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# 2019

## ANNUAL REPORT



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

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

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 and staff in Pittsburgh, Harrisburg, and Altoona, 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. 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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# WHO WE ARE

## *Message from our Board Chair*



Joyce Bender  
*Board Chair*

I am truly honored to serve as the Chair of the Board of Directors of the Epilepsy Association of Western and Central PA (EAWCP) and I promise you we will continue to work to end stigma and serve more people living with epilepsy in Pennsylvania.

We have a great treasure in the powerful board of leaders and advocates that support the EAWCP. As our 2019 report reveals, we are thrilled to have an impact on the lives of thousands of individuals and families who are dealing with consequences of epilepsy and seizures. Our volunteer Board of Directors listens to the voices of those affected by epilepsy and guides us in fulfilling our mission with passionate, thoughtful, and deliberate direction. Our Professional Advisory Committee provides us with the medical expertise, advice, and knowledge that allow us to provide efficient and effective programs. Our wonderful staff works tirelessly each day, helping people

to navigate the challenges of living with seizures and assisting volunteers in increasing awareness of epilepsy in our communities.

The EAWCP strives to celebrate day-to-day successes, acknowledge families experiencing hardships or loss, and meet the needs of people affected by epilepsy in their local neighborhoods. We are committed to the belief that those living with seizures deserve compassionate help now, and that our greatest challenge is to provide that care today to the very best of our ability.

We are inspired by and thank all of you who are donors and volunteers and who give us your time, energy, and financial resources to pursue our mission. You are moms, dads, teachers, corporate leaders, neighbors, family members, friends, co-workers, and like me, people living with epilepsy, and those who love someone living with epilepsy. You make it possible for us to continue to grow and reach out to those who deserve our help, and we thank you for that strength. You are helping us raise awareness and provide services to those who need it most.

We have accomplished great things together. Of course, we have many challenges and a lot of work on the road ahead. I hope that as you review this report, you are as encouraged as I am that our organization will continue to have a great impact, by any measure, on the goal of improving the quality of life for all Pennsylvanians affected by epilepsy and seizures.

Thank you for supporting the Epilepsy Association of Western and Central PA in 2019 and into the future. We hope you will join us in 2020 as we celebrate the monumental milestone of the 30th anniversary of the signing of the Americans with Disabilities Act, the most significant civil rights law for Americans living with disabilities!

*Joyce Bender*



Clockwise from top left: participants in the Share Your Story/PA Public Policy Conference brainstorm what to include when sharing their epilepsy story; the Huwalt children volunteer to help at the Expo that is part of the Epilepsy Awareness Day at Disneyland while on a dream trip funded by the Zonne Fund; longtime friends enjoy the Pittsburgh Holiday Party; two young adults recreate the epic photo showcased on the 1 in 26 Tour RV; Camp Frog campers explore the wilderness; handmade decorations adorn our epilepsy awareness tree in Harrisburg; a family enjoys painting pottery at the Prancing Pig

# WHO WE ARE

2019 By the Numbers



**6.160** trained to **recognize seizures and provide first aid**

**5.284** staff and students in schools

**184** first responders

**526** other community members

**166** 1 in 26 tour education event attendees



**939** families assisted with **individual consultation**

**391** new clients

**1.535** non-event interactions



**350** **respite care hours** covered



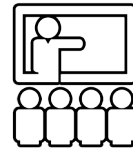
**38** advocates **sharing their stories** with legislators



**29** **support group meetings**



**21** **emergency medications** provided



**17** **education events**

**7** conferences and seminars

**7** health care transition events

**3** SUDEP events



**13** **movement monitors** granted



**10** **scholarships** awarded



**4** sessions of **Camp Frog & Camp Firefly**

**51** campers



**3** **Oscar dogs** placed



**\$725.660**

**raised** by our special events

**1** Mardi Gras Gala

**4** run/walk events

Highlights from 2019 that your support helped us provide:

## SUPPORT GROUPS FOR ADULTS

Monthly support groups in Hershey, Johnstown, and York

## SOCIAL EVENTS FOR FAMILIES

- Mar 23 PURPLE PARTY
- Sep 22 PITTSBURGH FAMILY PICNIC
- Sep 28 HARRISBURG FAMILY PICNIC
- Oct 16 HALLOWEEN SPOOKTACULAR
- Oct 19 BOO-LING: Bowling Event
- Oct 23 JOHNSTOWN HALLOWEEN PARTY
- Nov 16 BOWL FOR AWARENESS
- Nov 20 PAINT YOUR OWN POTTERY EVENT
- Nov 23 ZONNE FUND MOVIE: Frozen 2
- Dec 7 PITTSBURGH HOLIDAY PARTY
- Dec 14 CAMP HILL HOLIDAY PARTY
- Dec 17 ERIE HOLIDAY PARTY
- Dec 18 JOHNSTOWN HOLIDAY PARTY

## PATIENT EDUCATIONAL CONFERENCES AND SEMINARS

- Mar 2 HARRISBURG EPILEPSY MINI-CONFERENCE
- Apr 28-30 SHARE YOUR STORY CONFERENCE
- May 9 EDUCATIONAL SEMINAR: Challenges Facing Epilepsy Patients
- Jun 14 EDUCATION EVENT AT THE PITTSBURGH ZOO
- Sep 20 GATEWAY CLIPPER EDUCATION EVENT
- Oct 24 EDUCATIONAL SEMINAR: Challenges Facing Epilepsy Patients
- Nov 9 YORK EPILEPSY MINI-CONFERENCE

## CAMP PROGRAMS

- Apr 12-14 CAMP FIREFLY
- Jun 16-22 CAMP FROG @ Camp Conrad Weiser
- Jun 23-29 CAMP FROG @ Camp Fitch
- Oct 11-13 CAMP FIREFLY

## HEALTH CARE TRANSITION EDUCATION FOR TEENS

- Feb 6 WEBINAR: The Post-Millennial Transition Blues
- Apr 27-28 YOUTH LEADERSHIP SUMMIT
- May 4 MOVING UP. MOVING OUT MOVIE EVENT: Avengers Endgame
- Jun 29 MOVING UP. MOVING OUT MOVIE EVENT: Spider-man Far from Home
- Aug 9-11 NEXT STEPS TRANSITION CONFERENCE
- Aug 14 EDUCATIONAL SEMINAR: Ensuring a Smooth Sail to Adult Care
- Aug 28 EDUCATIONAL SEMINAR: Take Me Out to the Ballgame

## SUDEP EVENTS

- Apr 15 PROFESSIONAL DINNER: SUDEP Education for Doctors
- Apr 16 SUDEP SYMPOSIUM
- Oct 22 SUDEP FAMILY DINNER

## 1 IN 26 TOUR TO INCREASE EPILEPSY EDUCATION AND ADVOCACY

- Mar 10-14 York, Chambersburg, Harrisburg, Lebanon, and Bloomsburg
- Mar 16-21 Lewisburg, Williamsport, Towanda, Wellsboro, Saint Marys, and Clarion Washington
- Mar 24 Indiana, Clearfield, and State College
- May 9-14 New Castle, Meadville, Erie, Bradford, Oil City, and Butler
- May 16-17 Somerset and Altoona
- May 19 Greensburg
- May 21-22 Uniontown and Pittsburgh

## OTHER EVENTS

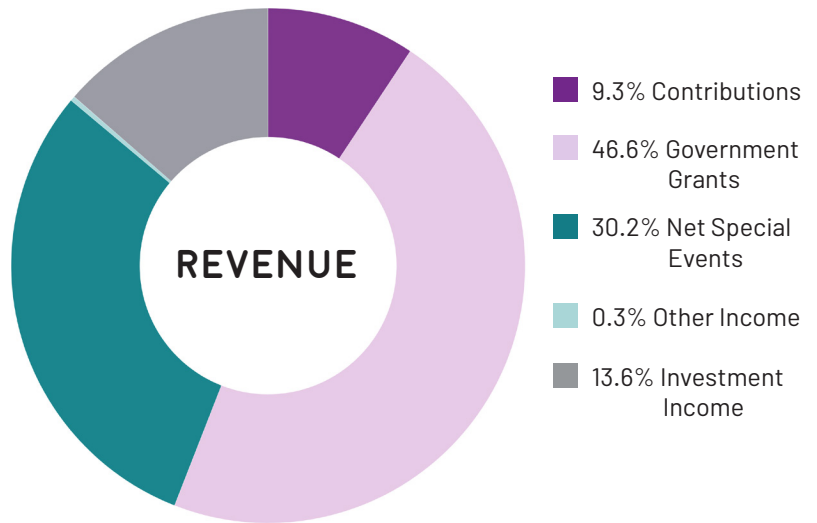
- Jan 18 LUNCH AND LEARN DISABILITIES JOB FAIR
- Jul 25 PROFESSIONAL EDUCATION: Special Needs Trust and Estate Planning
- Aug 20 PROFESSIONAL EDUCATION: Special Needs Trust and Estate Planning

# WHO WE ARE

*Our finances and making an impact*

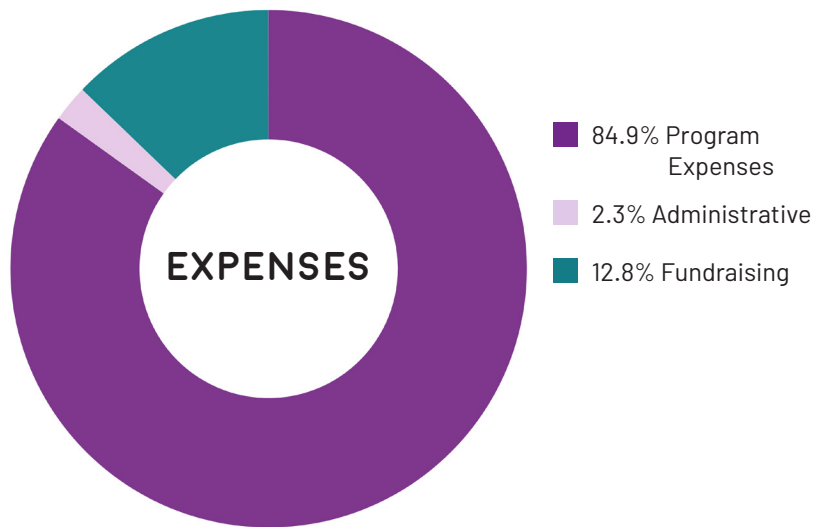
## Revenue

Contributions	\$153,715
Government Grants	\$767,814
Net Special Events	\$496,638
	<u>\$1,418,167</u>
Other Income	\$5,081
Investment Income	<u>\$223,991</u>
Total	\$1,647,239



## Expenses

Program Expenses	\$1,523,352
Administrative	\$40,635
Fundraising	<u>\$230,243</u>
Total	\$1,794,230



**Year End Net Assets** \$5,757,965



\* Numbers are from the EAWCP 2018-2019 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).



At a picnic for Oscar Project recipients, Alexis poses with her new service dog, Riley; Camp Firefly staff and campers gather for a group photo

## Highlights from 2019

- **Scholarships for High School Seniors**

Ten outstanding high school seniors, all of whom have epilepsy or a seizure disorder, received scholarships to further their education.

*\$1,500 Rohr Golden Family Scholarship*  
**Gabriella Sable**

*\$1,500 Mason Langford Memorial Scholarship*  
**Morgan Anderson**

*\$1,000 Celeste Katherine DeFrank Memorial Scholarship*  
**Haley Earl**

*\$1,000 Hinds Family Scholarship*  
**Renee Urda**

*\$1,000 Julie McCormick Memorial Scholarship*  
**Christine Easterday**

*\$1,000 UPMC Center for Inclusion and Engagement Scholarship*  
**Madison Callahan**

*\$1,000 EAWCP Scholarships*  
**Griffin Josephs**  
**Brooke Kennedy**  
**Heather Osterhout**  
**Luke Restiti**

- **Disabilities Job Fair**

Thanks to a grant from Lee Initiatives Health and Wellness Endowment, we hosted a *Disabilities Lunch and Learn Job Fair* in Johnstown.

Eighteen employers attended to discuss their available positions and resume writing help was available.

**38 individuals attended**



# HOW WE HELP

*Ensuring inclusion for individuals living with epilepsy*

Individuals with epilepsy should have the opportunities to go to camp, attend college, and live an independent life, just like their peers. We strive to make sure there is inclusion for all who are affected by epilepsy and seizures.



## Camp Frog

Our Camp Frog program places extra supportive and medical services into existing YMCA summer camp programs, allowing children who have seizures to enjoy summer camp just like their peers. Two separate week-long overnight sessions are held each summer at Camp Conrad Weiser in Wernersville and Camp Fitch in North Springfield. By having geographically diverse locations for camp, we hope to provide a camp that is convenient for everyone.

## Camp Frog Scholarships

All kids should have the chance to go to camp, regardless of their ability to pay for it. Financial assistance for Camp Frog is available through the Steve "Froggy" Morris/G. Peter Rockwell Endowment Fund.

**23 campers received full or partial scholarships**

## Camp Firefly

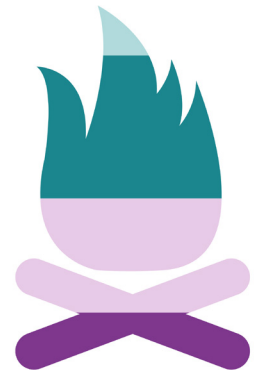
Camp Firefly is a weekend camp experience designed to accommodate campers with more complex seizure, medical, emotional, cognitive, and/or behavioral needs. Camp Firefly provides a one-to-one ratio of staff to campers at The Woodlands campsite in Wexford, a fully-accessible camp for individuals with special needs. Sessions were held in the spring and fall.



## Oscar Project

The Oscar Project is funded by the Michael R. Zupancic Seizure Response Dog Endowment Fund. Inspired by Michael's close relationship to his dog Oscar, and knowing that dogs can be trained to respond to seizures, the Zupancic Family established this endowment to both honor Michael, and to help others living with epilepsy. The fund pays for service dogs and their training for children and adults living with epilepsy who can gain independence with the help of a specially-trained service animal.

**3 Oscar dogs were placed in 2019**



## Kids at Camp

- 8** Camp Firefly, spring
- 16** Camp Frog @ Camp Conrad Weiser
- 20** Camp Frog @ Camp Fitch
- 7** Camp Firefly, fall



When I came out of the seizure, I didn't remember anything.

A coloring book presentation for elementary school students; a page from the coloring book, *My Not-So-Secret Seizures*

## Highlights from 2019

- **New EMS Training Certified**

We work with the PA Bureau of EMS to certify our trainings to provide continuing education credits whenever possible. In addition to the online course that is available on the TRAIN PA website, we certified an in-person presentation given by Dr. Jayant Acharya to interested EMS providers and organizations.

- **Seizure Smart Schools**

In 2019, six schools were recognized as being "Seizure Smart" for putting a priority on educating their staff and students about epilepsy and how to recognize and help someone who is having a seizure: Masontown Elementary (Masontown), Montour Elementary (McKees Rocks), and four Council of Three Rivers American Indian Centers - Rochelle, Hazelwood, Churchview, and Dorseyville (Pittsburgh).

- **My Not-So-Secret Seizures**

Our new coloring book program debuted this year. *My Not-So-Secret Seizures* is a picture book and accompanying coloring book that was written by our staff and illustrated by Kristen Baars. The book tells the story of a young boy named Ezra, how each of his best friends learned about his epilepsy, and how his friends support him when he has a seizure. *My Not-So-Secret Seizures* is more culturally diverse and addresses many more issues that relate to epilepsy than our old coloring book program. The presentation and coloring book are also available in Spanish as "*Mis ataques de epilepsia no son tan secretos.*"

# HOW WE HELP

*Training people to recognize seizures and provide first aid*

When a person has epilepsy, they must rely on the ability of the people around them to recognize when they have a seizure and provide the appropriate first aid. We provide free seizure recognition and first aid trainings to schools, first responders, and anyone else in the community who wants to know how to help.



## Project School Alert

Project School Alert is a free program that brings epilepsy education to our schools. We travel to schools throughout western and central Pennsylvania to educate students, teachers, nurses, bus drivers, and other support staff how to recognize and respond to seizures. Anyone can request Project School Alert trainings at any time – a parent, teacher, school nurse, or administrator.

**3,207** students, **1,116** teachers, **144** nurses, and **817** other school personnel were trained during 204 presentations



## First Responders

First responder is a general term that refers to those whose job it is to arrive first on the scene, including EMS personnel, firefighters, police officers, and more. While most of these jobs require training that includes general information about epilepsy and seizures, we offer free trainings that serve both as a refresher of basic seizure first aid and as a source of information about the latest advances in epilepsy treatment, including medical marijuana and devices that are used to manage epilepsy.

**131 first responders trained**



Grandparents of loved ones lost to SUDEP at a dinner for families; a guest speaker at the Hershey support group; a young girl loves her Olaf door prize at the Zonne Fund movie showing of Frozen 2

## Highlights from 2019

- **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 free showing of Frozen 2 for families in the Pittsburgh area. Families were treated to free popcorn and drinks, had the opportunity to win movie-themed door prizes, and even got to meet Princess Anna.

- **130 people attended the movie event**

We also sponsored a family of four to attend Epilepsy Awareness Day at Disneyland, which features a two-day epilepsy expo and then a day of fun in the Disneyland parks.

- **Language Inclusion**

As part of our efforts to be more inclusive, many of our more popular resources have been translated into Spanish. The end of 2019 found us researching closed-captioning for our transition videos and other visual media. Our goal is to provide material in whatever language or format is needed.

- **Mason Langford Center for Support and Learning on SUDEP**

As part of our efforts to support families affected by SUDEP, we launched a new resource on our website in the fall. The Mason SUDEP Center is named for Mason Langford, who was only 21 months old when he died from SUDEP. The Mason SUDEP Center is dedicated to providing information about SUDEP and resources that can help families. It also features a place where people can create memorial pages in memory of loved ones.

**SUDEP** is an acronym for **S**udden **U**nexpected **D**eath in **E**Pilepsy.

Each year SUDEP causes the death of 1 per 4,500 pediatric and 1 per 1,000 adult patients living with epilepsy. We dedicate our increased commitment to SUDEP education and awareness to all families who have lost a loved one to this tragedy.

# HOW WE HELP

*Building local epilepsy communities of support*

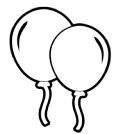
Epilepsy is a condition that tends to isolate people, by choice or by circumstance. We strive to connect people with epilepsy across all walks of life to help them to feel less alone, and to meet people going through the same struggles they face.



## Support Groups

Support groups are held monthly in Hershey, Johnstown, and York. These groups offer a chance for people to connect and share their experiences. Many sessions also include guest speakers who present on a variety of health and wellness topics.

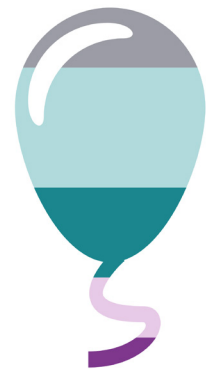
**29 support groups were held in 3 locations, 314 people participated**



## Social Programs

We host events throughout the year for children and adults living with epilepsy and their friends and family, providing an opportunity to relax and socialize. These events give anyone impacted by epilepsy the opportunity to meet and share their story with others who may be struggling with the same challenges or celebrating the same successes.

**786 people attended 1 Purple Party, 2 Family Picnics, 3 Halloween Events, 4 Holiday Parties, and 2 other events**



## Youth Leadership Summit

The Youth Leadership Summit is for teens living with epilepsy who have a desire to build personal and leadership skills. Both professional and student speakers led sessions throughout the weekend. At the end of the summit, participants presented on their story, what they learned, and their future goals.

**6 teens attended the Youth Leadership Summit**



A participant enjoys the sunset over Lake Erie after the Ensuring a Smooth Sail to Adult Care seminar; three teens use the skills they developed at the Youth Leadership Summit to advocate on behalf of themselves and all Pennsylvanians living with epilepsy; Dr. Barron and one of his patients star in our Transition with Ease videos

## Highlights from 2019

- **Take the NEXT Steps Transition Conference**

Transitioning from pediatric to adult health care providers can be a challenge for teens with epilepsy. Our *NEXT Steps Transition Conference* prepares teens to take control of their health care decisions and prepares parents to be supportive while letting their child gain independence.

**60 attended the conference**

- **Health Care Transition Education Series**

We hosted two educational seminars for teens and their families that focused on transition. *Ensuring a Smooth Sail to Adult Care* took place on a boat that cruised along the shore of Lake Erie. *Take Me Out to the Ballgame* took place in Altoona and was followed by a baseball game. Both events featured presentations from doctors to help families prepare for health care transition.

**102 attended the seminars**

- **Transition with Ease Videos**

Our new *Transition with Ease* series includes three videos: one that provides advice to parents, one that provides encouragement to teens, and one that walks teens through the health care transition process. We partnered with Dr. Todd Barron to film segments with his patients that were included in the videos.

- **QuILT and Professional Education**

The Quality Improvement Leadership Team (QuILT) is a group of individuals who work together to improve the quality and access to care that patients with epilepsy receive. This team includes neurologists, primary care physicians, families and teens affected by epilepsy, EAWCP staff, other community and statewide agencies, and clinical site partners. The QuILT mentors, supports, and provides training and technical assistance to the clinical sites.

At the QuILT's recommendation, we hosted trainings at Keystone Pediatrics and St. Christopher's Hospital for Children on Medical Assistance, Special Needs Trusts, and Estate Planning.

# HOW WE HELP

*Improving access to quality healthcare*

The “Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy” grant was a three-year Health Resources and Services Administration (HRSA) grant that ran from September 1, 2016 to August 31, 2019. Funding from this grant supported work on activities including telemedicine, mobile health (mHealth), transition to adult healthcare, community education, and increasing the capacity of medical home and other pediatric primary care practices to support children and youth with epilepsy and their families.

## Community Partnerships

Much of our project’s success is thanks to the amazing community partners that we worked with including: DLP-Conemaugh Adult Neurology, Drexel University-St. Christopher’s Hospital for Children Pediatric Primary Care, Drexel University-St. Christopher’s Hospital for Children Pediatric Neurology, Keystone Health/Keystone Pediatrics, Pediatric Care Specialists of Johnstown, Pediatric Specialists of Franklin County, WellSpan Adult Neurology, WellSpan Health/WellSpan Neurosciences, and WellSpan Health/WellSpan Pediatrics.

**14 professional education opportunities provided to our partners during the three-year grant**

**5 pediatric primary care, 2 pediatric neurology, and 2 adult neurology practices**

## Serving Children and Youth with Epilepsy

One of the goals of our HRSA grant was to serve 1,000 unduplicated children and youth with epilepsy over the duration of the grant. We exceeded the goal by providing support through direct clinical work with patients on transition, surveying youth and their families, and providing information through various educational events.

**3 Teen Leadership Summits, 3 NEXT Steps Transition Conferences, 10 transition education movie events, 5 transition seminars, and 1 webinar during the 3-year grant**

**1,644 children and youth with epilepsy served by this project during the 3-year grant**

## Telemedicine

We improved the access to care for patients in rural areas of the state by coordinating telemedicine visits to connect the office of their primary care provider to their neurologist. Telemedicine simplifies these visits, by preventing families from having to spend a lot of time and money going to and from their specialty care appointments.

**119 telemedicine visits conducted during the 3-year grant**



Dr. Buchhalter presents to families at the SUDEP symposium; a close up of the 1 in 26 RV; a young girl at one of our conferences

## Highlights from 2019

- **1 in 26 Tour**

A family of EAWCP supporters lent us their 35-foot RV to be used for our 1 in 26 Tour. We visited 26 mostly rural communities across Pennsylvania to reach families, towns, and cities that our staff are seldom able to visit due to time and geographical barriers. We wrapped the RV with a custom design created by IdeaMill that included EAWCP branding and information about our programs and services.

The 1 in 26 Tour ran from March through May. Along the way, each tour stop featured a local education event, lunch or dinner, a social element, as much public awareness as possible, and a chance for selfies with the RV. In all of the local communities, residents were welcoming, happy to meet our staff, and pleased to learn that we are here to help them, their family, neighbors, and friends.

**2,600 miles traveled to educate 166 individuals**

- **Two day event on SUDEP**

Dr. Jeffrey Buchhalter, a pediatric neurologist from St. Joseph's Hospital and Medical Center in Phoenix, AZ, spoke about SUDEP at a dinner for neurologists from Children's Hospital of Pittsburgh, UPMC, and Allegheny General Hospital.

**20 physicians attended**

The following evening, we hosted a dinner seminar for persons with epilepsy and their families. Dr. Buchhalter, and Dr. Anto Bagić of UPMC spoke about SUDEP. A panel of three families who lost a loved one to SUDEP, led by Dr. Miya Asato from UPMC's Children's Hospital of Pittsburgh, discussed why it is important to learn about SUDEP and shared how they are honoring their loved ones.

**66 people attended the seminar**



# HOW WE HELP

*Educating patients and the community about epilepsy*

We reach doctors and patients, parents and kids, and people with no connection to epilepsy through our varied education and outreach activities. There is always something more to learn about epilepsy, treatments, or first aid.



## Conferences and Seminars

We offer a variety of education event lengths, times, topics, and locations in order to try to reach the largest audience. *Seminars* are less than three hours and usually cover a single topic, *mini-conferences* are half day events meant to provide multiple topics in a single sitting, and *multi-day conferences* offer an in-depth learning experience around a single theme. In 2019 we held education events on topics such as epilepsy treatment options, autism and epilepsy, pediatric epilepsy surgery, special needs trusts, transitioning to adult health care, understanding the PA budget cycle, and advocating for epilepsy and your rights.



**386 people attended 1 multi-day conference, 2 mini-conferences, and 4 seminars.**

*Note: These numbers do not include the health care transition conference or seminars (pg 15-16) and SUDEP education events (opposite page).*

## Health Fairs

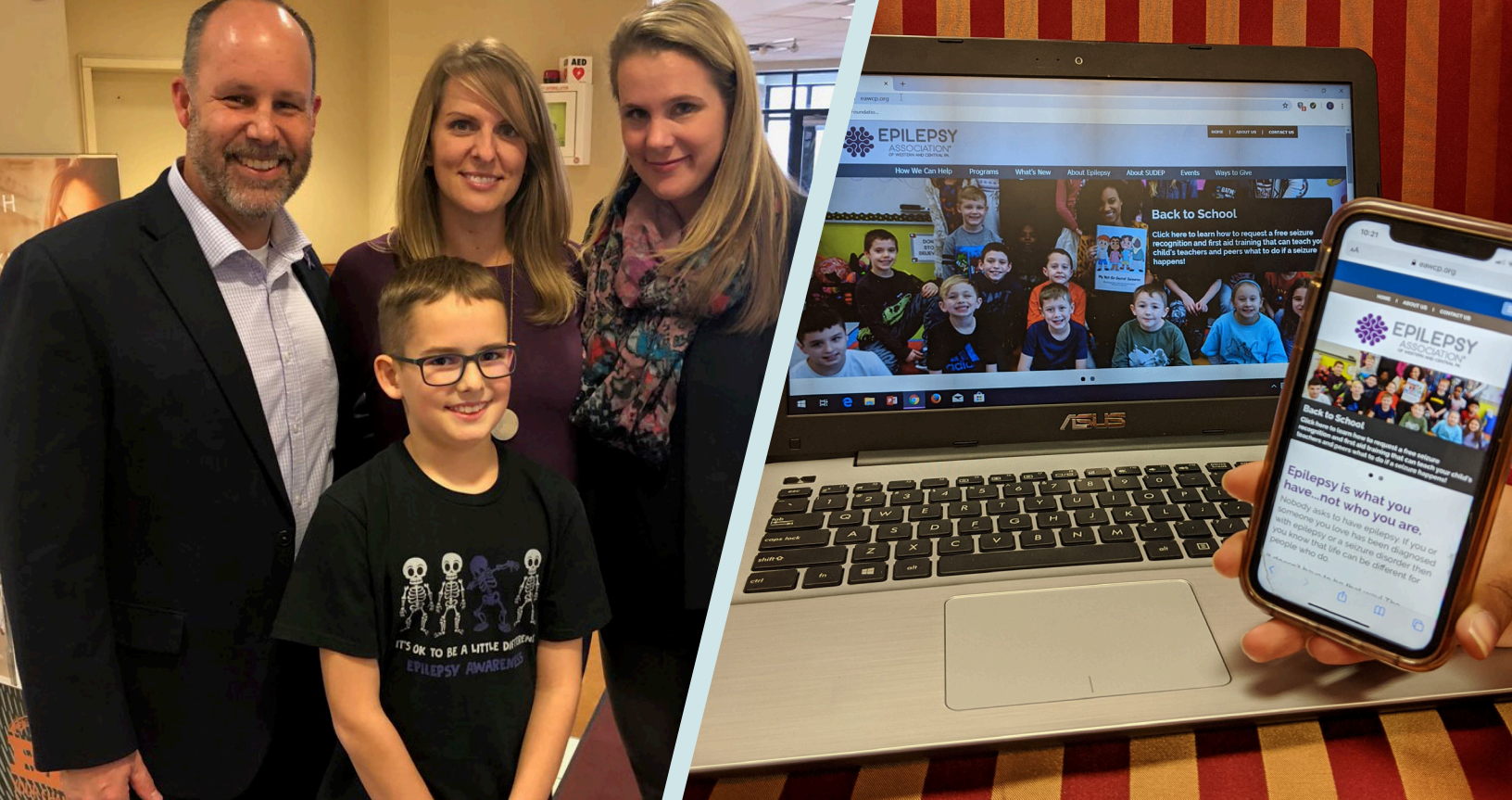
To reach new audiences, we frequently attend community health fairs and conferences to provide information about epilepsy and the services we offer.

**We attended more than 25 health fairs and conferences**

## Tree Events

We participated in two tree decorating events to help teach people about epilepsy during the holiday season. At the Saint Vincent Festival of Trees in Erie, the theme of our tree was *1 in 26*, and featured a photo opportunity for attendees to pose with our tree while holding a sign that described their epilepsy story (e.g. "I am one," "I love one," "I teach one," etc.). At the Parade of Trees in Harrisburg, trees are on display from Thanksgiving through the end of December. The theme of this tree was *everybody needs a hand at some point*.

**Over 11,000 people saw our trees, during these two events**



The Humphreys family hosted a dress down day at Central Penn College in support of their son; our newly redesigned website shrinks and stacks elements of the page in response to the size of the device you use to access it

## Highlights from 2019

- **Website**

2019 was the year we completely revamped our website. Our previous website was full of information, but you had to already know what you were looking for to find it. A lengthy process of asking “What would you call this if you didn’t know what it was called?” ensued. The website is now separated into over 50 pages organized by About Us, How We Can Help / Our Programs, and How You Can Help, which you may have noticed is how this annual report is also organized.

- **Digital Resources on Website**

As part of the redesign of the website, we added PDF copies of brochures and fliers that we distribute often. Many of these resources are also available in Spanish.

- **Caring for Your Child Binder**

In 2016 we published “Caring for Your Child”, a binder of information geared towards caregivers of newly-diagnosed children with epilepsy. In 2019, we revised the binder and expanded the resources section from only a few to over 50 pages. Although originally intended for families with newly diagnosed children, many parents have indicated the materials are useful for families who have been living with seizures for a long time. The binder is also available electronically in Spanish as “Cómo cuidar de su niño.”

**770 binders were printed in 2019, and 226 have been handed out**

# HOW WE HELP

*Supporting people when they do not know what help they need*

Epilepsy is a challenging diagnosis, and needs change as a person progresses through life with seizures. Many people who contact us are not sure what they need or how we can help. We spend time discussing each individual's situation to provide them with the best information and resources possible.



## Information and Referral

Coping with epilepsy can sometimes mean that you need information, support, and help from a variety of local service organizations. Knowing where to find and how to access these local services can vary greatly depending upon where you live and the specific help you need. Individuals and families can get help finding out about issues such as health insurance, medications, physicians, social security, driving laws, housing, education, and employment by contacting us.

**939 people contacted us for assistance**

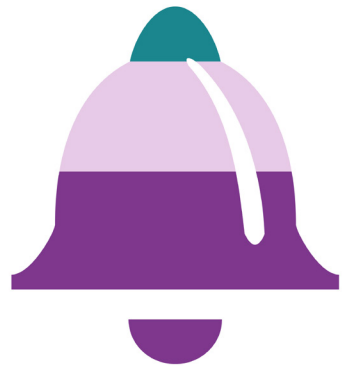


## Emma's Gift

The Emma's Gift grant program provides in-home movement detection monitors to qualified applicants through the Emma Bursick Memorial Fund. Movement monitors are designed to detect several seconds of sustained convulsive movement like that of a tonic-clonic (grand mal) seizure. They are often used to alert caregivers to nocturnal convulsive seizure activity.

**7 Emfit Movement Monitors, 4 SAMi Monitors, and**

**2 SmartMonitors were awarded totaling \$7,255**



## Emergency Medication

Our Emergency Medication Assistance Program can pay for up to a 30-day supply of anti-seizure medication. During those 30 days, we work with the individual to identify other patient assistance programs and find a long-term solution to the problem related to the cost of prescription drugs. A one month supply of a single anti-seizure medication can cost more than \$1,000.

**13 adults and 8 children received emergency medication assistance costing \$13,113**



photo by Mary Jane Bent



photo by Mary Jane Bent



photo by Vincent Bruno



Clockwise from left: The Berwick family poses with the Pirates mascot at the Pittsburgh Run/Walk; Mardi Gras Gala King Deborah L. Rice-Johnson flanked by dinner chairs; Amanda Langford and her daughter at the Mason Langford Memorial Golf Outing; walkers near the finish line at the Harrisburg Run/Walk

## Highlights from 2019

- **Golf Outings**

We provided assistance at two memorial golf outings that raised money in support of our organization this year.

The 4th Annual Mason Langford Memorial Golf Outing in Export included over 100 golfers and 30 additional dinner guests. The \$21,000 raised at this event will support the Mason Langford Center for Support and Learning on SUDEP as well as additional programs.

The 3rd Annual Paige Nagy Memorial Golf Outing was held in Uniontown. Perfect weather accompanied the 25 foursomes who helped to raise over \$16,000 to support our programs and services.

- **Every Fundraiser Matters**

Third-party events hosted by our supporters help to keep the lights on. We appreciate everyone who helps to raise funds or awareness. Some examples of fundraisers this year included:

- 14th Annual Julie McCormick Wiffleball Tournament

- Siblings selling purple bracelets for Purple Day (March 26th)

- A softball tournament

- A plumbing company that donates \$5 for every service call during November

- A car show

- A 3-on-3 basketball tournament

- Facebook fundraisers

- Selling hand-knitted scarves

- Partnering with a car dealership to donate a portion of sales during a month

- A furniture store that displays information and collects donations during November

# HOW YOU CAN HELP

*Supporting our fundraisers*

Fundraising events held throughout the year allow us to not only gather with corporate leaders, friends, and family, but also to raise awareness and much needed funds to support our mission.

## 25th Annual Mardi Gras Gala

Always held on Fat Tuesday, this year's Mardi Gras Gala honored Deborah Rice-Johnson of Highmark Health as the King of the Mardi Gras. Our \$25,000 Fleur de Lis sponsors included Highmark, PNC, and Peoples.

**Over 700 people attended the Mardi Gras Gala which was supported by 71 companies**

## The 31st Annual Pittsburgh Family Fun/Run Walk for Epilepsy

Over 1,500 people attended the Pittsburgh Run/Walk at PNC Park to raise funds and awareness for people affected by epilepsy. The festivities included breakfast, scholarship presentations, prize and t-shirt distribution, the 5K run/2 mile walk, tailgate party, music, bubbles, and the popular tribute garden which features pinwheel flowers planted in honor or memory of a loved one.

**1671 people and 124 teams registered for the Pittsburgh Run/Walk**



### Amount Raised per Event

## 17th Annual Harrisburg Senators Fun Run/Walk for Epilepsy

Held at FNB Park on City Island, the Harrisburg Run/Walk included breakfast, face painting and hair coloring, the 5K run/2 mile walk, encouragement from Harrisburg Cheerleaders, and a tailgate party featuring hot dogs, fruit, and sno-cones.

**494 people and 49 teams registered for the Harrisburg Run/Walk**

\$516,840	Mardi Gras Gala
\$5,563	Erie Walk
\$3,382	Altoona Walk
\$148,921	Pittsburgh Run/Walk
\$50,954	Harrisburg Run/Walk

## Highmark Walks for a Health Community

We participated in the Highmark Walks in both Altoona and Erie this year. These walks are subsidized by Highmark, so all of the money raised by participants comes directly to the organizations they are supporting. While these events do not represent a large portion of our fundraising income, we believe it is important for us to have a presence at these events to make the public aware of our programs in the region.

**92 people registered for the 2 events**



Purple Party attendees decorate tote bags with inspirational quotes and pictures; a participant dressed in purple for epilepsy awareness for the Harrisburg Run/Walk

## Ways to Give

- **One Time or Recurring Donations**

Consider a cash, check, or online donation to honor or memorialize a loved one or to celebrate a special event.

- **Gift Matching**

Many employers offer gift matching up to 100% of your personal gift. Check with your HR Department to see if your gift can be matched.

- **Plan Your Legacy Gift**

Legacy Gifts from individuals who believe in our mission, passion, and leadership will provide a base of financial stability on which to build the future. Call 412-322-5880 to set up a meeting. We can explore different gift options, and help you to decide if it is more beneficial to give immediately or through other giving strategies. Meet with your professional advisor to discuss the materials and documents we provide, and encourage them to call us when drafting your charitable giving plans.

- **Corporate Giving**

Gifts from businesses and foundations in the region allow us to grow and expand the reach of our programs and services. We look forward to discussing corporate philanthropy options with you.

- **Workplace Giving**

PA State Employees Combined Appeal (SECA): 2000-001

Combined Federal Campaign (CFC): 99717

United Way: Check with your campaign manager for the EAWCP number in your area

United Way Southwestern PA: 288

United Way Capital Region: 10070

The Epilepsy Association of Western and Central PA actively seeks diversified sources of income to support our programs. Individual and corporate donations, as well as special event fundraising, are critical to the long-term success and sustainability of the EAWCP.

# HOW YOU CAN HELP

*Message from our President & CEO*



Peggy Beem Jelley  
*President and CEO*

It is impossible to put into words the gratitude I feel for all of the things that our supporters do to make the programs of the EAWCP possible. Our epilepsy community in western and central Pennsylvania is thriving because of our passionate families, enthusiastic advocates, and committed patrons. We have a staff dedicated to providing the best programs, services, and events. The staff and I are thankful for the support of a committed Board of Directors, past and present, corporate partners, doctors and other medical personnel, volunteers, donors, and especially the families that we serve.

The pages of this annual report provide you with the numbers for the year. It includes fabulous photographs and accurate accounting of our activities. What it could never adequately convey is the true impact that so many of these programs have on the people who receive our help. How could I possibly explain how our programs transform lives or find words to say thank you to those who make these services possible? Did you know, for example that:

- Providing a seizure dog to a woman in her 30s who has epilepsy and is Deaf means giving her independence
- Paying for emergency medication for a youngster whose family temporarily lost their health insurance means that dad does not face a decision between paying for one child's seizure medication or another's insulin
- Conducting seizure first aid trainings in a second grader's school after he is diagnosed with epilepsy means his mom does not have to sit in the hallway at school all day anymore, just in case he has a seizure
- Giving a movement monitor to a family who has a child that has seizures at night means no one has to stay up all night watching the youngster sleep
- Arranging for nursing services and respite care for a family means that both mom and dad can attend an honors night with a sibling at school, secure in the knowledge that their child with uncontrolled seizures is well cared for at home

It's hard to know exactly what it feels like for these and the many other families who receive similar services, when they find out that the EAWCP is here and willing to help during a difficult time. I can tell you that the families we serve are overwhelmed with gratitude. I can tell you that, like them, I extend my sincere and heartfelt gratitude to everyone who makes our programs a reality. And, I can tell you that there are countless more families that need our help.

So, look past the numbers and into the faces in these photos. I hope they might inspire those who read this report to find new ways to get involved with our work. It is because of our collective efforts that we have been successful in the past. I know that coming together will propel us to even greater achievements in the future.

*Peggy Beem Jelley*



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