By providing supports and services, the Epilepsy Association of Western and Central PA (EAWCP) endeavors to improve the quality of life for persons with epilepsy/seizure disorders and to dispel the myths, stigmas, and misunderstandings associated with it.


ON THE COVER: The Griffith family visited the State Capitol in Harrisburg as part of the 2018 Share Your Story Conference.


Teens at the 2018 NEXT STEPS Transition Conference were challenged to think about the obstacles of transitioning to adulthood.


Before campers at Camp Frog @ Camp Fitch could be challenged to solve an Escape Room this summer, our Pittsburgh staff had to test out the puzzles.


At the Family Fun Run/Walks in Pittsburgh and Harrisburg, you can purchase a pinwheel flower in honor or memory of a loved one.


Adults with epilepsy and their loved ones joined us for a lunch and learn cruise down the river on a Gateway Clipper vessel.


Current and former Oscar Project recipients gathered for a picnic with their dogs and the Zupancic family, enjoying a delicious lunch and cupcakes that were inspired by each of the Oscar dogs.


Visit www.eawcp.org or contact one of our offices:

**Pittsburgh Office**
1501 Reedsdale Street
Suite 3002
Pittsburgh, PA 15233
412-322-5880
800-361-5885

**Harrisburg Office**
3507 Market Street
Suite 203
Camp Hill, PA 17011
717-730-6779
800-336-0301

**Altoona Area**
814-799-0345

**Erie Area**
814-451-1135

**TDD EOP / AUX AID**
800-855-2880
This issue of our newsletter highlights the changes we’ve gone through over the last several months, and shines a spotlight on our current programs and services.

The second half of the summer was a time of change for us – separating from the Epilepsy Foundation of America, renaming and rebranding ourselves, all while still providing all of the programs and services you have come to expect from us.

We are proud to announce the renaming of our organization, and are stepping out as the EPILEPSY ASSOCIATION OF WESTERN AND CENTRAL PA. That is quite a mouthful – so we will also call ourselves EAWCP. We also changed our website and social media accounts to use this new acronym.

Since we have this chance to redefine ourselves, we are focusing on our core mission of improving the quality of life for people with epilepsy and seizure disorders, taking a hard look at the programs and services we provide, and determining what we can improve upon and what is still needed to help those living with seizures.

To that end, we are working on content for a new SUDEP related section of our website, looking at how we can do more to assist individuals with employment issues, and laying the groundwork to reach out to some of the less populated areas of western and central PA to serve our neighbors there. We will also be providing more information through our social media channels, so if you haven’t already, join us on Facebook and Instagram.
Our name has changed, but we still have the same great programs and services that we have always had! Here are some of our programs that could help you and your loved ones and how to take advantage of them.

**CAMP PROGRAMS**

**Camp Frog** is a week-long overnight camp for children and teens (8-17 years old) with a primary diagnosis of epilepsy.

**Camp Firefly** is a weekend overnight camp for children and teens (11-18 years old) with active seizures and an intellectual disability.

Both camps provide extra supportive and medical services in a traditional camp setting. There is no fee for Camp Firefly and financial assistance is available for Camp Frog.

To learn more about Camp Frog and Camp Firefly, contact Amanda at 412-322-5880.

**MEDICAL ID CARD**

We can provide you with a free, customized wallet ID card and help you find the ID bracelet that is right for you.

**EMERGENCY MEDICATION**

If you find yourself running low on anti-seizure medication with no way to pay for your next refill, contact us to see if you are eligible for emergency medication assistance. Our program can pay for up to a 30-day supply of epilepsy medications.

**INDIVIDUAL/FAMILY CONSULTATION**

Our experienced and knowledgeable staff can provide you with a variety of supportive and educational services for you and your family as well as provide you with customized, one-on-one support.

Sometimes you don’t know what you need help with, and that’s okay. Give us a call and we can talk you through what programs, services, and community resources may be right for you.

**PROJECT SCHOOL ALERT**

Project School Alert is a free program that offers seizure recognition and response training to school nurses, school personnel, students of all ages, first responders, and community organizations. We will tailor all presentations to our audience.

To learn more about Project School Alert, contact your nearest EAWCP office. You can also request a copy of our Seizures in Schools brochure to share with your child's school, which includes additional information about epilepsy that is helpful for school personnel.

**LEGISLATIVE ADVOCACY**

You have the power to advocate on behalf of all Pennsylvanians living with epilepsy. We can teach you how to share your story in an impactful way and help you to form a relationship with your legislators.

To learn more about the Share Your Story/PA Public Policy Conference, highlighted on the cover of this newsletter, contact Andrea at 412-322-5880.

**HOW CAN I HEAR ABOUT UPCOMING EVENTS?**

The easiest way to hear about our upcoming CONFERENCES, SUPPORT GROUPS, and SOCIAL PROGRAMS is to make sure that we have your current mailing address - we often pull mailing lists based on proximity to the event. You can also read announcements about upcoming events on our Facebook page at www.facebook.com/eawcp. Turn to page 11 to see our current calendar of upcoming events.
The Oscar Project is funded by the Michael R. Zupancic Seizure Response Dog Endowment Fund. The fund helps by providing guidance and financial support to children and adults who have epilepsy/seizures who want to obtain specially trained dogs that provide assistance to seizure patients.

To learn more about obtaining service dogs or obtaining a seizure response dog through the Oscar Project, contact Francine at 412-322-5880.

High school seniors in western/central PA living with epilepsy/seizure disorders that have been accepted into a postsecondary academic or vocational program are encouraged to apply for one of several $1,000 scholarships.

Check out this year’s scholarship recipients on page 11.

Do you have questions about the rights your child with epilepsy has in school? Call us with all of your questions about IEPs, 504 Plans, the ADA, and more. We can also help you prepare to advocate on behalf of your child at school meetings.

SCHOLARSHIP PROGRAM

TEEN TRANSITION PROGRAMS

SPECIAL EDUCATION

OSCAR PROJECT SEIZURE RESPONSE DOGS

Emma’s Gift: Movement Monitor Grants

Does your child have nocturnal tonic-clonic seizures? Are you a teenager or an adult with tonic-clonic seizures that wants to continue living a safe, independent life? If so, you may be eligible for a movement monitor through our Emma’s Gift grant program. These movement monitors alert loved ones to seizure activity by sensing several seconds of sustained, convulsive movement like that of a tonic-clonic seizure.

There are three types of monitors offered through this grant:

- Emfit Monitor - A bed mat primarily for nocturnal seizures
- SAMI Alert - A video camera that runs on Apple products
- SmartMonitor - A smart watch that is worn day and night

This grant is generously made possible by the:

Emma Bursick Memorial Fund

To learn more about this grant and the monitor options available, please contact Amanda at 412-322-5880

What is respite care?

Respite is defined as “temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs” (Tipler, 2010).

Who can receive respite care services?

We are proud to provide this service to families and individuals who are primary caregivers for children and adults who have uncontrolled seizures. This program allows caregivers to take some scheduled time off from the demands of caring for a loved one. Respite care services are only provided to the program participant (person with epilepsy); other accommodations must be made for anyone else requiring care at the time of respite services.

How many hours of respite care services can I receive?

We provide a maximum of 25 hours of care in a one year period.

How do I request respite care services?

Contact Jordan at 412-322-5880 to discuss eligibility and registration!
Our organization is changing a little, and we wanted you to be among the first to know, because...

YOU are a valued and appreciated member of our epilepsy community; YOU are and have been an important ambassador and contributor to our mission and work; and YOU recognize and believe in the need to empower people living with epilepsy by providing them and their families with individualized help, and support through neighborhood services, and caring programs in local communities.

So, what’s the change?

Our new name is Epilepsy Association of Western and Central PA (EAWCP).

In order to continue providing the level of service you deserve, we have disaffiliated from the national organization, the Epilepsy Foundation of America (EFA).

The EFA’s mission and agenda has turned from the traditional emphasis on local services and personalized support to one that prioritizes research, fundraising for research, and public awareness related to research. Our leadership feels that going along with this mission shift would limit our ability to continue providing real-time, local programs that help people who are living with seizures today.

While our organization certainly sees the value in a research agenda and mission, it is just not the main part of the epilepsy mission that we address. It is not our primary purpose. Our services are NOT changing.

We have developed a new name, new local identity, and new rebranding strategy. We have a new look and a new name but remember, we are the same group of people, providing the same quality services and programs as always.

We’ve been here for 46 years and we plan to be here for as long as people are experiencing seizures and need our help.

We are so proud that our organization is renewing its promise to help individuals who live with epilepsy to live life without compromise; to create more ways to enhance life despite living with seizures; and to support you and your family on this journey toward a life free of seizures and side effects.

You will now see this new name and logo on all of our materials, mailings, social media, emails, and more. But remember, we are still the same organization that has always been here for you!
Frequently Asked Questions

What is your name?
Our new name is Epilepsy Association of Western and Central PA (EAWCP)! You may have noticed for a few weeks that we were temporarily using the name “Epilepsy Western/Central Pennsylvania.” Now that we have a new, official name and logo, you will start seeing that on everything we do!

Why did your name change?
We are no longer affiliated with the Epilepsy Foundation of America, so we needed to change our name. You can read more about these changes in our update on page 6.

Will this change affect the help I receive?
No! The only things that are changing are our name and logo. We are still providing the same great programs and services that we always have!

If I want to make a donation, what should I write on the check?
You can make donations payable to “EAWCP” or “Epilepsy Association of Western and Central PA” or donate online at www.eawcp.org/donate.

Can I request print resources about epilepsy and seizures?
We do have some print resources available now, and we are working on rebranding every resource we produce. If you are looking for a specific resource or information about a particular topic related to epilepsy and seizures, please contact Laura at lnorris@eawcp.org.

Can you answer other questions I have about this change or can I share some thoughts with you?
Yes please! You can call our office any time at 412-322-5880 or email us at staff@eawcp.org. We understand these changes may be confusing so we’re here to help along the way!
This section of our newsletter focuses on you - people who persevere with their epilepsy, who raise money, and who raise awareness. Send your stories and photos to staff@eawcp.org.

If you are looking for a fun way to raise money, take a tip from the 13th Annual Julie McCormick Memorial Wiffleball Tournament in Indiana, PA!

- **Make friends with local organizations.** The Indiana Elks, pictured here, made a $1,000 donation to the event this year!
- **Sell lollipops.** Pauline is wearing a shirt that says “Epilepsy Sucks.” At this event, if you were lucky enough to purchase a lollipop with a colored stick, you won a prize.
- **Organize a duck toss.** Sell small, numbered rubber ducks to event participants. Paint a large circle on the ground and have everyone throw the ducks at the same time at a target in the center of the circle. The closest to the target wins half of the money.

Mackenzie Rummings, an 8th grader at North East Middle School, planned and hosted a teacher jeans day on Monday, March 26th. Teachers and students were encouraged to wear purple and make a donation. She also hosted a free after-school viewing of the movie, Wonder, in April. She accepted donations and sold purple gear and purple baked goods. Way to go Mackenzie!

Two young men who have been very supportive of the EAWCP received scholarships from UCB this year. Congratulations Zach and Brandon!

Zach Shuckrow (top) has been a part of the Family Fun Run/Walk for about 13 years. His sister, Abby, has been severely affected by epilepsy. Zach graduated high school and decided to use the opportunity to raise awareness for epilepsy by decorating his graduation cap. Zach is attending the college of William and Mary.

Brandon Glenn (left) is a former member of our Quality Improvement Leadership Team (QuILT). The QuILT is a group of medical professionals, families affected by epilepsy, and other stakeholders in the epilepsy community who advise our organization. He is attending the University of South Carolina Aiken.

The Society for Creative Anachronism (SCA) is devoted to the research and re-creation of medieval skills, arts, combat, and culture. The SCA in Western PA held an event at Cooper’s Lake Campground in Slippery Rock, PA. The SCA donated $1,780 from the event to the EAWCP because they have a lot of people with epilepsy who attend and participate in their event.

Megan Young, of York, and her mother Kelly, had an epilepsy education table at First Friday York on July 6th. First Friday is a celebration of Downtown York shops, restaurants, cultural venues, and nightlife hotspots. The event attracts several thousand people. Megan was able to connect with several people and even got one of the young women she met to attend a support group!
Julie Rodgers crocheted a purple afghan for the EAWCP Pittsburgh Office.

Melissa West wore an epilepsy awareness t-shirt when she threw the first pitch at the baseball game during Harrisburg Senators Community Day.

At Holy Trinity School, the student council votes for a charity to benefit from one of the school’s fundraisers, a lollipop sale. This year, Audrey Flanagan suggested us, and we got the most votes!

Pictured here are Ethan Williams, Kate Mickle, and Audrey Flanagan.

The West Middlesex Presbyterian Church Vacation Bible School held a “Shipwrecked” contest this summer and raised $1,100 in change for one of their community friends, Madison Callahan, who has epilepsy. Madison spoke to the children about raising epilepsy awareness, and the children raided their parents’ couch cushions and car seats in hopes that their group would be the ones with the heaviest change buckets! The 3-5 year olds won the contest with over 66 pounds of change!
Social media is a great tool for change! It is a way for us to interact with you outside of our programs and events and it's a way for you to help raise awareness for epilepsy in your community and beyond!

Did you know? YOU chose the theme for our Pittsburgh Family Picnic through a poll on Facebook and Instagram!

Some of our best programs and services exist only because you asked for them and gave us your input. We are ramping up our social media presence and hope you will follow along and join in on the fun!

Starting with the next newsletter, we will be highlighting some of your posts in a new section of our newsletter called Social Media Sidekicks. Check out the tips on the right if you want to be featured!

Follow Us: /eawcp @eawcp

Forgo internet-famous - your social media posts could be featured in a new section of our newsletter!

Just follow these easy steps:

1. Follow us on Instagram, Facebook, and Twitter.
2. Tag us in your epilepsy-related posts.
3. Like, share, comment on, and retweet our posts to spread the word.
4. Use the hashtag #EpilepsySideKick and we will like, share, and retweet your pic! You may even be featured in our Social Media Sidekicks section of our next newsletter.
5. Help others find your posts by using descriptive hashtags like:

   #EAWCP
   #Epilepsy
   #EpilepsyAwareness
   #EpilepsyEducation
   #SeizureSmart
   #EpilepsyAssociationWCP
   #EpilepsyPittsburgh
   #EpilepsyAltoona
   #EpilepsyHarrisburg
   #EpilepsyErie
Upcoming Events

2018

October 24
Johnstown Support Group Halloween Party
Johnstown

October 25
Halloween Spooktacular
York

October 26-28
Camp Firefly
Wexford

NOVEMBER IS NATIONAL EPILEPSY AWARENESS MONTH (NEAM)

November 6
Hershey Support Group
Hershey

November 8
York Support Group
York

November 17
Supporting Families, Supporting You Conference
Pittsburgh

November 17
Harrisburg Mini-Conference
York

November 22-23
Offices closed for Thanksgiving

November 23-25
St. Vincent Festival of Trees
Erie

November 28
Johnstown Support Group
Johnstown

December 4
Hershey Support Group
Hershey

December 8
Zonne Fund Movie Event - Wreck it Ralph 2
Pittsburgh

December 8
Harrisburg Holiday Party
Mechanicsburg

December 9
Erie Holiday Party
Erie

December 12
Johnstown Support Group Holiday Party
Johnstown

December 15
Pittsburgh Holiday Party
Pittsburgh

December 24-25
Office closed for Christmas

2019

January 1
Offices closed for New Year’s Day

January 18
Lunch and Learn Disabilities Job Fair
Johnstown

March 5
Mardi Gras Gala
Pittsburgh

May 18
Highmark Walk
Altoona

June 1
Highmark Walk
Erie

SAVE THE DATES for our November Conferences

We are hosting two conferences in November designed for families and individuals living with epilepsy. What better way to celebrate NEAM than with some education!

YORK AREA
Saturday, November 17, 2018
9:00am - 1:00pm
Wyndham Garden York
Contact Gretchen for details
717-730-6779

PITTSBURGH AREA
Saturday, November 17, 2018
9:00am - 4:00pm
Sheraton Station Square
Contact Andrea for details
412-322-5880

Congratulations to our 2018 scholarship recipients!

Mia Belgie
$1,500 Rohr Golden Family Scholarship

Chelsea Bisi
$1,000 Julie McCormick Scholarship

Tyler Drehar
$1,000 Stabler Foundation Scholarship

Austin Felicetti
$1,000 Mason Langford Memorial Scholarship

Grace Gilbert
$1,000 Stabler Foundation Scholarship

Jackson Hattfeld
$1,000 Celeste Katherine DeFrank Memorial Scholarship

James Henry
$1,000 EAWCP Scholarship

Blake Johnson
$1,000 Hinds Family Scholarship

Megan Kelley
$1,000 EAWCP Scholarship

Teddy Kunkel
$1,000 Center for Inclusion at UPMC Scholarship

Be sure to check our calendar for upcoming family events near you!
November is

Epilepsy Awareness Month

but individuals living with epilepsy need our help every month.

* You can help make our programs and services available to those in need every day of the year by using the enclosed donation envelope to show your support.

Thank you for your support