



# 2024 ANNUAL REPORT



**EPILEPSY**  
ASSOCIATION®  
OF WESTERN AND CENTRAL PA



*Joyce Bender (right), EAWCP Board Chair, with Logan Huwalt (left) at the 2024 Mardi Gras Gala.*

Meet Joyce from Pittsburgh.

She is the EAWCP Board Chair, a disability rights advocate, and a Pittsburgh Pirates fanatic.

She is 1 in 26.

As I travel around meeting people who live with epilepsy, I am astonished by their tenacity. People who live with seizures have an unwavering determination. They have persistence to achieve and a grit that leads to success. This is why we call people who live with epilepsy warriors!

These qualities that I so often find in people living with epilepsy motivate our Board of Directors, staff and volunteers to do what we can to provide help, hope and encouragement to those who continue to struggle with epilepsy and seizures. The 1 in 26 who continue to seek a treatment that will control their seizures are the most tenacious of us all. And, it is so important to the EAWCP that you know that you are not alone in your journey. EAWCP is most especially here for you.

If you are donating your time, talents or treasures to the EAWCP, I simply cannot thank you enough. Your efforts make it possible for EAWCP to bring services and programs to the neighborhoods where people live, work, play and go to school. Providing assistance to people who need our help right now, right here where they live, is central to our mission. And those who help to sustain the EAWCP, help to sustain the more than 133,000 Pennsylvanians who live with seizures.

I am proud to say that all of the proceeds from all of our events, all of the donations and contributions received by the EAWCP stay right here in western and central Pennsylvania. As you review our report for 2024, I am confident that you will see the impact that EAWCP has had in our community and on the lives of the 1 in 26 people living with epilepsy.

Joyce Bender

EAWCP, Board Chair

1 in 26 will develop epilepsy in their lifetime.

Throughout this report you will be introduced to some of the other epilepsy warriors supported by the EAWCP who, like Joyce, are so much more than their diagnosis.





*The EAWCP provided epilepsy awareness bracelets to and encouraged schools and companies throughout western and central Pennsylvania to host epilepsy awareness days. Several schools participated, including these students from Neshannock Township School District.*

# About Us

The Epilepsy Association of Western and Central PA (EAWCP) is a private, non-profit service organization providing public education and supportive services to individuals and families affected by epilepsy/seizure disorders.

Established in 1972, and with offices in Pittsburgh and Harrisburg and staff in Erie, the EAWCP offers its programs and services to residents throughout western and central Pennsylvania.

The work of the EAWCP is supported through private donations, a variety of grants, a contract with the Pennsylvania Department of Health, and special fundraising events.

The EAWCP is also a founding member of Epilepsy Alliance America, helping to build a nationwide network of organizations who are working to improve the lives of those affected by epilepsy by providing local programs and services today.

With support from a volunteer Board of Directors and Professional Advisory Committee that provides medical expertise, the EAWCP works to ensure an improved quality of life for those who face the challenges presented by epilepsy or seizure disorders.

## **EAWCP Board of Directors**

### **Policy Board**

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*This year we celebrated 10 years of the Oscar Project, which has provided 22 seizure response dogs to 23 people living with epilepsy. This year's recipients include Aaliyah, pictured here with her service dog Hazel, and Max, on the cover with his service dog Tillie.*

# By the Numbers

403 unduplicated individuals with epilepsy served  
132 new clients

## Support Programs

2,919 outgoing referrals

142 respite care hours covered  
10 families assisted

23 support group meetings

12 individuals received emergency medication assistance

7 Camp Frog campers

10 scholarships awarded

21 families provided movement detection monitors

6 social/peer support programs  
422 total attendees

2 families provided with travel assistance

35 SMART self-management program participants, unduplicated  
3 8-week sessions

2 Oscar Project seizure response dogs placed

## Education Programs

9,214 trained to recognize seizures and provide first aid

3,712 staff in schools

3,215 students

1,915 first responders

372 other community members

6 educational events

228 total attendees

## Public Awareness

24,095 visitors to EAWCP website

54,071 page views

8,550 social media followers

5,216 Facebook followers

1,287 Instagram followers

2,047 X followers





*Camp Frog campers were excited to board the bus to camp this year, as Camp Frog resumed its schedule as a full week of sleep away summer camp for the first time since 2019.*





Meet Abby from Bethel Park.

She is a bowler, a baseball player, and an amazing volunteer at the tailgate party for the Pittsburgh Family Fun Run/Walk. She is 1 in 26.

## Oscar Project

This year the Oscar Project celebrated 10 years of placing seizure response service dogs with people with epilepsy. Since the inception of the program, we have placed 22 service dogs.

The Oscar Project is funded by the *Michael R. Zupancic Seizure Response Dog Endowment Fund*. The fund pays for service dogs for children and adults living with epilepsy so they can gain independence. This year we placed two service dogs. The recipients included a teen with epilepsy who hopes to become an independent young adult and go to college and a young boy who has struggled in school both with his seizures and social life.

## Camp Frog

Camp Frog, a week-long overnight summer camp experience, took place June 16 – 22, 2024 at Camp Fitch in North Springfield, PA. This was the first full week of camp since 2019, and we had seven campers. Camp activities included: beach water sports, canoeing, archery, arts and crafts, horse trails, and more. A neurologist and nurse were on-site during the entire week of camp. Counselors were also fully trained to recognize seizures and provide first aid, build confidence, and provide guidance to campers in a fun-filled atmosphere. Financial assistance was provided to 4 campers through the *Steve "Froggy" Morris/G. Peter Rockwell Endowment Fund*.



*Aboard the Gateway Clipper, event participants can enjoy beautiful views of the city after hearing the presentation from Dr. Valeriano and visiting the tables of our event sponsors to learn about the newest treatments available for epilepsy.*



Meet Ezra from Beaver.

He is funny, loving, and loves to build puzzles.

He is 1 in 26.

## Project School Alert

The EAWCP provides free seizure recognition and response training through Project School Alert to school staff, students, and other community organizations. We also provide training and education to first responders. This year, 9,214 people were trained.

## Conferences

The EAWCP hosted two conferences this year, one that took place in Pittsburgh and one in Harrisburg. These conferences featured local epileptologists, neurosurgeons, and other experts in fields related to epilepsy. There were also resource tables with information from pharmaceutical and medical device companies. Combined, these conferences had a total of 67 attendees.

## Gateway Clipper Cruise

The EAWCP hosted an educational and social event aboard the Gateway Clipper. Attendees cruised the rivers around Pittsburgh while enjoying an educational talk about treatment options for epilepsy by Dr. James Valeriano, Allegheny Health Network. After the presentation, there was time for socializing and relaxing.





*The annual Purple Party includes a photo booth where participants can take a photo that they are then encouraged to share on social media to help raise epilepsy awareness.*



*Meet Mindy* from South Fork.

She is kind, sweet, and lovable.

*She is 1 in 26.*

## **Emma's Gift**

The Emma's Gift: Movement Detection Monitor Grant Program, created in 2015, is a partnership between the Emma Bursick Memorial Fund and the EAWCP. Movement detection monitors can alert parents or caregivers when a person makes repetitive movements indicative of a tonic-clonic seizure. The grant provides a family in need with one of three monitors of their choice to lower the risk of Sudden Unexplained Death in Epilepsy (SUDEP). This year, 21 movement monitors were granted.

## **CareShare Respite Care**

In an effort to assist the primary caregivers of youth and adults who have uncontrolled seizures, the EAWCP offers a temporary respite care program. Participants can receive up to 25 hours of respite care per year from a trained service provider, paid for by the EAWCP. This year, 10 families benefited from the program.

## **Support Groups**

The EAWCP hosts virtual support groups over Zoom that give adults with epilepsy an opportunity to interact with their peers and learn from knowledgeable guest speakers. We also hosted a virtual Paint Night social activity for the support group. This year 23 meetings were held, with a total 125 participants.





In November, three local families traveled to California for the annual Epilepsy Awareness Day and Expo at Disneyland, a three-day event filled with educational presentations, various booths, and an awareness day in Disneyland Park.





Meet Giana from South Park.  
She is beautiful, resilient and stylish.  
She is 1 in 26.

## Social Events

The EAWCP hosted 6 social events throughout the year, which were attended by a total of 422 people. These events included: a Winter Party, a Purple Party, a Family Picnic, two Fall Family Carnivals, and a Holiday Party. Although advertised as social events, these activities also give people with epilepsy and the people who support them a fun way to meet others and form peer support connections.

## Zonne Fund

The Zonne Fund was established in memory of Mark Zonneveld to support fun activities for children and families living with epilepsy. This year, the Zonne Fund sponsored a family of three to travel to Anaheim, California for the 12th Annual Epilepsy Awareness Day and Expo at Disneyland (EADDL). This event is the largest gathering of epilepsy families, physicians, and organizations in the country, and features a two-day educational expo followed by an awareness day in Disneyland Park. The Zonne Fund paid for the flights, ground transportation, and park tickets for the family.

Two additional families were sponsored by the EAWCP to attend EADDL this year, thanks to a grant from Sofie's Journey and additional funds from the EAWCP and the Zonne Fund.



At the Epilepsy Alliance America Member Organization Meeting in North Carolina, EAWCP staff attended a session focused on using social media platforms like LinkedIn to promote both themselves and the EAWCP. Pictured here are staff from other EAA member organizations.



Meet Allison from Harrisburg.  
She is brave, strong, and beautiful.  
*She is 1 in 26.*

## Epilepsy Alliance America

The EAWCP is a founding member of Epilepsy Alliance America (EAA), a nation-wide network of community based epilepsy organizations. The Alliance is dedicated to confronting the spectrum of challenges created by seizures through the promotion of independence and quality of life for people with epilepsy and their families. As a member of EAA, the EAWCP participated in national initiatives to raise awareness of resources for people with epilepsy.

This year, EAWCP staff traveled to North Carolina for the first official EAA Member Organization Meeting. This multi-day meeting allowed member organizations to share best practices and develop new skills to take home to their local communities. Sessions focused on topics like social media/marketing and program evaluation. EAWCP staff member Colleen Fulkerson presented a session on planning a successful fundraiser.

## Centers for Disease Control Grant

The EAWCP, in partnership with Epilepsy Alliance Ohio, the Epilepsy Association in Cleveland, and Case Western Reserve University, received a five-year grant from the Centers for Disease Control (CDC) to support epilepsy programs in Pennsylvania, Ohio, Kentucky, and West Virginia.

This year the EAWCP hosted three sessions of the self-management program called SMART (Self-Management for People with Epilepsy and a History of Negative Health Events), which is run by a nurse educator and peer educator. Across all cohorts, we had 35 participants in this program, though many chose to go through the program multiple times. You can learn more about SMART at [www.managemyseizures.org](http://www.managemyseizures.org).





Summer is run/walk season at the EAWCP and a huge crowd gathered at PNC Park for the Pittsburgh Family Fun Run/Walk for Epilepsy this year.



Meet Liam from Erie.

He is happy, mischievous, and strong.

He is 1 in 26.

## **Pittsburgh Family Fun Run/Walk for Epilepsy**

The Pittsburgh Family Fun Run/Walk for Epilepsy was held on Saturday, June 15th at PNC Park. It was a spectacular day on the North Shore as over 1,100 pre-registered runners and walkers filled Federal Street. We had 94 teams registered for the event. In addition, we were joined by local cosplay members: Captain America, Batman, Thor and other superheroes, who were on hand to take pictures and start the festivities. Andrew Stockey from WTAE and local comedian Jimmy Krenn joined Joyce Bender and Peggy Beem Jelley to award 5 of our 10 scholarships to recent area high school graduates who have epilepsy and are continuing their education. This event raised a total of approximately \$144,200.

## **Harrisburg Senators Family Fun Run/Walk for Epilepsy**

On Saturday, August 3rd we hosted the 22nd Annual Harrisburg Family Fun Run/Walk for Epilepsy on City Island. We had 34 Team Captains and over 250 pre-registered participants. Our Co-Chairs, Kennedy Miller and Yasmine Cowan from WHP-CBS 21 and Denny Logan from WINK 104 helped us to kick off the morning by awarding EAWCP scholarships. This event raised a total of approximately \$45,400.

## **Highmark Walks for a Healthy Community**

The EAWCP participated in the Highmark Walks for a Healthy Community in both Erie and the Laurel Highlands/Altoona. Highmark underwrites the cost of the walk so that 100% of the money raised by the walkers supports their participating organization. Combined, these events raised approximately \$6,400.





Mr. Jim McQuade (seated), President and CEO of Dollar Bank, was honored as the King of the 30th Annual Mardi Gras Gala. Also pictured (back row, left to right): Eric Boughner, Charlie and Latasha Batch, Deb Rice Johnson, and David Hall.



## Meet Bella.

She will be forever in our hearts. Bella passed away in 2024 from complications related to her medical conditions. *Bella will be an inspiration to us always.*

## Mardi Gras Gala

The 30th Annual Mardi Gras Gala honoring Mr. Jim McQuade, President and CEO of Dollar Bank, was held on Fat Tuesday, February 13th at the Westin Pittsburgh. Mr. McQuade's Dinner Chairs included: Deb Rice Johnson, Highmark Inc., Eric Boughner, BNY Mellon, David Hall, Emerus Holdings, and Dave Malone, Gateway Financial. We had 34 companies commit to supporting the event and had 450 revelers in the ballroom that evening. This event raised approximately \$366,600.

The evening started with our traditional Mardi Gras parade through the cocktail reception. For Mr. McQuade's entrance, the EAWCP worked with our families to create a video on what they would do if they were King. We then had all past honorees that were in attendance come to the dance floor to welcome Mr. McQuade to this elite group; the past honorees in attendance included Charlie and Latasha Batch (2023), Jeff Broadhurst (2020), Deb Rice Johnson (2019), and Randy Dearth (2018).

Each year a person with or family impacted by epilepsy talks about how it has affected their life and the role that the EAWCP has played in their journey. Emily Burkhart, a Dollar Bank employee, recorded a video about her youngest daughter, Bella, who lived with a rare genetic disorder and epilepsy. The video was shared with the Mardi Gras audience. Bella unexpectedly passed away several weeks later from complications caused by her CASK Gene Mutation.



**Donate today!** Scan this QR code or visit [www.eawcp.org/donate](http://www.eawcp.org/donate) if you would like to make a donation to support the programs and services of the EAWCP.



*Throughout the year the EAWCP also participates in community events, like the Carnegie Science Center's SciTech Day that focused on neurology. At our resource table, we used a plasma ball to demonstrate what happens in the brain during a seizure.*

# Year in Review

January 26	1 in 26 Day
January 27	Harrisburg Winter Party
February 13	Mardi Gras Gala
February 21	SMART Program, Spring Cohort (weekly through April 10)
March 9	Erie Purse Bingo
March 23	Purple Party
April 13	Harrisburg Mini-Conference (Epilepsy: Treating the Whole Person)
May 4	Pittsburgh Everything Epilepsy Conference
May 22	Harrisburg Team Captain Party
June 1	Erie Highmark Walk for a Healthy Community
June 15	Pittsburgh Family Fun Run/Walk for Epilepsy
June 15	Altoona Highmark Walk for a Healthy Community
June 16-22	Camp Frog
July 12-14	Oscar Project Training
July 18	SMART Program, Summer Cohort (weekly through September 5)
July 21	Harrisburg Senators Community Day & First Pitch
July 27	Family Picnic @ the Erie SeaWolves
August 3	Harrisburg Family Run/Walk for Epilepsy
August 16-18	Oscar Project Recertification
September 13	Gateway Clipper Cruise
September 23	Intro to EAWCP Central PA Services Zoom
September 25	SMART Program, Fall Cohort (weekly through November 13)
October 5	Pittsburgh Family Fun Fall Carnival
October 19	Harrisburg Fall Family Festival
November	Epilepsy Awareness Month
November 18-20	Epilepsy Awareness Day and Expo at Disneyland
December 7	Pittsburgh Holiday Party





*In April, EAWCP staff member Andrea Zonneveld visited the State Capitol to share her story about losing her brother to Sudden Unexpected Death in Epilepsy (SUDEP) in support of two bills that would help increase awareness of SUDEP, HB 1871 and HB 1872.*

# Financials

## Revenue

Contributions	\$180,604
Government Agency Grants	\$676,720
Net Special Events	\$465,767
Investment Income	<u>\$631,382</u>
	\$1,954,473

## Expenses

Program Expenses	\$1,286,891
Administrative	\$52,379
Fundraising	<u>\$125,712</u>
	\$1,464,982

**Year End Net Assets** \$6,770,511

*Includes Donor Restrictions of \$2,817,732*

\* Financial numbers are from the EAWCP 2023-2024 Fiscal Year. Revenues and Expenses are reported on a fiscal year, not calendar year, basis. Our fiscal year ends June 30.

Audited financial statements and the 990 are available on our website at [www.eawcp.org](http://www.eawcp.org).





Some of the younger Pittsburgh Family Fun Run/Walk for Epilepsy participants dressed up for the walk as Epilepsy Heroes.



# How We Help

If you are someone living with epilepsy or know someone who is, please contact the EAWCP to learn more about our programs and services and how we can help.

## EAWCP Programs and Services

- Adult Support Groups
- Conferences, Workshops, and Seminars
- Emergency Medication Assistance
- Individual and Family Consultation
- Information and Referrals
- Legislative Advocacy Assistance
- Medical ID Cards
- Oscar Project Seizure Response Dogs
- Parent/Peer Connect
- Resource Library
- CareShare Respite Care Program
- Scholarship Program
- Emma's Gift Seizure Monitor Information and Support
- Seizure Recognition and First Aid Presentations
- SMART Seizure Management Program
- Social Events
- Special Education Information and Advocacy
- SUDEP Support
- Summer Camp
- Teen Transition Programs
- Telephone Support

### **EAWCP Staff**

Peggy Beem Jelley  
*President and CEO*

Colleen Fulkerson  
*Senior Manager, Special Events*

Lynne Gensamer  
*Financial & Benefits Administrator*

Jordan Hinds  
*Senior Program Manager*

Sarah Kuhns  
*Community Education Coordinator,  
Harrisburg*

Marissa LaBant  
*Program Coordinator, Harrisburg*

Stacey Randall  
*School and Community Resource  
Coordinator, Erie*

Megan Woods  
*Community Education Coordinator*

Andrea Zonneveld  
*Director of Community Education &  
Outreach*



# EPILEPSY

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