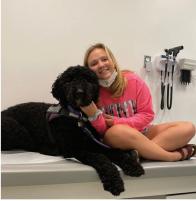
2022 ANNUAL REPORT



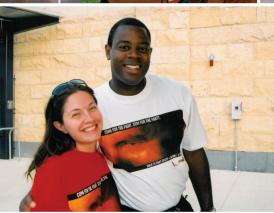


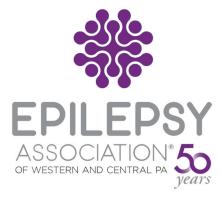




















Celebrating 50 years of service to the epilepsy community!

50 Years of Distinguished Service

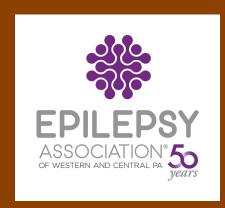
This year, the Epilepsy Association of Western and Central PA (EAWCP) is celebrating 50 years of serving the epilepsy community.

Throughout this Annual Report, we will highlight significant moments in the history of the EAWCP in color blocks like this one along the left side of many of the pages. Looking back at our history helps to show how far we have come as the organization has grown through the decades, evolving to meet the needs of all individuals living with epilepsy and the communities that support them.

1972 A group of parents and friends, concerned about the lack of services for people with epilepsy, establish what will become the officially incorporated Allegheny Plateau Chapter of the Epilepsy Foundation of America on May 30, 1972. Later this chapter becomes the Epilepsy Foundation of Western/ Central Pennsylvania, expanding to serve 49 counties.

2018 The Board of Directors decides to end the organization's status as an affiliate of the Epilepsy Foundation of America (EFA), to maintain the organization's focus on providing direct programs and services to local families. The organization is rebranded as the Epilepsy Association of Western and Central PA, debuting a new logo designed by Board member Anthony Musmanno's company IdeaMill.

2022 The Epilepsy Association of Western and Central PA begins a 50th Anniversary Celebration.



DEAR FRIENDS.

At EAWCP our purpose is to deliver helpful, supportive programs that elevate some of the stress and negative consequences of living with epilepsy. We strive to increase awareness of epilepsy and want to expand the public's understanding of epilepsy. We have been dedicated to that mission for 50 years.

There was a time when accomplishing that mission seemed straight forward. But the global health emergency has changed the way we do business, how we deliver programs, where we work, and what constitutes help in the eyes of those we seek to support.

What hasn't changed is our core values and passion for making life better for those living with seizures. The EAWCP Board of Directors and staff have never lost sight of the fact that, regardless of where you live or your individual circumstances, you deserve access to encouraging friends, neighbors and professionals who will help you to cope with the negative consequences of living with epilepsy.

Since 1972, the Epilepsy Association of Western and Central PA (EAWCP) has been there for those living with seizures. Many things have changed over the years - we've become dependent on our cell phones, communicate through emails and webinars - but the dedication and kindness of our donors has remained constant. Families and corporations supporting our programs make it possible for the EAWCP to do the important work that makes life a bit easier for those living with epilepsy and for those caring for someone with epilepsy. We are forever thankful for every donation, foundation grant, corporate contribution, and government contract that allows us to deliver services.

We've presented a snap shot of 2022 accomplishments in this report, along with a reminder of how far we've come over the last 50 years. We thank each of you who have played a role in each of our successes. We ask that you continue to support our programs and look forward to many more years of service to community.

Peggy Beem Jelley
President & CEO
Epilepsy Association of
Western and Central PA

FINANCIALS

Revenue

Contributions \$165,855
Government Agency Grants \$534,628
Government Grant - CARES Act \$310,415
Net Special Events \$297,760
Investment Income \$363,818

Expenses

Program Expenses \$995,920

Administrative \$45,845

Fundraising \$137,533

\$1,179,298

Year End Net Assets \$5,916,509

Includes Donor Restrictions of \$2,347,336

* Financial numbers are from the EAWCP 2021-2022 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.

BY THE NUMBERS

Information and Referral

families assisted with individual consultation and referrals

> 49 new clients

1,034 outgoing referrals

Support Programs

respite hours covered

17 families helped

52 support group meetings

8 individuals who received emergency medication assistance

10 scholarships awarded

13 Camp Frog campers

21 families provided movement detection monitors

social/peer support programs

total attendees

families provided with travel 2 assistance

10 **SMART** self-management program participants



Education

5,006 trained to recognize seizures and provide first aid

1,772 staff in schools

1,353 students

1,707 first responders

174 other community members

3 educational events

> 76 total attendees

1985 Through the help of board member Bobbie Martha, a 2-year grant from the Junior League of Pittsburgh is secured and the first paid program staff member is hired to formally develop a loosely existing school and community education program that she had been supporting on a volunteer basis.

1992 A full-time community education specialist is hired to give Project School Alert presentations to teachers, students, and other organizations interested in learning about epilepsy, seizure recognition, and first aid training.

1993 Project School Alert program designs two giant story books based on *Lee the Rabbit* and *Because You are My Friend*.

1996 The first Regional Family Conference on Epilepsy is held in Pittsburgh to offer an indepth look at the issues that affect people with epilepsy; more than 250 people attended.

2002 The Because You Are My Friend book

is turned into a coloring book for Project School Alert presentations for pre-K and elementary schools.

Dr. Patricia Crumrine has been

volunteering her time and expertise to speak at epilepsy

conferences for decades.

2018 EAWCP staff write a new children's picture book called *My Not-So-Secret Seizures* to teach young children about epilepsy and seizures.



My Not-So-Secret Seizures is currently used for teaching our youngest audiences about epilepsy.

NEIHINOW

2022

Apr 6 EAWCP provides first in-person Project School Alert presentation since the start of the COVID pandemic

May 19 Education Planning for Kids with Special Healthcare Needs: Evaluation and Developing IEP versus Section 504 Plans (parent education event)

Oct 12 Where are we Wednesday? weekly Facebook post debuts

Nov 12 Everything Epilepsy: Stronger Together - Connecting Epilepsy Communities Conference

EDUCATION

Project School Alert

The EAWCP provides free seizure recognition and response training to school staff, students, and other community organizations. As schools began to relax their restrictions this year, we returned to providing more in-person programs.

Follow us on Facebook and check out our Where are we Wednesday? posts to see where EAWCP staff is providing seizure training.

Everything Epilepsy Conference

The Everything Epilepsy: Stronger Together - Connecting Epilepsy Communities
Conference was held in Pittsburgh in
November as part of National Epilepsy
Awareness Month. The conference featured
a keynote speaker, Megan Young, who spoke
about living with epilepsy, her life with a
service dog, and how to bring awareness
to your local community. There were three
tracks of breakout sessions, including one
that focused on medical topics for adults
with epilepsy, one on pediatric topics, and
one that addressed other epilepsy-related
topics. Thank you to all of our speakers who
volunteered their time and expertise!



Dr. James Valeriano, Allegheny Health Network, presented Anti-Epilepsy Medications: New Options for Seizure Management at the 2022 Everything Epilepsy Conference.

2001 A scholarship program is created, and five \$1000 scholarships are awarded to teens with seizure disorders to attend a secondary school.

2006 The Steve "Froggy" Morris – G. Peter Rockwell Endowment Fund is established. The endowment will provide scholarships to young people with epilepsy so that they can attend Camp Frog.

2012 A major gift is received from the Zupancic Family to create the Oscar Project, which places up to three seizure response dogs a year with individuals living with epilepsy to help them gain greater independence.



Campers pose together for a photo at Camp Frog in 2006.

2013 The Zonne Fund is established in memory of Mark Zonneveld to provide fun, once-in-a-lifetime experiences for individuals and families impacted by epilepsy.

2014 A new respite care program, eventually branded as CareShare, is started to provide up to 25 hours of skilled nursing care per year to families impacted by epilepsy. The first respite care hours were awarded in 2015.

2015 Emma's Gift, a program that provides movement detection monitors that can alert caregivers when nocturnal seizure activity is detected, is created. This project was established and is supported by the Emma Bursick Memorial Fund in memory of Emma Bursick.

2020 A new Travel Assistance program is started to help families with the cost of traveling to doctor's appointments.



In 2014, the Zonne Fund hosted families for a free day of fun at the World Series Suite at PNC Park.

2022

Jul 15-17 Oscar Project Recertification

Nov 7 Book Club begins

SUPPORT

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.

Support Groups

The EAWCP hosted support group meetings five times a month. These groups offer a chance for people to connect and share their experiences. Some sessions also included guest speakers who presented on a variety of health and wellness topics. This year all of our support groups continued to be hosted virtually.

Oscar Project Recertification

Although no new Oscar dogs were placed this year, the EAWCP hosted a recertification event, inviting all Oscar Project recipients and their service dogs to brush up on their training and be recertified. To date, the EAWCP has placed 18 dogs into service since 2015.



One of the recipients of the Mother's Day flowers shared: "Mother's Day is a bittersweet holiday for those of us who have experienced the unimaginable pain of losing a child. Thank you so much for the kind gesture of this bouquet that will bring me joy and thoughts of Mark for years to come."

Mother's Day

Recognizing how difficult the loss of a child is, the EAWCP sent pop-up, paper flower bouquets with a message of support to 24 moms who have lost a child to SUDEP or another epilepsy-related cause.

1998 A new and improved newsletter, Interaction, is unveiled. Published quarterly and mailed to over 6,300 residences, it puts a face on epilepsy by telling the stories of people living with seizures.

1999 A billboard campaign is launched in Pittsburgh during National Epilepsy Awareness Month, which increases awareness and donations with the slogan: Epilepsy is What You Have, Not What You Are.

2001 A public relations campaign launches the distribution of four display boards, each targeting specific audiences in an effort to connect individuals experiencing epilepsy with the existing services. The display boards are distributed to doctor's offices, epilepsy medical clinics, pharmacies, and libraries throughout western Pennsylvania.

2006 The Pittsburgh Steelers, and Steelers offensive lineman Alan Faneca, invite families to training camp at St. Vincent College in Latrobe. Alan also speaks with two local TV stations to promote epilepsy awareness.



Alan Faneca and several other players took time after practice to sign autographs.

2007 A video is created

to raise awareness about the impact epilepsy/seizure disorders can have on families and how the support services can help them to improve quality of life.

2019 The EAWCP travels 2,600 miles to 26 cities and towns in western and central Pennsylvania on the 1 in 26 Tour in a 35-foot RV that has been custom wrapped with information about the EAWCP and local programs and services.

2021 The EAWCP invents a new epilepsy holiday on January 26th, called 1 in 26 Day, in honor of the 1 in 26 who will develop epilepsy in their lifetime. Over the course of the day, 26 epilepsy warriors are recognized on EAWCP social media platforms with photos and the three words or phrases that best described them, celebrating our warriors for being so much more than their diagnosis.

MONTHEN

2022

Jan 26 1 in 26 Day

Aug 14 Cooper Family Epilepsy Awareness Day at Kennywood

Oct 22 ZooBoo event in Erie

Oct 23 Harrisburg Christian
Performing Arts Center Trunk or
Treat program

Oct 27 Track or Treat at Harborcreek High School

Nov 26 Erie Otters Epilepsy Awareness Night

AWARENESS

Cooper Family Epilepsy Awareness Day at Kennywood

The EAWCP hosted its first ever Epilepsy Awareness Day at Kennywood Park on August 14th. Discounted tickets were available and thanks to the generosity of Sam Cooper and the Cooper Family, we were able to offer free tickets to 15 families (67 people) who enjoyed a fun day in the park. The EAWCP hosted an ice cream social in the afternoon for everyone who attended the event.

Halloween Events

The EAWCP participated in two Trick or Treat events this year. The first was a Trunk or Treat in Harrisburg that was hosted by the Christian Performing Arts Center and attended by more than 600 families. The second was a Track or Treat attended by approximately 2,000 people, which took place at Harborcreek High School in Erie.

The EAWCP also participated in ZooBoo, a Halloween event at the Erie Zoo, where staff hosted a resource table and gave out candy to approximately 500 attendees.

1 in 26 Day

The EAWCP celebrated our invented holiday on January 26th by sharing Facebook posts throughout the day that included photos and descriptions of 43 Epilepsy Warriors



Over 100 people joined the EAWCP for our ice cream social as part of the Cooper Family Epilepsy Awareness Day at Kennywood.

Erie Otters Awareness Night

The Erie Otters Hockey Night is a community event that gave the EAWCP a chance to integrate into the community in a fun way. The EAWCP had a public service announcement broadcast during the game and a resource table and raffle basket giveaway. Bella Zielger and her family were invited to drop the puck at the beginning of the game to recognize Epilepsy Awareness Night.

1994 The first state funding in Pennsylvania's history to finance epilepsy programs and services begins. This enables the organization to expand services in local territories, and establish the first epilepsy support services ever available in central Pennsylvania.

1998 The Pennsylvania General Assembly and the Governor's office double the appropriation for epilepsy services in the 1998-1999 state budget, which ensures continual full-time status of Project School Alert in western Pennsylvania, and enables the creation of such services in central Pennsylvania.

2010 A federal grant under the US Department of Health & Human Services (HRSA), Maternal and Child Health Services Division's Innovative Strategies in Serving Children & Youth with Epilepsy Project Access Program is received. This project creates an opportunity for the local staff and medical community event for families. to work with quality



In 2018, as part of the HRSA grant, the EAWCP hosted a Halloween-themed education

improvement programs within both primary pediatrics and specialty care. This grant is renewed in 2013 and 2016.

2012 In partnership with UPMC Health Plan, the organization develops Start SMART, an epilepsy selfmanagement program to make sure families have good communication with their care team, and connect to appropriate community resources.

2018 The EAWCP is one of eight former EFA affiliates who come together to found Epilepsy Alliance America, a national organization representing like-minded local, regional, statewide, and even other national agencies dedicated to serving the everyday needs of people who live with seizures and epilepsy every day.

2021 The EAWCP receives a 5-year grant from the Centers for Disease Control (CDC) in partnership with Epilepsy Alliance Ohio, Epilepsy Association Cleveland, and Case Western University.

2022

Jul 19-	SMART Self-
Sep 9	Management program
O a t 71	Enilanay Awaranasa

Epilepsy Awareness Oct 31-Nov 2 Day at Disneyland

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, including a tool for communicating with your doctor and resources for students for back-to-school season. We also sent staff to the 10th Annual Epilepsy Awareness Day and Expo at Disneyland to represent EAA and share information about resources that are available to families impacted by epilepsy.

CDC Grant

The EAWCP, in partnership 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.



The Zonne Fund paid for the Griffith Family to travel to the 10th Annual Epilepsy Awareness Day and Expo at Disneyland.

This year the EAWCP hosted our first self-management program called SMART (Self-Management for People with Epilepsy and a History of Negative Health Events), which had 10 participants and a nurse educator and peer educator.

As part of this project, we are also working to expand access to community programs and resources through our information and referral services, with an emphasis on outreach to families living in rural communities.

1984 The organization creates and facilitates a summer camp program for children with epilepsy. Volunteers begin transporting 25 kids in a donated van each summer to various camps. The annual camp becomes known as Camp Frog in honor of Steve "Froggy" Morris.

1989 An adult employment program, Job Seeking Skills Training Project (JSST), is initiated to help adults with epilepsy secure permanent employment by providing a job club, and individual vocational counseling. An Epilepsy Family Action Services project is also added.

1998 First Teen Getaway offers teens that have epilepsy the opportunity to share experiences and feelings about living with the disorder, while also building friendships and having fun.

2000 The first Family Picnic is held in Pittsburgh to provide the opportunity to socialize with other individuals and families affected by epilepsy in a fun, relaxed atmosphere.

2001 First Gateway Clipper cruise socialization and education event is held in Pittsburgh, featuring Dr. James Valeriano as an educational speaker. Nearly 100 adults cruised the three rivers.

event held in the spring.



In 2003, the organization included a hayride as part of the annual Family Picnic.

2014 The first Purple Party is held on March 26th, an internationally celebrated Epilepsy Awareness Day. The Purple Party is an annual social and peer support

2015 Teen Getaway is transformed into a Teen Leadership Retreat which brings together teens with epilepsy who have expressed interest in developing leadership skills.

2016 Camp Firefly, a new camp designed for children and teens with epilepsy and complex medical or behavioral needs is held at the Woodlands in Wexford.

2022

Mar 26	Purple Party
Sep 9	Gateway Clipper Cruise
Sep 16- Sep 18	Camp Frog @ Camp Allegheny
Dec 4	Erie Holiday Party
Dec 17	Pittsburgh Holiday Party & Mason's Movement Trolley Ride
Dec 17	Harrisburg Sugar

Cookie Social

SOCIAL

Purple Party

The EAWCP hosted our annual Purple Party at the Cardello Building in March, in recognition of Purple Day. The party included crafts and a "Purplest Person" contest.

Camp Frog

Campers were excited to be reunited in person for a Camp Frog weekend at Camp Allegheny in September. Extra medical and support staff were on hand all weekend to care for our campers and ensure their safety. Thirteen campers attended and enjoyed rock climbing, horseback riding, ropes courses, archery and building new friendships.

Gateway Clipper

The EAWCP hosted a social event aboard the Gateway Clipper. Attendees cruised the rivers around Pittsburgh while enjoying lunch, learning about the SMART selfmanagement program, and having an opportunity to form connections with their peers.

Holiday Parties

The Erie Holiday Party was held at Brewerie at Union Station and included a mac and



The Erie Holiday Party was held at a local train station that has been converted into a restaurant and bar.

cheese station, a cookie buffet, and a hot cocoa bar. Crafts and volunteers were provided by local community organizations. Santa also stopped by to say hi to the families.

The Pittsburgh Holiday Party was held at the Cardello Building and included brunch, crafts, and a visit from Santa. After the party, families were invited on a trolley tour of the holiday decorations in Pittsburgh, sponsored by Mason's Movement.

For the Harrisburg Holiday Party, we hosted a Sugar Cookie Social at the EAWCP office in Camp Hill. Families stopped by to decorate cookies and make holiday crafts. **1982** The Board and volunteers host the first-ever fundraiser, honoring new University of Pittsburgh Football Coach Foge Fazio.

Froggy's Golf Classic is created by Steve "Froggy" Morris, Peter Rockwell, John Phillips, and other board members to raise funds for epilepsy services.

1989 Fundraising expands with the addition of the first Pirates Family Fun Run/Walk to raise awareness and funds for epilepsy; more than 1,000 people participate.

1995 Dr. Louis Catalano coordinates the Westmoreland County Sports Dinner and Auction; it is the first fundraiser held outside Allegheny County for epilepsy services.

The first Mardi Gras Gala is held, which honors a prominent community/ business leader. Mardi Gras quickly becomes a popular fundraiser.

2003 The first Harrisburg
Senators and Erie SeaWolves
Family Fun Run/Walks
are held to expand the
fundraising footprint to two
new areas of the service region.



The first Mardi Gras Gala honored Hartley King of King's Family Restaurants.

2009 The Bursick Family hosts a fundraiser called Fair Play in memory of their daughter Emma. This event starts a trend of large third party events that donate all or a significant portion of their profits to the EAWCP to fund local epilepsy programs.

2011 The organization participates in the Highmark Walk for a Healthy Community in Erie for the first time, and, in 2012, also starts participating in the Highmark Walk for a Healthy Community in Johnstown (later moved to Altoona).



In 2010, we got help from the Pittsburgh Pirates' mascot to start the run/walk at PNC Park, now in its 35th year.

2022

May 3	Mardi Gras Gala
Jun 3	Erie Highmark Walk for a Healthy Community
Jun 12	Altoona Highmark Walk for a Healthy Community
Jun 25	Pittsburgh Family Fun Run/Walk for Epilepsy
Aug 6	Harrisburg Senators Family Fun Run/Walk for Epilepsy

FUNDRAISING

Mardi Gras Gala

This year, the EAWCP celebrated Mardi Gras in May with an annual gala to raise funds to support epilepsy programs and services. Although the celebration was delayed and attendance numbers were restricted for health reasons, it was great to be back in person as we honored Audrey Russo, President and CEO of the Pittsburgh Technology Council, as the King of the Mardi Gras. Over 350 revelers and 44 companies, including \$25,000 Fleur de Lis Sponsors Highmark/AHN, PNC, and UPMC/UPMC Health Plan, supported this event.

Run/Walk Events

The EAWCP hosted our 34th Pittsburgh Family Fun/Run Walk for Epilepsy at PNC Park and 20th Harrisburg Senators Family Fun Run/Walk at FNB Field. We also participated in the Highmark Walks for a Healthy Community in Erie and Altoona, which Highmark subsidizes so all of the money raised by participants comes directly to the organization they are supporting.

In total for all of the events, we welcomed over 1,300 walkers and runners and raised over \$150,000.



This dynamic duo is a brother and sister team who volunteered for the Pittsburgh Family Fun Run/Walk for Epilepsy. We regularly reach out to volunteers for help with educational, social, and fundraising events. We appreciate their time and dedication to the epilepsy community!

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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.

ABOUT EAWCP

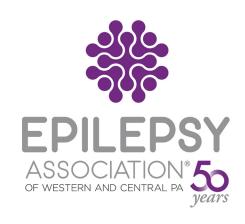
The Epilepsy Association of Western and Central PA (EAWCP) is a private, non-profit service organization providing public education and supportive services to individuals and families affected by epilepsy/seizure disorders.

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 Board 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.



Our Mission

We endeavor to improve the quality of life for persons with epilepsy/seizure disorders, and to dispel the myths, stigmas, and misunderstandings associated with epilepsy.



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