

FALL/WINTER NEWSLETTER 2018

E CONNECTION

WWW.EAWCP.ORG



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



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.



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.



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.



Photo by Vince Bruno

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.

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

Pittsburgh Office

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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

A Note from the President and CEO...

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.

Peggy



Peggy Beem-Jelley
President and CEO



Look for this ParentLink icon to find articles in our newsletter that may be especially helpful for parents of children with epilepsy.

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Spotlight on... Our Programs and Services



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.



SCHOLARSHIP PROGRAM

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.



TEEN TRANSITION PROGRAMS

Transition-aged teens (14+) should start taking charge of their future and we can help. We offer youth leadership programs to educate teens on how to advocate for themselves and take an active role when transitioning to adult healthcare. We also have resources for parents to help guide their teens to a more independent future.



OSCAR PROJECT SEIZURE RESPONSE DOGS

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.



SPECIAL EDUCATION

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.

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



RESPITE CARE PROGRAM

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 LOOK & NAME ARE

CHANGING

YOU Are Our Reason for Change

You probably received a letter in your mailbox in August explaining the changes our organization has gone through. In case you missed it, here is an update:

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!



...BUT WE'RE NOT

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?

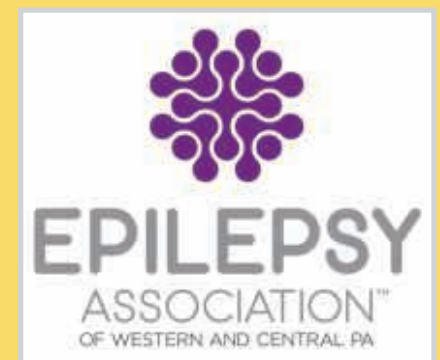
Yes please! You can call our office any time at 412-322-5880 or email us at staff@eawcp.org. We understand these changes may be confusing so we're here to help along the way!



Did you know?

Your brain is full of billions of brain cells called neurons. These neurons send electrical messages to each other to make you think, move, and do everything else the brain is responsible for. If your neurons start sending messages all at once, that can cause a seizure to occur.

Our new logo is inspired by this and features a stylized representation of a neuron.





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.

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 (QulLT). The QulLT 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.



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.



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.

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!



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

SEND US YOUR VIDEOS!

Have you recorded your loved ones' seizure activity?

Are you willing to share the video with us?

We are looking for real-life seizure scenarios to show during our seizure recognition and first aid presentations.



Contact Paige or Yazmin at 412-322-5880 for details.



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.

IS YOUR SCHOOL SEIZURE SMART?

Seizure Smart Schools are schools that have taken the time to ensure that all students, faculty, and staff have been properly educated in what to do if someone were to have a seizure. Last school year, we had six schools reach this designation!

Shout out to last year's Seizure Smart Schools:

- ACL D Tillotson
- Connoquenessing Elementary School
- CoTRAIC: Churchview
- CoTRAIC: Dorseyville
- CoTRAIC: Rochelle
- Seton Hill Child Services: Irwin



This school year, we want to designate TEN schools as Seizure Smart! Can you help us!? Call your school to request a Project School Alert presentation for all faculty, staff, and students and have your school call us at 412-322-5880.

CALLING ALL OF OUR SOCIAL MEDIA SIDEKICKS

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!

Forget 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
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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
Offices closed for Christmas



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

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

Congratulations
 to our 2018 scholarship recipients!

Mia Belgie
 \$1,500 Rohr Golden Family Scholarship

Chelsea Bisi
 \$1,000 Julie McCormick Scholarship

Tyler Dreher
 \$1,000 Stabler Foundation Scholarship

Austin Felicetti
 \$1,000 Mason Langford Memorial
 Scholarship

Grace Gilfert
 \$1,000 Stabler Foundation Scholarship

Jackson Hatfield
 \$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

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
 Wyndam Garden York
 Contact Gretchen for details
 717-730-6779

PITTSBURGH AREA

Saturday, November 17, 2018
 9:00am - 4:30pm
 Sheraton Station Square
 Contact Andrea for details
 412-322-5880

Congratulations
 to our 2019
 King of Mardi Gras

**Deb
 Rice-Johnson**
 President, Highmark Inc.



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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*