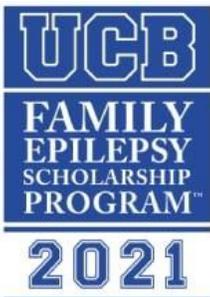


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## Taylor Huth Scholarship Fund

We are pleased to announce that Epilepsy Alliance Ohio will again be awarding the Taylor Huth Memorial Scholarship for individuals with epilepsy who are attending or will be attending college. Applications must be postmarked by **March 31, 2021**. A committee will review all applications and announce the winners in late March. Details about the scholarship can be found on our website at [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org) and look under the Program tab for Scholarship.

This scholarship is given annually thanks to the generosity of the family and friends of Benjamin "Taylor" Huth who passed away after having a seizure. Our annual golf outing also supports this fund.



UCB will award 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 honoring the late Sandra Helmers, MD, MPH and the late John M. Pellock, MD, two prominent figures in the epilepsy community who passed away in 2016. Additionally, UCB will award one applicant 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.

The recipients of the Epilepsy Leader Scholarships and the Joe D'Souza Memorial Scholarship will demonstrate academic and personal achievement and will also exemplify some of the qualities that Drs. Helmers and Pellock were best known for including a desire to advocate for and serve others, an interest in positively contributing to the epilepsy community and a persevering spirit.

Applications for the 2021 scholarship program are due Monday, **March 15, 2021**.



### **EAO Online Store**

We are very excited to announce the opening of our online store. This has been a dream of ours for years and we are very happy to see it up and running. You can order uniquely designed t-shirts, hoodies, fleece pull-overs, hats, bags and more. Visit the store on our website at [epilepsy-ohio.shop](http://epilepsy-ohio.shop) to see all that we have to offer.



# Camp Corner

## Camp 2021

Although Covid caused us to cancel all our camp programs in 2020, we are hopeful that we can offer these programs again in 2021. From our residential camps for kids to our day camp and adult weekend camp, we hope to make many memories at camp this year. Presently we have the following camps for children scheduled at Camp Kern. Please mark them on your calendar and look for more details as the dates approach:

Spring Camp - March 26 - 28, 2021

Summer Residential Camp - July 11-15, 2021

Fall Camp - September 24-26, 2021

To take part in our camps in 2021, call Mark Findley at (513) 721-2905 or email [mfindley@epilepsy-ohio.org](mailto:mfindley@epilepsy-ohio.org).



*Local high school senior with epilepsy shares her "Love from Lillian" kit*

Kit includes:

- Small blanket of comfort
- Friendship bracelet
- Word of encouragement

Call 877-804-2241 to request a kit

The background of this section features a young woman with long dark hair, wearing a tan jacket over a floral top, holding two white kits. The text "LOVE from Lillian" is written in a stylized font behind her. The background is a warm, golden glow with soft white hearts.



## Remembering Linda Daffin

The epilepsy community in Ohio, lost a great friend and advocate in the fall of 2020, with the passing of Linda Daffin. Linda worked for over 20 years at OhioHealth as an EEG Tech and Neurodiagnostic Clinical Educator. She worked with countless people living with epilepsy and always treated them with the upmost care and respect. As one of her colleagues noted: "Linda was a wonderful human being and the matriarch of the epilepsy department... she knew the right way an EEG should be performed and could interpret EEG's with the best of them! She shared her knowledge with kindness and grace and treated everyone like family.

Linda died November 15th after a hard-fought battle with Covid. Our condolences go out to Linda's family and friends.

Linda was a regular attendee at our Living with Epilepsy Conference, and we are working with the epilepsy team at OhioHealth to present an annual award for EEG Techs who serve with excellence. Stay tuned for more details.

## Epilepsy Support

Feeling alone is difficult. Not knowing where to turn to be heard regarding how epilepsy is affecting you and your family can be lonely and scary. Health, finances, employment, relationships, education, and more can all be negatively impacted by a chronic medical condition. We are here to help!

**Groups:** Epilepsy Alliance Ohio has several regularly scheduled support groups which had been meeting in-person monthly across our service area. We've made the necessary changes to virtual meetings via Zoom which has the added benefit of making it possible to attend whichever group(s) work for your schedule. The meeting times for all of our groups are listed on the following page and will resume in-person when restrictions allow. Until then feel free to join one or all of our groups by Zoom (Meeting ID: [298-517-2353](#)) or by phone.

**Counseling:** Our counselors are here for anyone affected by epilepsy by phone, Zoom, and in-person. All of our community services are free of charge.

Contact us for more information about support groups or counseling at  
**513-721-2905** or **877-804-2241**.

## 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

**\*\*All Support Groups are currently meeting remotely via Zoom and phone.\*\***

## **February 3, 2021 6:00-8:00 PM**

Columbus Adult Support Group:

\*First Wednesday

## **February 6, 2021 7:00-9:00 PM**

Rockstars for Epilepsy

## **February 10, 2021 5:30-7:00 PM**

Warren County Support Group:

\*2nd Wednesday

## **February 11, 2021 2:00-3:30 PM**

All Epilepsy Support Group:

\*2nd Thursday

## **February 11, 2021 3:00 PM**

Living with Epilepsy: COVID Vaccine and Epilepsy, Dr. Sarita Mautura, OSU Wexner Medical Center

## **February 15, 2021 6:30-7:30 PM**

[Webinar: An Introduction to VNS](#)

## **February 17, 2021 6:00-7:30 PM**

Hamilton County Support Group:

\*3rd Wednesday

## **February 22, 2021 6:30-8:00 PM**

Parent Support Group:

\*Last Monday

## **March 3, 2021 6:00-8:00 PM**

Columbus Adult Support Group

## **March 10, 2021 5:30-7:00 PM**

Warren County Support Group

## **March 11, 2021 2:00-3:30 PM**

All Epilepsy Support Group

## **March 17, 2021 6:00-7:30 PM**

Hamilton County Support Group

## **March 26-28, 2021**

Spring Camp

## **March 29, 2021 6:30-8:00 PM**

Parent Support Group

## **March 31, 2021**

Taylor Huth Scholarship - Deadline

## **April 7, 2021 6:00-8:00 PM**

Columbus Adult Support Group

## **April 14, 2021 5:30-7:00 PM**

Warren County Support Group

## **April 15, 2021 2:00-3:30 PM**

All Epilepsy Support Group

## **April 21, 2021 6:00-7:30 PM**

Hamilton County Support Group

## **April 26 2021 6:30-8:00 PM**

Parent Support Group

## **May 5, 2021 6:00-8:00 PM**

Columbus Adult Support Group

## **May 12, 2021 5:30-7:00 PM**

Warren County Support Group

## **May 13, 2021 2:00-3:30 PM**

All Epilepsy Support Group

## **May 19, 2021 6:00-7:30 PM**

Hamilton County Support Group

## **May 31 2021 6:30-8:00 PM**

Parent Support Group

## **June 2, 2021 6:00-8:00 PM**

Columbus Adult Support Group

## **June 9, 2021 5:30-7:00 PM**

Warren County Support Group

## **June 10, 2021 2:00-3:30 PM**

All Epilepsy Support Group

## **June 16, 2021 6:00-7:30 PM**

Hamilton County Epilepsy Support

## **June 28, 2021 6:30-8:00 PM**

Parent Support Group

*Executive Director:* Kathy Schrag

Board of Directors

*President:* Jake 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 Epilepsy Alliance Ohio (EAO). 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 2020 Grants that were received and the programs to which they were designated include:

### **Camp:**

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

### **Counseling Program:**

Anonymous Foundation (Columbus)...\$15,000

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

Anonymous Fund of the Columbus Foundation...\$2,500

Elsa M. Heisel Sule Foundation...\$7,000

Greater Cinti Foundation/United Way Covid-19 Regional Response Fund...\$10,000

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

The Maxwell Weaver Foundation...\$5,000

PhRMA...\$1,000

The PNC Charitable Trust...\$10,000

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

The Sutphin Family Foundation...\$20,000

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

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

### **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**

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(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)