



EPILEPSY AWARENESS MONTH TOOL KIT

November 2018

Your Guide to Creating Epilepsy Awareness



**EPILEPSY
FOUNDATION**
Eastern Pennsylvania

NOVEMBER EPILEPSY AWARENESS MONTH

A LETTER FROM OUR PRESIDENT



Dear Friend & Advocate,

Did you know that epilepsy is the fourth most common neurological disease after migraine, stroke, and Alzheimer's disease? In fact, **1 in 26 people will be diagnosed with epilepsy at some point in their lifetime and an estimated 3.4 million people in the US are living with epilepsy.** Despite these staggering numbers, epilepsy remains a disorder that is largely misunderstood by the general public, discriminated against, and underfunded in research initiatives.

Anyone can develop epilepsy at any time, and everyone should know about the prevalence and impact and what to do if someone is having a seizure.

Let's make a promise this November Epilepsy Awareness Month. Let's utilize November as our chance to teach others what a seizure is, and, what it is not. Let's use our social media channels as a platform to talk about epilepsy. Let's plan events to gather our family and friends together to inform, educate and fundraise. **Let's imagine a society free of stigma, fear, isolation, discrimination and seizures.** A community that's safe, supportive and accommodating of those living with epilepsy.

Together, we can make a seizure smart community a reality. Let's work together to create it.

During the month of November, the Epilepsy Foundation Eastern PA will be spreading awareness throughout our region with community events, local partnerships, social media campaigns, and lighting the towns and cities of our 18 counties purple. But, **we can't do it alone.**

You can play a critical role by being an advocate! The following toolkit is a guide to help you **take action in your community.** Included are tips, ideas and resources to help you spread awareness and plan informative events. Implement these tools and visual aids at school or work, in your neighborhood, social groups and community spaces.

By working together, we can ensure our voice is clear and united in creating awareness, education and change for our epilepsy community.

Gratefully,

Elizabeth Beil
President and CEO

P.S. Want more information on how to get involved this Epilepsy Awareness Month?
Please email efepa@efepa.org or call 215-629-5003.

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EPILEPSY 101: THE FACTS AND KEY POINTS

As an epilepsy advocate, you're going to interact with a lot of people—and that's great! But there are so many sources of information out there that it's easy to get facts confused. Here's a list of key talking points and statistics (provided by the Center for Disease Control) to use when spreading awareness:

- **Epilepsy is a brain disorder that causes seizures. Seizures are abnormal activity in the brain.**
These seizures are not caused by a temporary or underlying medical condition such as a high fever or extremely low blood sugar. An individual is diagnosed with epilepsy when they have had two or more unprovoked seizures OR one seizure with the likelihood of having more.
- **In approximately 70% of epilepsy diagnoses, the cause is unknown.** Some common causes include: stroke, brain tumor, brain infections, traumatic brain injury and other genetic or neurological diseases.
- **150,000 people in the US are diagnosed with epilepsy each year, and 3.4 million Americans are living with active epilepsy.** This means they are currently diagnosed and taking medication to control seizures and/or had one or more seizure in the past year.
- **110,000 people in Eastern PA** are currently living with epilepsy.
- **1 in 26 people will have epilepsy at some point in their lifetime,** meaning they will be diagnosed, but may find medication or treatment to control it.
- **1 in 10 people will have a seizure in their lifetime.** Not everyone who has a seizure will be diagnosed with epilepsy, but everyone diagnosed with epilepsy has seizures.
- **There are many different kinds of seizures** that can present in all different types of ways. Some seizures may look like a staring spell while other seizures can cause a person to mumble, chew or smack their gums. Some seizures may cause a person to wander or be unaware of their surroundings, while others may cause a person to collapse or shake. Some seizures only occur when an individual is sleeping and are referred to as nocturnal seizures.
- Seizures may last only **a few seconds or up to a few minutes.**
- **1/3 of people diagnosed with epilepsy live with uncontrolled seizures** because there are no available treatments or medications that work for them.
- **There is no cure for epilepsy but there are a wide range of treatments.** Treatments for epilepsy vary and include medicine, surgery, special diets, medical implants and devices.

Epilepsy 101: FAQs

Q: I've heard I should put something like a wallet in a person's mouth while their having a seizure because they might swallow their tongue. Is that true?

A: No, a person having a seizure cannot swallow their tongue. Never put something in their mouth—it could actually cause them to choke.

Q: Can someone with epilepsy drive?

A: The rules vary from state to state, but generally someone needs to be seizure free for a certain amount of time in order to drive. In Pennsylvania you must be seizure free for six months. The EFEPA can help someone with epilepsy find transportation assistance if they cannot drive.

Q: Can someone with epilepsy work?

A: Yes! People with epilepsy can work just the same as anyone else. They may need accommodations in the workplace to help make sure they are safe, and that right is protected under the Americans with Disabilities Act.

Q: Is epilepsy contagious?

A: No, epilepsy is not contagious. You cannot “give” someone epilepsy the way you can the common cold.

Q: Can people with epilepsy play sports and exercise?

A: Yes, but they may need to take special precautions. Exercise is rarely a trigger for a seizure, but it's always a good idea to be safe. Some smart tips are to have a workout buddy or wear a medic alert bracelet.

Q: Can someone die from having a seizure?

A: Although most people with epilepsy can live full, healthy lives, death due to having a seizure is a possibility. The risk of dying for a person with epilepsy is 1.6 to 3 times higher than that for the general population. During a seizure, a person could suffer a brain injury or other traumatic injury.

Another complication is Sudden Unexplained Death in Epilepsy (SUDEP), which is when someone with epilepsy dies unexpectedly and no other cause of death is found. SUDEP occurs in 1 out of 1,000 persons with epilepsy.

Q: What can I do to help those living with epilepsy?

A: Having a conversation is a great start! If you hear someone make inaccurate comments about epilepsy, share with them what you've learned. Knowledge is key in creating change and a safer community. You can take the next step by contacting and supporting organizations like the Epilepsy Foundation Eastern PA, who help those living with epilepsy. You can sign up for our e-newsletters, come out to support one of our community events, form a Walk for Epilepsy team, create a fundraiser of your own, or donate to help continue our free programs and services.

Epilepsy 101: A Special Word on Language

There are so many misconceptions surrounding epilepsy that it's easy to accidentally add to the negative image of the disorder merely by making the wrong word choice. We're here to help with that!

When talking about epilepsy, here's a list of words we try to avoid using:

"Epileptic"

Like all individuals living with disabilities, people with epilepsy often prefer not to be labeled or defined by their diagnosis, such as "S/He's an epileptic." The reasoning can be summed up by the statement, **"epilepsy is what I have, not what I am."** The preferred terminology is "person living with epilepsy" or "child living with epilepsy." Use of epileptic as an adjective in other situations, such as "an epileptic seizures," is appropriate.

"Fit"

Although the term "fit" is commonly used by medical professionals outside of the U.S., most individuals with epilepsy in the U.S. are particularly sensitive to the description of seizures as fits. The feeling is that this word connotes mental derangement or loss of emotional control. Some associate the word with the symptoms of rabies in animals. Seizures, or, in some cases, convulsions, is preferred. Convulsion is a more specific term that more aptly describes a single type of seizure involving muscle contractions throughout the entire body. Not all epileptic seizures are convulsions.

"Control"

We use the word "controlled" a lot in our community, but as it relates to whether or not an individual's seizures are controlled or not. Seizures are controlled with medication and treatment, persons with epilepsy are not. "Controlled epileptic" in particular should always be avoided as it gives the impression that the person needs to be restrained from willful, aggressive behavior.

"Violent"

The adjective "violent" as a description of a seizure is also unfortunate. The term implies a threat to others and a force that is out of control.

EPILEPSY 101: SEIZURE FIRST AID

SEIZURE FIRST AID

STARTS WITH USING YOUR BRAIN

STAY SAFE SIDE

STAY with the person until the seizure ends.

Keep the person **SAFE** and start timing the seizure.

Turn the person on their **SIDE** if they start convulsing or are not awake.

CALL 911

- If the seizure lasts longer than 5 minutes
- If another seizure starts or the person is injured or in distress

- ⊗ Do NOT hold someone down or restrain them
- ⊗ Do NOT put anything in their mouth

Simple Seizure First Aid. **STAY. SAFE. SIDE.**

Learn more at: ENDEPILEPSY.ORG



END EPILEPSY®

DETAILED SEIZURE FIRST AID

STAY with the person until the seizure ends • Remain calm • Check for medical ID • Keep the person **SAFE** • Move nearby hazards and guide them away from danger • If the person starts convulsing, is not awake, or can't respond, ease them to the ground • Turn the person on their **SIDE** and continue to make sure they are **SAFE** • Loosen anything tight around their neck • Put something soft under their head • Time the seizure • Most seizures end in a few minutes and don't need emergency medical help • **STAY** with them until they are awake and alert • After the seizure, reassure the person and explain what happened • Offer to call someone for them • **CALL 911** if the seizure lasts longer than 5 minutes • **CALL 911** if the seizure repeats or breathing is difficult • **CALL 911** if seizure happens in water • **CALL 911** if person is injured, pregnant, sick or does not return to full awareness • **Do NOT** hold someone down or restrain them • **Do NOT** put anything in their mouth.

EPILEPSY 101: FLYERS & POSTERS

Flyers and posters are a great way to capture attention and teach people about epilepsy. You can click below to download some of our educational materials to post and share in your community. If you do not have access to a printer, simply let us know and we can mail a package to you!

What is Epilepsy?

What is Epilepsy?

Epilepsy is a chronic disorder defined by recurrent, unprovoked seizures. Many people with epilepsy have more than one type of seizure & may have other symptoms of neurological problems as well.

Epilepsy affects an estimated **3.4 Million** Americans and over **110,000** residents of Eastern PA

1 in 26 will be diagnosed with epilepsy in their lifetime.

There is no cure for this life altering condition

But there is hope.

The EPEPA is here to help you. It's our mission to stop seizures, find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate leaps into therapies.

1/3 of people with epilepsy live with uncontrolled seizures because no medication or surgery will work for them.

In 60% of the cases, the cause of epilepsy is unknown.

The EPEPA is here to help you. It's our mission to stop seizures, find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate leaps into therapies.

The Epilepsy Foundation Eastern Pennsylvania (EPEPA) is a non-profit organization dedicated to serving those affected by epilepsy through education, support & advocacy.

Phone or Text: 610-255-5003 • Contact and Don'tations: 215-629-5003
 Email: info@efepa.org • Website: www.efepa.org

EPILEPSY FOUNDATION
 Eastern Pennsylvania

NEAM Poster

ANYONE CAN HAVE EPILEPSY

Everyone Should Know

THREE MILLION Americans have Epilepsy, a brain disorder that causes **seizures**.

1 in 26 People will be diagnosed with Epilepsy at some point in their lifetime.

70% Of cases, the cause of Epilepsy is **unknown**.

November Is Epilepsy Awareness Month

Learn First Aid. **Spread the Word.**

215-629-5003 **EPILEPSY FOUNDATION** Eastern Pennsylvania **www.efepa.com**

First-Aid for Tonic Clonic (Grand Mal) Seizures

First Aid for Seizures
 (Convulsive, generalized tonic-clonic, grand mal)

DO NOT PUT ANYTHING IN MOUTH

LOOK FOR MEDICAL ALERT IDENTIFICATION

TIME THE SEIZURE WITH A WATCH

DO NOT HOLD DOWN

AS SEIZURE ENDS, OFFER HELP

CUSHION HEAD, REMOVE GLASSES

LOOSEN TIGHT CLOTHING

TURN ON SIDE

Most seizures in people with epilepsy are not medical emergencies. They end after a minute or two without harm and usually do not require a trip to the emergency room. But sometimes there are good reasons to call for emergency help. A seizure in someone who does not have epilepsy could be a sign of a serious illness.

Other reasons to call an ambulance include:

- A seizure that lasts more than 5 minutes
- No "epilepsy" or "seizure disorder" identification
- Slow recovery, a second seizure, or difficulty breathing afterwards
- Pregnancy or other medical diagnosis
- Any signs of injury or sickness

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 Eastern Pennsylvania

www.efepa.org 215-629-5003 info@efepa.org

First-Aid for Complex Partial Seizures

First Aid for Seizures
 (Complex partial, psychomotor, temporal lobe)

1. Recognize common symptoms

2. Follow first-aid steps

TIME THE SEIZURE

DO NOT GRAB OR HOLD

EXPLAIN TO OTHERS

BLOCK HAZARDS

SPEAK CALMLY

People who've had this type of seizure should be fully conscious and aware before being left on their own. Make sure they know the date, where they are, and where they're going next. Confusion may last longer than the seizure itself and may be hazardous. If full awareness does not return, call for medical assistance.

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 Eastern Pennsylvania

www.efepa.org 215-629-5003 info@efepa.org

SHARE YOUR STORY

Make it personal! People are much more likely to support you in your efforts if they are personally connected to the cause and understand the needs and challenges.

If you have a personal story and connection to epilepsy that you feel comfortable sharing with your community, we strongly encourage you to do so! Not only will you be spreading awareness, you will also be helping your network understand epilepsy and increase the chances of receiving their support.

A personal letter to your local newspaper editor is another great way to gain media exposure for NEAM! If you're stuck on ideas, use our simple template below to get started:

Date:

[Insert contact's address]

[Insert city, State]

[Insert zip code]

Dear **[Insert name of editor]:**

1 in 26 people will have epilepsy at some point in their life, however, the public is largely unaware how prevalent and serious the condition can be. Although it's a challenge to increase awareness, it's time to learn the facts. November is National Epilepsy Awareness Month and I am working with the Epilepsy Foundation Eastern PA to create a community that is safe and supportive of those living with seizures.

Epilepsy is very common – in fact, 1 in 10 Americans will have a seizure in their lifetime and there are over 110,000 people living with epilepsy in Eastern Pennsylvania. Yet most people cannot properly identify a seizure nor do they know what to do when someone is having one. As a result, individuals living with epilepsy often feel socially isolated, discriminated against, and afraid to live their lives.

Help me increase public knowledge and understanding around epilepsy so that individuals living with seizures can have access to all of the resources necessary to live full, happy, healthy lives. Here are a few simple facts that can go a long way to creating a seizure safe community:

- Seizures are not always convulsive; there are many different types of seizures
- If you see someone having a convulsive seizure, you should turn them on their side and cushion their head, but **do not put anything in their mouth.**
- A seizure isn't always an emergency—*only call 911 if the seizure lasts longer than 5 minutes.*
- Epilepsy is not contagious and seizures are not dangerous to anyone witnessing one.
- **Purple is the official color for Epilepsy Awareness.** You can show your support by wearing purple in November and posting on social media!

Making a difference isn't hard—knowledge and understanding goes a long way. As someone affected by epilepsy, I strongly encourage everyone to get educated by visiting www.efepa.org. The first steps towards creating change are often the smallest.

[Insert your name]

[Insert your address]

[Insert daytime telephone number]

[Click here to download a PDF of this letter.](#)

Easily find contact information for your local media outlets by clicking [here](#).



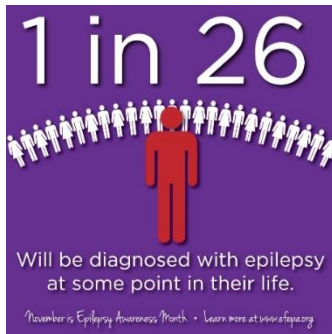
SOCIAL MEDIA

Join us as we turn Facebook, Twitter and Instagram PURPLE for Epilepsy Awareness Month! All month long, the EFEPA will be posting facts, statistics and pictures to educate the public and spread epilepsy awareness. Help us create an active dialogue and online community while reaching new audiences by sharing, liking and commenting on our daily posts. Through social media, new individuals and families in your network can learn about epilepsy, as well as the EFEPA's community events, programs and resources.



Personally posting about epilepsy on social media is a great way to spread awareness and raise funds for epilepsy! Craft your own messages on social media to let your friends know why November and epilepsy awareness are important to you. Follow our social media tips below for the most effective awareness posts:

1. **Keep it short and punchy.** The most effective posts are factual and to the point.
2. **Tying facts and statistics to your posts can be a powerful tool.** Use the examples below on social media (Facebook is still our favorite, but Instagram, LinkedIn, and Twitter are great, too), via email, in person or on the phone!
3. **Strengthen your posts with visual aids.** Check out our social-media-ready graphics below to help catch your network's eye. Use these images in conjunction with the provided sample content for super effective posts!

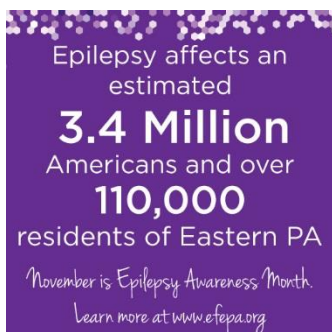


\$26 for the 1 in 26

1 in 26 people will be diagnosed with epilepsy in their lifetime. Everyone knows someone affected by seizure disorders. Did you know I am (or my child/parent/sibling/loved one is) the 1 in 26? This #EpilepsyAwarenessMonth, I'm asking you to consider making a donation of \$26 in recognition of those who are living with epilepsy and seizure disorders. (Insert link to personal fundraising page)

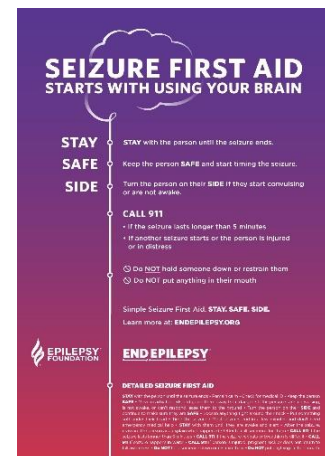
10 Friends for 1 in 10

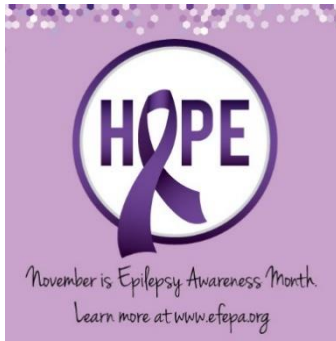
1 in 10 people will have a seizure at some point in their life. For #EpilepsyAwarenessMonth I'm sharing tips on how to be #SeizureSmart with 10 of my friends. Will you do the same? Check out www.EFEPA.org for more tips and ways to get involved. (Tag 10 friends)



3.4 million

3.4 million people in the US and over 110,000 residents of Eastern PA are living with epilepsy. I'm (or my child/parent/sibling/loved one is) one of them. This #EpilepsyAwarenessMonth, I'm talking about it to work towards ending it. Visit www.EFEPA.org to learn more and help spread awareness this November.





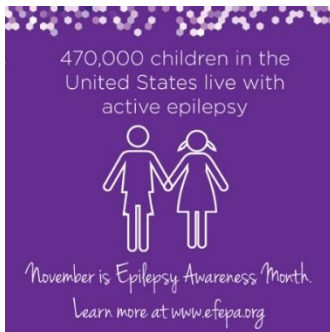
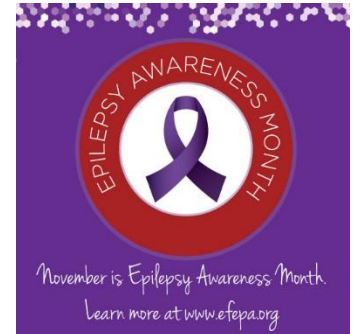
\$33 for the 33%

33% of people diagnosed with epilepsy are living with uncontrolled seizures because no medication or surgery will work for them.

This #EpilepsyAwarenessMonth, I am honoring the 33%. Please visit www.EFEPA.org to learn more and consider donating \$33 to help provide programs, resources, services and HOPE for the 33%.

Did You Know?

Did you know that epilepsy is the fourth most common neurological disease after migraine, stroke, and Alzheimer's disease? Everyone knows someone living with epilepsy, yet the disorder is underfunded in research initiatives and rarely talked about. This #EpilepsyAwarenessMonth, join me in shining a light on epilepsy by raising awareness. Visit www.EFEPA.org to learn more.

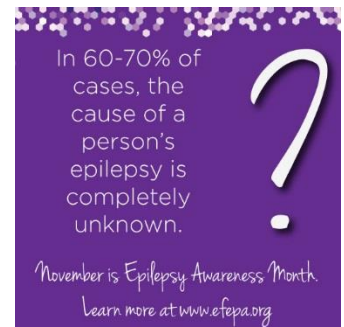


\$470 for the 470,000

470,000 children under in the US are living with epilepsy and seizure disorders. This November, I'm trying to raise \$470 for #EpilepsyAwarenessMonth in recognition of the hundreds of thousands of kids living with seizures. Will you help me reach that goal? No donation is too small - every little bit counts and gets me one step closer! (Insert link to personal fundraising page)

\$70 for the 70%

Anyone can have epilepsy at any point in their lifetime. In 60-70% of the cases, the cause of epilepsy is unknown. I'm asking seven of my friends to donate \$10 to raise \$70 by the end of today so that someday we might know more about what causes this disorder and how we can stop it. #EpilepsyAwarenessMonth (Tag 6 friends) (Insert link to personal fundraising page)



What is a Seizure?

A seizure is a symptom of an electrical disturbance in the brain.

What is Epilepsy?

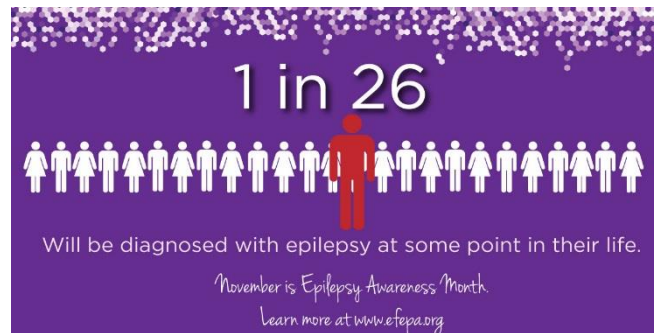
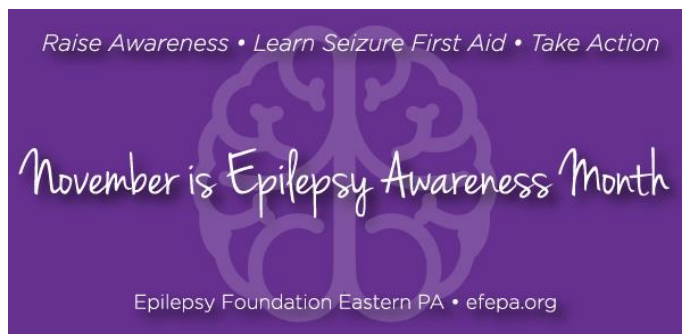
Epilepsy is a brain disorder defined by recurrent, unprovoked seizures.

November is Epilepsy Awareness Month. Learn more at www.efepa.org

Epilepsy Facts

Epilepsy is a brain disorder that causes seizures. Seizures are abnormal activity in the brain. 1 in 10 people will have a seizure in their lifetime, and 1 in 26 people will be diagnosed with epilepsy in their lifetime. Not everyone who has a seizure will be diagnosed with epilepsy, but everyone diagnosed with epilepsy has seizures. #EpilepsyAwarenessMonth

Below are some additional Epilepsy Awareness Month graphics that look particularly great as your Facebook banner image!



FACEBOOK FUNDRAISERS

Facebook now has a feature to create fundraisers which enables our supporters to raise money for the EFEPa directly on Facebook. You can set up a dedicated fundraiser page to share your personal story, tell others about the EFEPa's mission and rally around a fundraising goal.

EMAIL SIGNATURE

Updating your email signature to include information about Epilepsy Awareness Month is a simple and easy way to educate and connect with everyone you contact. Below are several examples to use:

- I support Epilepsy Awareness Month because someone I love is battling epilepsy. Learn the facts about epilepsy at www.efepa.org.
- Did you know that November is Epilepsy Awareness Month? 3.4 million Americans live with epilepsy. Learn more at www.efepa.org.
- 1 in 26 will be diagnosed with Epilepsy in their lifetime. November is Epilepsy Awareness Month. Join me in spreading the word. Learn more at www.efepa.org/neam.

REGIONAL EVENTS & ACTIVITIES

With you on our team, we're sure this November will be the best Epilepsy Awareness Month yet. That's why we're hopeful you'll join us at some of our hosted events throughout the region this November! You can stay up to date with the full calendar of events on our website, www.efepa.org/neam.

We encourage you to share pictures of you and your friends, family and loved ones attending our events throughout the month. Encourage everyone to wear purple to show your solidarity and support!

HOST YOUR OWN FUNDRAISER!

One great way to increase your efforts is by planning a creative fundraising event based around your interests or hobbies.

Here's some ideas of events your fellow all-star supporters have hosted in the past:

- Host a donation based yoga class, spin class, barre class, or whatever type of fitness class you're into!
- Host a happy hour or guest bartend at your favorite local watering hole! Work with the establishment to sell wristbands or have a percent of the evening's proceeds benefit your fundraising efforts. Put donation boxes around the restaurant for any local patrons who might be feeling generous as well.
- Organize a donation based bowling night at your local bowling alley.
- Host a wine & cheese night at your home! Ask your friends to make a \$10 donation.
- Organize a "Jeans Day" at your workplace. For anyone who donates \$5 to your fundraising page, they'll be allowed to wear jeans to work that Friday.
- Have a good old fashioned bake sale! Get your nearest and dearest together to bake their best dessert and sell them locally.
- Organize a week-long change collection at your child's school. That pocket change adds up quickly!
- Host a Paint Night party. Work with one of the local organizers to invite your friends out for some wine and painting with a percentage of the class fee going to your fundraising page.

You name it, people have turned their hobbies into creative events to benefit the EFEPa. For more ideas, visit our ['Tips and Ideas for a Successful Event'](#) page.

Want more information on how to get involved this Epilepsy Awareness Month?
Please email efepa@efepa.org or call 215-629-5003.