

# The Update



**2021, Volume II**

Epilepsy Alliance America proudly embraces SK Life Science Inc., a subsidiary of SK Biopharmaceuticals, as its marquee sponsor and supporter in our noble effort to serve hundreds or thousands of people with epilepsy, and their families, caregivers, and communities.



## September 4, 2021

# The 2<sup>nd</sup> Annual EAO/WEBN Frog Legs 5K Run/Walk

Join Epilepsy Alliance Ohio as we host the 2<sup>nd</sup> annual Frog Legs 5K. This event adds to the weekend of fun that WEBN delivers every year. You will enjoy a beautiful course along the river as well as great food and drinks after the race. Be sure to purchase a pair of Frog Legs socks to compliment the awesome race shirt!



- All proceeds from this event benefit the programs and services of Epilepsy Alliance Ohio.
- Top male and female runner will have a front row view of the fireworks.

For more information and to register go to <https://runsignup.com/Race/OH/FrogLegs5K>

## Transition from Pediatric to Adult Care

Emily Nurre MD, MPH

Assistant Professor, University of Cincinnati Gardner Neuroscience Institute



The transition from pediatric to adult care can be a challenging time for everyone involved. Families and patients often feel a sense of loss as they leave pediatric providers who have been there since the child's diagnosis. Patients and families often have fears about a new healthcare system and need time to trust new providers during transition. This transition time has additional challenges as adolescents/young adults are developing self-control and self-management skills, while simultaneously taking on more responsibility for their own health care. This is understandably challenging, and planning, discussion and practice can help.

Ideally, it is recommended to discuss transition several years before transfer to adult care to create a transition plan. Timing may vary depending on epilepsy type and time of transfer. 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 care is necessary and it can be helpful to practice skills to make the transition process successful, such as:

- taking medicine independently
- ordering medicine
- knowing your medical history, medications, and allergies
- understanding a seizure action plan
- making and keeping appointments
- discussing health issues with your providers

Not all patients have the same goals, they differ depending on the patient's skill levels.

Further information for transition can be found at

<https://www.childneurologyfoundation.org/transitions/>

The Epilepsy Transition Clinic is a partnership between Cincinnati Children's Hospital Medical Center, UC Health, and the Epilepsy Alliance Ohio. We recommend discussing transition by around age 16 with your pediatric epilepsy provider and checking skills yearly after. It is important to start practicing seeing your provider on your own if able, and to discuss financial and legal needs prior to transition such as guardianship and insurance changes, as well as other conditions like depression and anxiety that will need treatment on the adult side. Early discussion allows for a smooth transition! Adult epilepsy specialists from UC Health see patients at the University of Cincinnati Gardner Neuroscience Institute in Clifton, West Chester and Florence.

Based on input from our patients, it is important to have a friendly face to help guide transfer from the last pediatric to first adult clinic visits. We are very grateful to Epilepsy Alliance 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 smooth path to adult providers and community resources available for patients with epilepsy.

*Greetings!*

Time flies when you are busy, that's for sure. I can't believe summer is coming to a close and our children are heading back to school.

We do have some exciting news with regard to Ohio House Bill 373, otherwise known as Sarah's Law. HB373 would require schools to create an individualized Seizure Action Plan for each student diagnosed with epilepsy. Additionally, it would require all staff (teachers, school nurses, bus drivers, etc.) to receive epilepsy / seizure first aid training every two years.

Doug Simmons, our Director of Advocacy has worked very hard on this bill on behalf of children living with epilepsy. It is so important for your state representatives to know the importance of this bill. Please reach out to your representative in support of HB373. If you would like additional information in ways to help, please contact Doug at our office.

With schools back in session, let us know if you would like us to contact your child's school for one of our many school-based training curriculums. We provide trainings for young children (a great puppet presentation), middle school, high school, teacher and school nurse trainings. This is such a wonderful way to bring awareness and education about epilepsy to our schools. Education empowers empathy!

If you are interested in a training at your school, please contact Seve Hutton in the Cincinnati and Northern Kentucky areas, or Karen Brown in Central Ohio.

*Wishing you the very best,*

*Kathy Schrag*

Executive Director - Epilepsy Alliance Ohio

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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.



## Legislative Update: "Sarah's Law" Seizure Smart Schools HB 373

One of the best ways to protect students with epilepsy is to educate those people who come in contact with those students. Epilepsy Alliance Ohio has always offered epilepsy education and IEP/504 supports for students with epilepsy across our service area and now we have the opportunity to craft legislation mandating training for all school personnel across the State of Ohio. EAO has been working with state legislators to introduce "**Sarah's Law**", Ohio House Bill 373, which promotes seizure smart schools and is applicable to all public and chartered nonpublic schools in Ohio.

**Sarah's Law** provisions include:

- Requiring schools create an individualized Seizure Action Plan for each student diagnosed with epilepsy in their respective schools.
- Requiring schools provide training for all staff every two years in the care of students with epilepsy. This training is to be provided by a nonprofit organization that supports the welfare of people with epilepsy, such as Epilepsy Alliance Ohio or other similar organization.



Sarah Lenardos

### What can I do?

- Contact your Ohio State Representative to voice your support of Ohio HB 373. The full text of the bill can be found at <https://ohiohouse.gov/legislation/134/hb373> and contact information for your representative can be found at [www.OhioHouse.gov](http://www.OhioHouse.gov)
- Opportunities to testify in committee will be needed. If you have a compelling story in support of HB 373 please let us know. Contact Doug Simmons at [dsimmons@epilepsy-ohio.org](mailto:dsimmons@epilepsy-ohio.org) or 513-721-2905.

## *Art Therapy - 2021*

Hey, Columbus! Epilepsy Alliance Ohio is proud to offer Art Therapy to adults 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 Ashley Skelly, LPCC-S, ATR a local licensed art therapist, using a variety of artistic media to open up about their individual experiences in epilepsy through visual expression.



For more information and to register contact Karen Brown at [kbrown@epilepsy-ohio.org](mailto:kbrown@epilepsy-ohio.org) or 614-725-1031. Epilepsy Alliance Ohio offers Art Therapy 2021 free to those living with epilepsy. **Seating is limited.**

# Camp Corner

## Camp Programs are back in the Swing of Things

We are happy to share that our camp programs are back in action after a little break because of the pandemic. We hosted our summer camp in July and had a great time exploring the outdoors with the kids and enhancing friendships. Watch the video below to get a glimpse of what went on at camp.

<https://www.youtube.com/watch?v=GWKw4Zr1vfs>

As we look towards the fall, we will be offering two camp programs.

**Fall Camp for Kids** – The weekend of September 24-26 we will gather at Camp Kern for our annual fall camp. Here the kids will be able to horseback ride, canoe, fish, do crafts, play games and so much more. Space is limited so register early to take part.

**Fall Camp for Adults** – The weekend of October 29-31 we will gather with adults who have epilepsy at Lutheran Memorial Camp, north of Columbus, Ohio, for an awesome weekend of fellowship and exploration. We will be able to enjoy the beautiful fall colors while hiking, sitting around the campfire and much more. Camp is limited to 10 campers so register today.

To register for either of these programs simply call our office at (513) 721-2905 or email [mark.findley@epilepsy-ohio.org](mailto:mark.findley@epilepsy-ohio.org).



## Taylor Huth Memorial Golf Outing

Dust off your clubs and join us at Elks Run golf course in Batavia, Ohio, for an outstanding day of golf, fellowship, food and drinks. Tee off begins at 9:00 a.m. on Friday, September 10<sup>th</sup> and golfers will enjoy a beautifully manicured course as well as contests, prizes, beer, Skyline Coney's and much more.

Cost is only \$125.00 and includes your round of golf, cart, golf shirt, lunch and much more. We hope to fill the course so register early to reserve your place.



## Buckeyes for Hope

Join us on Saturday, October 2nd as we gather at The Hub in Columbus to watch the OSU Buckeyes take on the Rutgers Scarlet Knights. As you watch the game with us you will be able to enjoy delicious food and plenty of drinks while supporting our local services. We will also be honoring people in our community who have made a difference in epilepsy.

Tickets and more details can be found on our website at [epilepsy-ohio.org/events/buckeyes-hope-watch-party](http://epilepsy-ohio.org/events/buckeyes-hope-watch-party)



2021 Sponsor

## 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

**\*\* Due to the uncertainty surrounding Covid restrictions, the locations of our Support Groups may have changed or gone to Zoom and call-in only. Follow us on our [Facebook](#) page for up to date information on your group's meeting.\*\***

## **Sept 1, 2021 6:00-8:00 PM**

Columbus Adult Support Group:

\*First Wednesday

## **September 4, 2021**

Frog Legs 5K - Cincinnati

## **Sept 8, 2021 5:30-7:00 PM**

Warren County Support Group:

\*2nd Wednesday

## **September 10, 2021**

Taylor Huth Memorial Golf

Tournament - Elks Run Golf Course

## **September 13, 2021**

Advocate in Epilepsy Educational Program - Virtual

## **Sept 15, 2021 6:00-7:30 PM**

Hamilton County Support Group:

\*3rd Wednesday

## **Sept 24-26, 2021**

Fall Weekend Camp - Camp Kern

## **Sept 27, 2021 6:30-8:00 PM**

Parent Support Group:

\*Last Monday

## **Sept 29, 2021 6:00-7:30 PM**

All Epilepsy Support Group:

\*Last Wednesday

## **October 2, 2021**

Buckeyes for Hope Watch Party -

Columbus

## **October 6, 2021 6:00-8:00 PM**

Columbus Adult Support Group

## **October 13, 2021 5:30-7:00 PM**

Warren County Support Group

## **October 16, 2021**

Living With Epilepsy Conference -

Columbus

## **October 20, 2021 6:00-7:30 PM**

Hamilton County Support Group

## **October 25, 2021 6:30-8:00 PM**

Parent Support Group

## **October 27, 2021 6:00-7:30 PM**

All Epilepsy Support Group

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

Columbus Adult Support Group

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

Warren County Support Group

## **November 12, 2021**

Seize Hope Gala - Cincinnati

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

Hamilton County Support Group

## **Nov 24, 2021 6:00-7:30 PM**

All Epilepsy Support Group

## **Nov 29, 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.



# Living With Epilepsy Conference

We are happy to announce that this great Columbus tradition will continue this fall with an in-person conference on Saturday, October 16<sup>th</sup> at the Fawcett Center at OSU. An all-star lineup of neurologists will be presenting a host of topics that will bring understanding to epilepsy and various treatment options, including surgeries that are available to stop seizures. There will be large keynote talks as well as smaller breakout sessions to give the participants valuable information as well as the opportunity to talk with renowned doctors.

Besides outstanding talks on epilepsy, we have also partnered with UCB to offer a Virtual Reality program that gives people a glimpse of what it is like to have a seizure. We will also have a host of vendors at the event who will share information and materials.

This is a conference you do not want to miss. Register on our website at <http://www.epilepsy-ohio.org/events/2015-fall-seminar>



## Park National Making a Difference in Many Different Ways

We are honored to partner with Park National Bank to reach out in service in our communities. Park National Bank is graciously sponsoring our upcoming golf outing and Seize Hope event and are putting their support into action in concrete ways too.

During Park Cares Week in September, employees from the local bank branch will be

volunteering at our group homes to do much needed repairs and maintenance. The volunteers will be painting, landscaping and much more as they beautify our homes.

Thanks, Park, for your generosity and support!



### 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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