

# The Update

**2015, Autumn  
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**Fall Seminar**

**Living with Epilepsy**  
Saturday, October 31st, 2015  
8:00 AM – 3:30 PM

[Click here to learn more!](#)

OhioHealth Riverside Methodist Hospital

This symposium will highlight several experts on current issues facing people with epilepsy sharing their knowledge of recent advances and the latest findings on a variety of topics that people with epilepsy experience on a daily basis. This educational day is not only for people with epilepsy, their families and caregivers but also the professionals who treat people with epilepsy.

CEU's are available for social workers and nurses.

Admission is \$10 for the Symposium, or \$40 for the Symposium and CEUs.

*For more information please call toll free at 877-804-2241*

*A Celebration of Hope for Those Living with Epilepsy*

Enjoy a night out meeting others who have *Seized Hope* and attained success through their accomplishments. This event is to honor all of those individuals living with epilepsy who did not allow their epilepsy to stop them from achieving their goals and reaching great success. The night will be filled with fun, great company and a silent auction.



A CELEBRATION OF HOPE FOR THOSE  
LIVING WITH EPILEPSY

Friday, November 6, 2015 [American Sign Museum](#), 1330 Monmouth Street, Cincinnati, Ohio 45225. 7:00—11:00 PM.

Visit [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org) for more information and registration.



Thursday November 12th, 2015

6:00 pm– 9:00 pm

Grange Insurance's Haaf Hall

671 South High Street Columbus, OH 43206

Please visit [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org) for more information and registration.

The Update is a periodic newsletter published by the Epilepsy Foundation of Greater Cincinnati and Columbus (EFGCC). The EFGCC 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.

Executive Director: Kathy Schrag

Board of Directors

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Member at Large: Chad Schaefer

Members

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**More Pics Here**

*Greetings*

I am very excited and pleased to announce that we have hired a new Program Director for Central Ohio. Jessica Lilly started working for the Epilepsy Foundation of Greater Cincinnati and Columbus at the end of July. Jessica has been very busy learning about all of the programs and services we provide across our service territory and will be responsible for overseeing the Central Ohio territory, which will include marketing, advertising, event planning, volunteer development, and cultivating corporate and individual donors. Through Jessica's hard work our goal is to grow and expand the programs and services in Central Ohio. If you are interested in volunteering for events or serving on a fundraising committee, please feel free to email Jessica at [jlilly@epilepsy-ohio.org](mailto:jlilly@epilepsy-ohio.org).

We are also very pleased to announce that we will be opening an office in Columbus. The location of our new office is 3857 North High St., Suite 206, Columbus, Ohio, 43215. Jessica and Karen Brown will be moving in to their new office on September 1st.

As fall approaches, we are gearing up for a variety of different events and activities. We have multiple community care day projects, our Fall Living Well With Epilepsy Seminar, Mason Half Marathon, Seize Hope Event, Viva Las Vino event, and Epilepsy Awareness Month Activities in November. We encourage you to check out each event on our website and [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org).

Best Regards,

-Kathy



**Thank You!**

# **Ask the Expert: Medical Marijuana for Seizures – What Do We Know?**

David Ficker, MD  
University of Cincinnati Neuroscience Institute Epilepsy Center

Over the past two years there has been much attention focused on marijuana for epilepsy. This article will briefly summarize what we know and don't know about marijuana for epilepsy.

Marijuana is also known as cannabis. Marijuana contains chemicals called cannabinoids that act on cells in the body (called cannabinoid receptors) that cause effects on the brain. Two major components in marijuana include:

Tetrahydrocannabinol (also known as THC). This compound causes the psychoactive effects of "getting high."

Cannabidiol (also known as CBD) does not cause psychoactive effects but has shown some positive effects on certain body systems and may potentially affect seizures.



## What we know

There are various strains of marijuana that are higher in CBD and lower in THC that have been tried in some epilepsy syndromes. Charlotte's Web is one strain that has been reported by several news outlets as working in some patients with devastating epilepsies. It should be emphasized that the reports in the media are considered "anecdotal" evidence. This means that CBD for epilepsy has not been studied under the rigorous methods required by the FDA for approval of new drugs. In the past there have been reports of many different treatments possibly working for seizures, but when studied in a rigorous scientific fashion, the treatment did not work.

There is enough anecdotal evidence of an effect of CBD on seizures to stimulate several studies. A company from England (GW Pharma) is studying a CBD product (Epidiolex) in two epilepsy syndromes (Dravet Syndrome and Lennox-Gastaut Syndrome) under methods that the FDA considers to be scientifically rigorous (a double blind study). CBD is provided in an oil that is swallowed; the marijuana derivative is not smoked. Cincinnati Children's Hospital and the University of Cincinnati are enrolling patients in these studies. A previous open label study showed that seizures decreased by an average of 54% in 137 people who completed 12 weeks of Epidiolex.

## What we don't know

There is much we do not know about CBD for epilepsy. Like many approved seizure medications, not every medication works well in all patients. We expect the same for CBD – it should not be considered as a miracle cure for epilepsy. The long term effects of CBD (or marijuana) on memory, concentration and motivation in adults or children are not fully understood.

Current forms of CBD that are available in states where medical marijuana is legal may contain differing amounts of CBD or THC. This may result in an unreliable impact on seizures. We also do not know how many people do NOT respond to CBD as the media has only reported those who benefited. A recent study from Colorado found that only 1 of 3 children treated with CBD had seizures decrease by half. Four in ten had significant side effects with CBD. We also do not know how CBD reacts with other seizure medication. Carefully done medical studies are also needed to accurately determine side effects and possible interactions with other medications, including anti-seizure medications. Also, just like any other medication used for a serious medical illness, the strength of the medication must be known. None of the reports have used CBD preparations where exactly the same dose is given each day (like we have for anti-seizure medications).

## Current recommendations

There is not enough evidence to recommend medical marijuana as a treatment for epilepsy. It may work for some types of seizures. More rigorous scientific studies are needed to understand who CBD may work for and their potential risks. Please discuss with your health care provider before considering using CBD for your seizures.

## **Strategies for Managing Your Epilepsy: Ask the Expert Patient Symposium**

**Saturday, November 21, 2015**

**Conference Center at  
The Daniel Drake Center  
151 West Galbraith Road  
Cincinnati, Ohio 45216-1015**

**Register at  
[www.UCHealth.com/events/Epilepsy](http://www.UCHealth.com/events/Epilepsy) or  
by phone at 513-558-5440 or  
the day of the event at 8:30 am.**

## Camp Flame Catcher Overflowing with Fun!!!

In spite of two days of torrential rains, power outage and a cancelled rafting trip because of high waters, everyone had an awesome time at camp this summer. Reminding the kids that when life gives you lemons (seizures) you have to make lemonade, they lived out this motto through and through at camp. With the heavy rains, brought the perfect opportunity for Mud Soccer (everyone was covered head to toe!) When the power went out, a portable boom box brought the dancing outside complete with a homemade shower in our "dunking booth". And when the kids did have seizures, there were plenty of friendly faces to encourage the camper to get back up and keep going. The friendship and camaraderie at camp was contagious! There were many wonderful memories to last a lifetime.

We would like to thank our many donors throughout the year who provide scholarships for our needy children to attend camp. We also want to thank the Simpson and Vonderhaar families for not only providing scholarships for the kids but also backpacks, water bottles and many other goodies. Additionally we would like to thank the Greater Cincinnati Summertime Grant Program for giving our older kids at camp the chance to do the Ozone Zipline. As one camper said, it was AWESOME!!!

We love the joy and enthusiasm that is so evident at camp and can't wait to do it again at our Fall Camp, Sept. 25-27. If you would like to take part please call 513-721-2905 ASAP as space is limited.



**Studio E** has wrapped for the 4th time with some fresh faces in Cincinnati and now Columbus too. Thanks to the partnership with Lunbeck, a total of 15 people in both locations were able to express themselves in a variety of medium. Thank you to St. John's Episcopal Church for hosting Studio E in Columbus, and thanks to our returning Art Therapists Natalie Carpenter and Christy Wolfram as well as our new Art Therapist, Ashley Tilberg.



This years artwork can be viewed on [Photobucket](#) and will be on display at various upcoming events in recognition of National Epilepsy Awareness Month in November.



## Unique, but Appreciated Donations

Since 1953 the Epilepsy Foundation has relied upon the generosity of others to provide needed services in the community. This generosity typically takes the form of monetary gifts which are greatly appreciated and essential to our growth. However, sometimes a gift comes in odd shapes. For example, almost 10 years ago a local doctor donated his small Nissan to our agency. We are still driving that car to in-services around the state dispelling the myths and bringing understanding to epilepsy. We have also had people donate chickens, goats and doves to our farm at Benton Center. Recently, another gift came our way that will greatly enhance Benton center. A family had purchased a 6 foot tall, four-tiered fountain for their yard. They found out their home owners association would not allow the large fountain so now it has found a home at one of our group homes. Unique, but very cool!!

Thank you to the many people who keep our mission alive with their generosity; from gifts to our annual appeal to fountains that enhance the quality of life for residents of our group homes. We appreciate you partnering with us!

## Taylor Huth Golf Outing Has another Record Year

On Saturday, June 13<sup>th</sup> Elks Run Golf Course was filled to capacity for another great round of golf for the Epilepsy Foundation. Led by a dedicated group of volunteers that included: Jack Freyvogel, Brian Redden, Matt Salyers, Chad Schaefer, Joe Stonitsch and Mike Webster; the outing raised a record amount of money for our college scholarship fund and many other programs. Besides a great round of golf on a beautiful course, the day was capped off when five young adults with epilepsy were awarded college scholarships from the proceeds from this event. These individuals demonstrated a great tenacity to overcome challenges created by seizures and reach for their dream of a college education.

We would also like to thank our corporate sponsors who made the event possible. These include: our Title Sponsor – **Dentsmart**, our Shirt Sponsors – Dayton Freight and Gem City Tire, our Scholarship Sponsor – Reynolds & Reynolds, our Beverage Cart Sponsor – Window World, our Trophy Sponsor – Neusole Glass, Sklyine as our Coney Sponsor, Bridgestone as our Ball Sponsor, our Hole in One Sponsor – Holman Motors and our Golf Cart Sponsors – Hydro, Lundbeck, OPW, Buechner Haffer & Meyers.

Additionally we would like to thank our Hole Sponsors: Lundbeck, Health Care Services, Andrew Garman, The Huth Family, Hearing Aid Solutions, UC Health, Dinsmore, Carstar, Newman Tractor, Radin Advisory, Amish Made USA, OPW, Eastgate Animal Hospital, Hyde Park Animal Clinic, HTT Insurance, Franz CPA, DeanHouston, People's First Bank, Taybi Family, Professional Sealants, Buechner Haffer Meyers and Mercedes Collison. Thanks also to the countless others who donated items for our raffle and auction.

This outing is another example how together we are making a huge difference for people with epilepsy!!!!

### What is the Taylor Huth Memorial Scholarship Award?

A 1 year, \$1,000 Scholarship honoring local, outstanding students who have:

- Overcome or are working to overcome the challenges of epilepsy
- Been successful in school
- Done well in activities outside the classroom or in the community
- Shown a desire to make the most out of college or graduate school

For more info and to apply go to [www.epilepsy-ohio.org/news/taylor-huth-memorial-scholarship-program](http://www.epilepsy-ohio.org/news/taylor-huth-memorial-scholarship-program)

**Deadline for application is  
February 26, 2016**



**You may apply for the Taylor Huth Memorial Scholarship Award if you are:**

- Under a doctor's care for epilepsy
- In school as either:
  - A high school senior who has applied to college
  - A freshman, sophomore or junior in college
  - A college senior who has applied to graduate school
  - An adult interested in pursuing a college degree

# Tech Stuff

Applications being accepted for a **FREE EMBRACE WATCH**



Embrace is a watch that looks great on anyone. It can track your activity, stress and overall balance. It is designed to bring a better lifestyle to people that live with epilepsy: they get an alert when an unusual event happens, like a convulsive seizure, warning them and their loved ones.

Empatica, creators of Embrace, is partnering with the Epilepsy Foundation. Due to the generosity of a group of donors that know Empatica and its mission, 1,500 Embrace watches purchased through the [Embrace Indiegogo campaign](#) are being matched 1:1, loaded with the seizure detector app, and donated to the Epilepsy Foundation for distribution to families in need.

More information about the Embrace Watch and the application can be found at [www.epilepsy.com/article/2015/2/applications-now-being-accepted-embrace-watch](http://www.epilepsy.com/article/2015/2/applications-now-being-accepted-embrace-watch)

## About the SmartWatch

**SMART  
WATCH**

SmartWatch is an easy-to-use, non-invasive wristwatch that continuously monitors movements and instantly alerts connected family members and caregivers upon the onset of repetitive, irregular shaking motion. Other features include: enables the user to quickly summon help with the press of a button; alerts and recorded events include the GPS physical location of your loved one; records the time, location, duration and severity of all alerted events; data is available for secure access and review by wearers and their clinicians; and users can schedule customized medication reminder alerts.

For more information about the SmartWatch and for \$50 off the activation fee, go to [www.smart-monitor.com](http://www.smart-monitor.com) and enter EFOHO815.

## West Virginia Services Update

Led by a dedicated group of volunteers in the Huntington, West Virginia, area the Tri-State Epilepsy Support Group is meeting monthly to chart a course to address the needs of individuals with epilepsy in this area. Recently Tom Koprowski trained many of the members in Epilepsy Education so they can go out in the community and be ambassadors for epilepsy. They hope to dispel many of the myths that persist and provide meaningful services for individuals struggling with seizures.

In November they look forward to partnering with the Epilepsy Center at Cabell Huntington Hospital to plan Epilepsy Awareness activities for the community. These include an Epilepsy Awareness Walk on November 8<sup>th</sup> at Ritter Park at 1:00 p.m. and an Epilepsy Awareness Educational Day in the Atrium at Cabell Huntington Hospital on November 10<sup>th</sup>. At this event will be an Art & Essay Exhibit highlighting the unique gifts of people with epilepsy. Thanks to Cyberonics for providing awards for these artists.

## 3<sup>rd</sup> Annual Fundraiser Benefits Camp

For the third year in a row Kayla Conroy, an employee in the neurology department at Cincinnati Children's Hospital and long time volunteer at our camp, hosted her Light My Fire fundraiser on August 21<sup>st</sup>. Designed to provide scholarships for needy children at our camp; the evening included a Hawaiian theme, delicious dinner, raffle baskets, music and more. Over 50 people attended the event which raised approximately \$1500. for Camp Flame Catcher. Thanks Kayla and her family and friends for hosting this great event! Pictures from the luau can be seen of our Facebook page [here](#).

**September 2, 2015 6:00–8:00 PM**

Columbus Adult Support Group: Bing Cancer Center at Riverside Methodist Hospital (500 Thompson Ln., Columbus, OH 43215). Park in the purple parking garage! \* First Wednesday

**September 8, 2015 5:30–7:00 PM**

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

**September 15, 2015 6:00 PM**

Huntington, WV Epilepsy Support Group (Enslow Presbyterian Church 1338 Enslow Blvd Huntington, WV 25701) \*3rd Tuesday

**September 16, 2015 6:00-7:30**

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

**September 16, 2015 7:00– 8:00 PM**

Young Adult Group: Lookout Joe Coffee Roaster (2901 Robertson Ave, Cincinnati, OH 45209) \*3rd Wednesday

**September 17, 2015 9:00 AM–**

**12:30 PM** Seminar: "Mindfulness in Clinical Practice" The Health Foundation of Greater Cincinnati; \$55

**September 25-27, 2015**

Camp Flame Catcher

**September 29, 2015 6:30–8:00 PM**

Columbus Parent Support Group and Teen Support Group: Bing Cancer Center at Riverside Methodist Hospital ( 500 Thomas Ln., Columbus, OH 43215). Park in the purple parking garage! \*Last Tuesday

**October 7, 2015 6:00–8:00 PM**

Columbus Adult Support Group

**October 14, 2015 5:30– 7:00 PM**

Warren County Support Group

**October 20, 2015 6:00 PM**

Huntington, WV Support Group

**October 21, 2015 6:00 7:30 PM**

Hamilton County Support

**October 21, 2015 7:00–8:00 PM**

Young Adult Group: Lookout Joe

**October 27, 2015 6:30-8:00 PM**

Columbus Parent Support Group and teen Support Group

**October 29, 2015 9:00 AM–12:30**

**PM** Seminar: "Applications of Crisis Theory" The Health Foundation of Greater Cincinnati; \$55

**October 31, 2015 8:00 AM–3:30 PM**

Fall Seminar—Living With Epilepsy OhioHealth Riverside Methodist Hospital, Columbus, Ohio 45214

**November 4, 2015**

Mason Half Marathon and 5K Run / Walk

**November 4, 2015 6:00– 8:00 PM**

Columbus Adult Support Group

**November 6, 2015 7:00–11:00 PM**

Seize Hope, 1330 Monmouth St, Cincinnati, Ohio 45225

**November 8, 2015, 1:00 PM**

Epilepsy Awareness Walk, Ritter Park, Huntington, West Virginia

**November 10, 2015**

Epilepsy Awareness Educational Day, Cabell-Huntington Hospital, Huntington, West Virginia

**November 11, 2015 5:30-7:00 PM**

Warren County Support Group

**November 12, 2015 6:00–9:00 PM**

Viva Las Vino, Haaf Hall, Columbus, Ohio 43206

**November 17, 2015 6 PM**

Huntington, WV Support Group

**November 18, 2015 9:00 AM–12:30**

**PM** Seminar: "Motivational Interviewing" The Health Foundation of Greater Cincinnati; \$55

**November 18, 2015 6:00– 7:30 PM**

Hamilton County Support Group

**November 18, 2015 7:00– 8:00 PM**

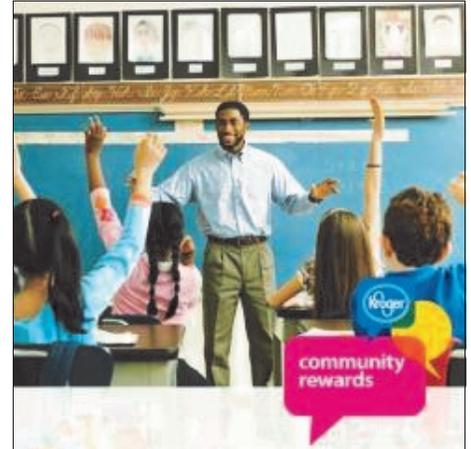
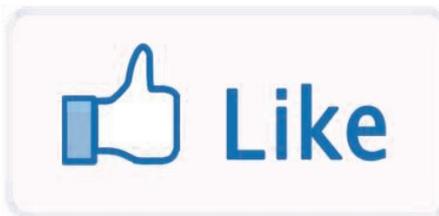
Young Adult Group: Look Out Joe

**December 10, 2015 9:00 AM–12:30**

**PM** Seminar: "Natural Approaches to ADD/ADHD" The Health Foundation of Greater Cincinnati; \$55

**\*\*There will not be any Support Group Meetings in the month of December\*\***

**Like us on Facebook to keep up with all of our events!**



**Have you enrolled for the Kroger Community Rewards Program yet? If you have, we thank you so much for your participation! As a reminder, participants must re-enroll each year to continue earning rewards during the coming year. If you haven't enrolled yet, it is easy to participate and there are no strings attached—shop at Kroger and scan your Rewards Card when you check out and a percentage of your purchase will be donated to the Epilepsy Foundation. Enroll or re-enroll at [www.krogercommunityrewards.com](http://www.krogercommunityrewards.com). Our organization number is 82140**

**Thank You!**





## **IDEA (Individuals with Disabilities Education Act)**

School is back in full swing and with that many parents and students can feel the added pressure of dealing with the effects of epilepsy on education. From increased absences due to doctor's appointments or seizures, medication side effects such as sleepiness and loss of concentration, epilepsy can have a direct impact on a child's ability to successfully manage their educational responsibilities.

Disability discrimination is not limited to the workplace as educational settings can also abridge the rights of children and adults with disabilities by failing to offer programs and services that identify and address these problems. Special provisions are provided for evaluation and planning for those having academic difficulties which can include 504 and Individual Educational Plans (IEPs), as well as resources such as Offices for Students with Disabilities on college campuses. The Foundation offers information and material on educational protections and referral to agencies that can assist the parent or individuals in resolving educational concerns. Call Doug Simmons at (513) 721-2905 to find out more about advocating for your child.

## **Community Education**

Educating the community about epilepsy is a tremendous part of our responsibilities. It includes going into schools, police departments, fire departments, nursing homes, businesses, clubs, health fairs, or in general, *anywhere* we are requested to teach people what epilepsy is and proper first aid for seizures. It usually involves teachers, classmates, co-workers, employers, caregivers and those in public service jobs, but it has no limits.

Epilepsy is often a misunderstood disorder and much of the information that people have about epilepsy is based on myths. These myths often make social adjustments for people with epilepsy more difficult as they prejudice society and often put a negative stigma on a person who experiences seizures.

Together, our Community Educators, along with the help of The Epilepsy Foundation of America and all of the Epilepsy Foundation affiliates have developed uniquely tailored educational programs that explain the different types of seizures, what causes seizures, how to respond to a person who is having a seizure, when it is necessary to call for emergency medical services and much more. Each program is designed to cater to the audience that it is presented to.

Please call the Epilepsy Foundation of Greater Cincinnati and Columbus to schedule a training for your group or to request information for yourself.

In Central Ohio contact: Karen Brown at (614) 315-0572

In Greater Cincinnati contact: Tom Koprowski at (513) 721-2905

### **Epilepsy Foundation of Greater Cincinnati and Columbus**

895 Central Ave., Suite 550 ◇ Cincinnati, OH 45202 ◇ Phone: (513) 721-2905 / (877) 804-2241 ◇ Fax: (513) 721-0799

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