



2023 ANNUAL REPORT



EPILEPSY
ASSOCIATION®
OF WESTERN AND CENTRAL PA



EPILEPSY
HERO

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 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.

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Each year, the epilepsy community gathers for the Pittsburgh Family Fun Run/Walk for Epilepsy to raise funds that support the programs and services of the Epilepsy Association of Western and Central PA.

EAWCP Board of Directors

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Impact

Information and Referrals

412 unduplicated individuals with epilepsy served
132 new clients

2,557 outgoing referrals

Support Programs

117 respite care hours covered
10 families assisted

26 support group meetings

22 individuals received emergency medication assistance

11 scholarships awarded

20 families provided movement detection monitors

8 social/peer support programs
439 total attendees

2 families provided with travel assistance

36 SMART self-management program participants

2 Oscar Project seizure response dogs placed

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Owen McLaren earned his Eagle Scout Award this year by raising funds and awareness for the EAWCP.

Education Programs

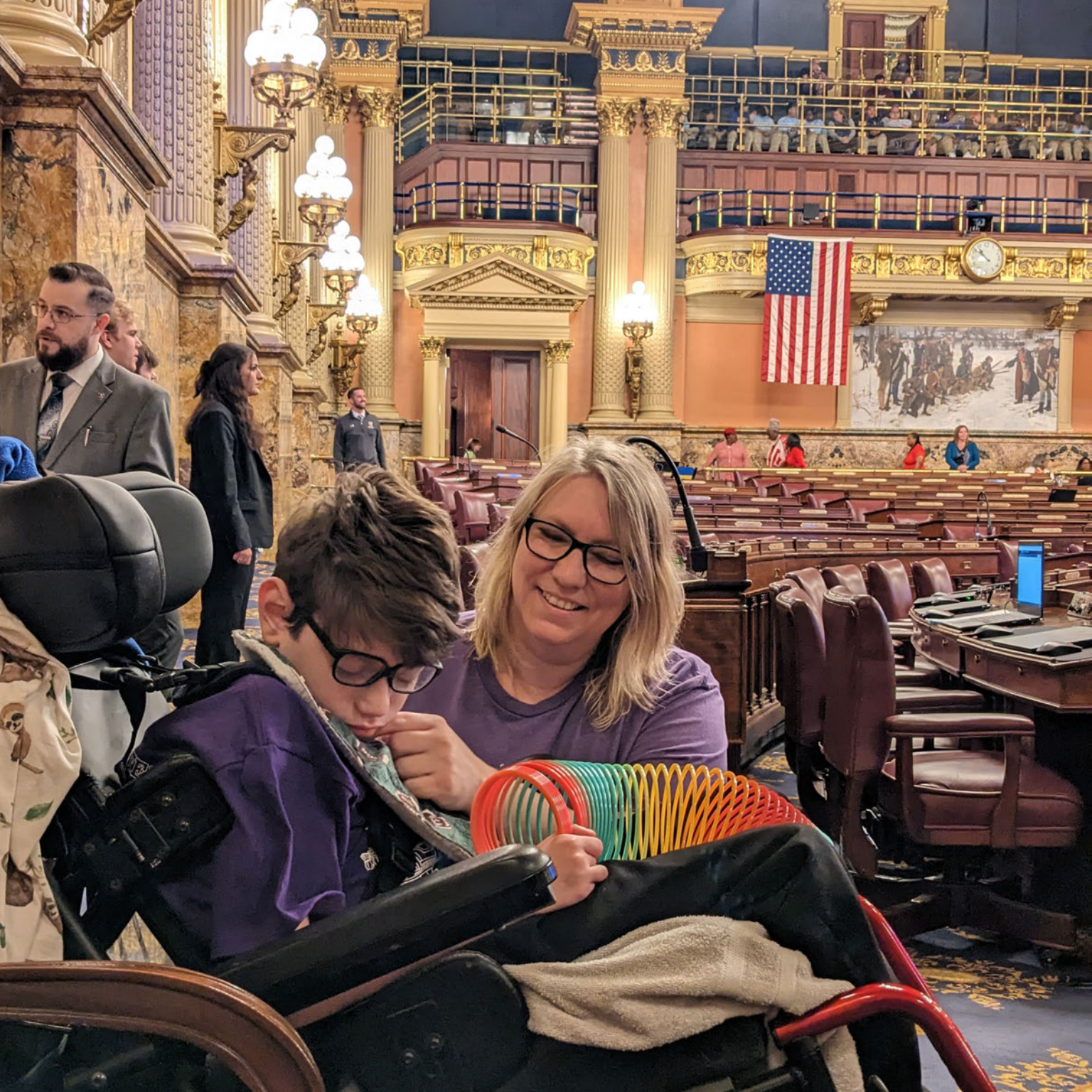
6,535 trained to recognize seizures and provide first aid
766 staff in schools
2,221 students
3,324 first responders
224 other community members

6 educational events
430 total attendees

Public Awareness

23,655 visitors to EAWCP website
56,656 page views

8,304 social media followers
5,063 Facebook followers
2,028 Instagram followers
1,213 X followers



Empower

SMART Program

This year the EAWCP hosted three rounds of a self-management program called SMART (Self-Management for People with Epilepsy and a History of Negative Health Events). This free program features a nurse educator and peer educator who guide participants through an online, 8-week course that covers everything from seizure management to goal setting.

Oscar Project

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 college student who planned to return to campus after a hiatus with the aid of her service dog and a young woman who currently lives with her parents but hopes to live in an apartment one day.

Share Your Story Conference

Families from across the state traveled to Harrisburg to learn how to be advocates and share their epilepsy story at the Share Your Story Conference. Sixty-five advocates from across the Commonwealth participated in this event, which culminated in a trip to the state capitol to advocate for funds to support epilepsy programs and services.

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During our annual legislative advocacy trip to the Pennsylvania State Capitol, staff member Stacey Randall and her son, Liam, were invited to be recognized on the floor of the Chamber of the House of Representatives.

BE THE
REASON
SOMEONE
SMILES
TODAY



My Not-So-Secret Seizures

Written by Paige Smith, Thomas Potts, and Andrew Campbell
Illustrated by Kristin Smith

Educate

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, 6,535 people were trained.

Summer Webinar Series

A series of presentations were held as webinars over the summer to educate families on a variety of pediatric topics, including seizure recognition and first aid training for family members, epilepsy treatment options, and surgical options for epilepsy.

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 by Dr. James Valeriano, followed by time for socializing and relaxing.

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Amanda Langford worked with her daughter's school to schedule a classroom program of My Not-So-Secret Seizures for her daughter's class.



Support

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 their risk of Sudden Unexplained Death in Epilepsy (SUDEP). This year, 20 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. This year 26 meetings were held, with a total 185 attendees.

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Don Petrelli, pictured here with his wife Trudy, has been volunteering with the EAWCP for almost 50 years, including helping with the original support groups that were held in a basement room of a building on 5th Avenue in Pittsburgh.



Innovate

Minor League Baseball Mini-Conferences

A series of educational events were hosted by the EAWCP at the stadiums of Minor League Baseball teams in western and central PA, including the Erie SeaWolves, York Revolution, and Washington Wild Things. At each stadium, a speaker presented information about an epilepsy-related topic before the start of the game. Attendees were invited to stay and watch the game, while socializing with their peers. A total of 238 people attended these events.

Teen Fun Day

The EAWCP organized a Teen Fun Day in Pittsburgh that included tie-dying t-shirts and painting a sloth using watercolors. In the afternoon, the group traveled to the National Aviary to explore exhibits and participate in interactive animal experiences.

Book Club

The EAWCP hosted a Book Club, reading and discussing *A Mind Unraveled* by Kurt Eichenwald. In the memoir, Kurt shares his personal experience with epilepsy and the challenges he had to overcome when confronted with the truth about his condition. The book club met weekly for 18 weeks to discuss two chapters at a time, while comparing the author's epilepsy journey with their own. The final 9 meetings were held at the beginning of 2023.

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This year, teens visited the National Aviary and fed nectar to Rainbow Lorikeets as part of our Teen Fun Day.



EXIT ONE

SATURDAY
APRIL 15TH

BADGE
#6



THE SUPER
MARIO
BROS.
MOVIE

VIP

Community

Social Events

The EAWCP hosted 8 social events throughout the year, including the movie event below. A total of 439 people attended these events, which included a Purple Party to celebrate an international day of epilepsy awareness, a cookie decorating party for our support group attendees, a Disney Trivia Breakfast Social to introduce our new staff in the Harrisburg office, two Holiday Parties, and more.

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 we hosted a private showing of *The Super Mario Bros. Movie* for families in the Pittsburgh area. Families were treated to a free movie, snacks, and the chance to win one of several door prizes.

The Zonne Fund also sponsored a mother and son to travel to Anaheim, California for the 11th Annual Epilepsy Awareness Day and Expo at Disneyland. This event is the largest gathering of epilepsy physicians and patients, 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.

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The Zonne Fund Movie Event includes door prizes for families, which this year featured Mario plush toys, family games, a giant Lego Bowser set, and more.



EPILEPSY
DOESN'T COME WITH A
MANUAL
IT COMES WITH A
DAD
WHO
NEVER GIVES UP

EPILEPSY
1 IN 26
AWARENESS

SOME PEOPLE
NEVER
MEET THEIR
HERO
I GAVE BIRTH TO ME

Partnership

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, an EAWCP-created holiday, 1 in 26 Day was adopted by EAA, receiving engagement from over 20 member and non-member organizations. Many member organizations chose to celebrate 1 in 26 Day like the EAWCP, by highlighting Epilepsy Warriors who are so much more than their diagnosis. Search #1in26Day on social media to see the current reach of this epilepsy awareness campaign.

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 36 participants in this program.

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The EAWCP partners with local businesses on epilepsy awareness activities, which this year included hosting a dog-friendly Yappy Hour event at a brewery in Erie.



Inspire

Pittsburgh Family Fun Run/Walk for Epilepsy

The Pittsburgh Family Fun Run/Walk for Epilepsy was held on Saturday, July 22nd at PNC Park. We had over 1,200 pre-registered runners and walkers and 102 teams registered for the event. Mike Clark from WTAE and Jimmy Krenn, a local comedian, served as event co-chairs. They were joined by our top fundraising Team and Individual from 2022, Bea Quallich and Dan Liebman, who were invited to start the run/walk with sirens, air horns, and cowbells.

Harrisburg Senators Family Fun Run/Walk for Epilepsy

On Saturday, August 5th, the EAWCP hosted the 21st Annual Harrisburg Family Fun Run/Walk for Epilepsy on City Island. We had 32 Team Captains and over 250 pre-registered participants. Our co-chairs, Candace Scalese from WHP-CBS 21 and Denny Logan from WINK 104 helped us to kick off the morning by awarding 2 EAWCP scholarships.

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.

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At the end of the Harrisburg Senators Family Fun Run/Walk for Epilepsy, participants cross over the Walnut Street Walking Bridge and under an arch of balloons.



Gratitude

Mardi Gras Gala

The 29th Annual Mardi Gras Gala honoring Charlie and Latasha Batch was held on Fat Tuesday, February 21st at the Westin Pittsburgh. Charlie and Latasha’s Dinner Chairs included: Diane Holder from UPMC Health Plan, John Reale from Pepsi, and Art Rooney from the Pittsburgh Steelers. We had 36 companies commit to supporting the event and had close to 500 revelers in the ballroom that evening. Our top sponsors this year included Highmark and AHN, PNC, UPMC and UPMC Health Plan.

Each year we have a person with epilepsy speak about how epilepsy has affected their life and the role that the EAWCP has played in their journey. Our speaker this year was 14 year old Logan Huwalt, who presented the EAWCP with a surprise check for \$1,830.



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

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King and Queen of the 2023 Mardi Gras Gala, Charlie and Latasha Batch entered the Mardi Gras in a giant transparent ball, showered in confetti.



Year in Review

January 9	Book Club (weekly through March 6)
January 26	1 in 26 Day
February 2	Support Group Social: Cookie Decorating Party
February 21	Mardi Gras Gala
March 25	Purple Party
April 5	SMART Program, Spring Cohort (weekly through May 24)
April 15	Zonne Fund Movie Event: Super Mario Bros. Movie
April 30 - May 1	Share Your Story Conference
May 6	York Mini-Conference and Revolution Game
June 3	Erie Highmark Walk for a Healthy Community
June 10	Laurel Highlands Highmark Walk for a Healthy Community
June 26 - 29	Summer Webinar Series
July 9	Washington Wild Things Education and Family Fun Event
July 22	Pittsburgh Family Fun Run/Walk for Epilepsy
July 26	Teen Fun Day in Pittsburgh
August 3	SMART Program, Summer Cohort (weekly through September 21)
August 5	Harrisburg Senators Family Fun Run/Walk for Epilepsy
August 6	Erie Mini-Conference and SeaWolves Game
September 8	Gateway Clipper Cruise
September 24	Family Tailgate
September 27	SMART Program, Fall Cohort (through November 15)
October 14	Disney Trivia Breakfast Social
December 3	Erie Holiday Party
December 9	Pittsburgh Holiday Party

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The final events of the year were a pair of Holiday Parties in Erie and Pittsburgh, where families could enjoy delicious food, make festive crafts, and meet other families impacted by epilepsy.



Financials

Revenue

Contributions	\$156,541
Government Agency Grants	\$638,929
Net Special Events	\$256,094
Investment Income	<u>\$490,878</u>
	\$1,542,442

Expenses

Program Expenses	\$997,979
Administrative	\$51,415
Fundraising	<u>\$128,537</u>
	\$1,177,931

Year End Net Assets \$6,281,020

Includes Donor Restrictions of \$2,557,333

* Financial numbers are from the EAWCP 2022-2023 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.

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Advocates visit the State Capitol in Harrisburg each year to ask for continued funding of epilepsy programs and services in Pennsylvania.



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
Special Events Coordinator

Lynne Gensamer
Financial & Benefits Administrator

Jordan Hinds
Community Program Coordinator

Sarah Kuhns
Community Education Coordinator, Harrisburg

Brooke Mohr
Children and Family Services Coordinator

Stacey Randall
School and Community Resource Coordinator, Erie

Cristina White
Program Coordinator, Harrisburg

Megan Woods
Community Education Coordinator

Andrea Zonneveld
Director of Community Education & Outreach

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New EAWCP staff members, Sarah Kuhns (left) and Cristina White (right) combined some of their favorite things - Disney and trivia - as inspiration for a social event where they could meet local individuals and families around the Harrisburg office.



EPILEPSY

ASSOCIATION[®]

OF WESTERN AND CENTRAL PA

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