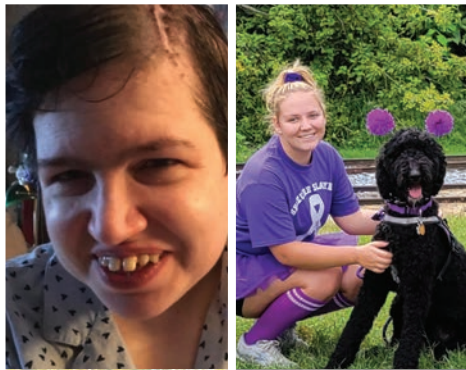




# 2021



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

Annual Report



I am fighting Epilepsy.  
What is your superpower?

#

IN



2021 brought the continuation of a pandemic, but it also reminded us all of why we do the work we do - for the 1 in 26 who will develop epilepsy and the entire community that rallies behind them.

We have filled the pages of this report with the faces of epilepsy, not just those who live with seizures, but also those who love and support their 1 in 26. As we adapted to the ever-changing landscape of last year, with each obstacle we encountered, we reminded ourselves that better days were coming and we would soon be able to be with all the people we have missed.

Along the way we have been inspired by the strength and resilience of our epilepsy warriors, the generosity of donors, and the tenacity of our Board of Directors and staff.

I want to thank everyone who has helped the Epilepsy Association of Western and Central PA in 2021, in years past and those that I know will support us in the future. Our successes are truly shared by all.

*Joyce Bender*  
EAWCP Board Chair

## A Review of the Year

# By the Numbers

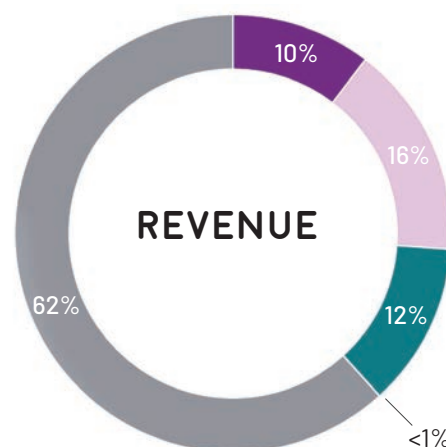
<b>477</b>	families assisted with <b>individual consultation and referrals</b>	<b>22</b>	Virtual <b>Camp Frog</b> campers
182	<i>new clients</i>	36	<i>hours of virtual programming</i>
<b>2,363</b>	<b>individual contacts</b> with clients	<b>3</b>	<b>Oscar dogs</b> placed
		18	<i>total dogs in service</i>
<b>329</b>	<b>respite care hours</b> covered	<b>29</b>	families provided with <b>movement monitors</b>
18	<i>families helped</i>		
<b>63</b>	<b>support group</b> meetings	<b>11</b>	<b>social events</b>
518	<i>total attendees</i>	287	<i>total attendees</i>
<b>8</b>	families helped with <b>emergency medications</b>	<b>2</b>	families provided with <b>travel assistance</b>
<b>15</b>	<b>educational webinars</b>	<b>5,555</b>	trained to <b>recognize seizures and provide first aid</b>
345	<i>total attendees</i>	1,469	<i>staff in schools</i>
		1,068	<i>students</i>
		2,940	<i>first responders</i>
		78	<i>other community members</i>
<b>11</b>	<b>scholarships</b> awarded		



## Financials

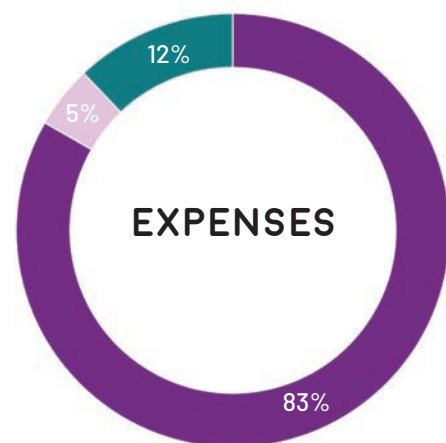
### Revenue

Contributions	\$225,516
Government Grants	\$343,750
Net Special Events	\$265,034
Other Income	\$180
Investment Income	\$1,343,137
	<u>\$2,177,617</u>



### Expenses

Program Expenses	\$833,930
Administrative	\$46,260
Fundraising	\$121,204
	<u>\$1,001,754</u>



**Year End Net Assets**     \$6,731,989

*Includes Donor Restrictions of \$2,759,290*



\* Numbers are from the EAWCP 2020-2021 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).



## Everything Epilepsy & Education Day

# Adapting Education

The pandemic limited our ability to gather indoors for educational programs and led us to adopt a virtual platform, giving us the ability to reach a vast geographic area to deliver information about important topics related to epilepsy.

### Everything Epilepsy

We created an ongoing program of webinars called Everything Epilepsy. In the fall of 2020 and continuing through most of this year, we hosted a new webinar series each season. Each series featured a different area of focus: general epilepsy information, information for parents and caregivers, treatments for epilepsy, and legal rights for individuals with disabilities. In total, we hosted 15 webinars with a total audience of 345 attendees. Most of the Everything Epilepsy webinars were recorded and are available on our website and YouTube channel.

### Epilepsy Education Day

Every year on March 26th, people wear purple to support epilepsy awareness and support their family and friends living with seizures.

This year, we celebrated March 26th with a Virtual Epilepsy Education Day. We invited teachers in schools throughout western and central Pennsylvania to join us for virtual presentations of our My Not-So-Secret Seizures or 1 in 26 program. This program was announced through a direct mailing to school nurses in all public schools in western and central Pennsylvania and an email sent from the Division of School Health of the PA Department of Health. All marketing efforts also included copies of the new *Epilepsy in the Age of COVID-19* first aid poster. With 860 students, we broke our record for the most students educated about epilepsy in one day.



WOW WE LIVE THIS

IN TRAINING

Certified Oscar Dog

Tesia Thomas

Oscar Dog



## Oscar Project & Support Groups

# Creating Support Systems

Support comes in many forms - from a curly, four-legged companion who becomes an invaluable sidekick to a virtual room of strangers who quickly become friends.

### 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's memory, and to help others living with epilepsy. The fund pays for service dogs for children and adults living with epilepsy so they can gain independence with the help of a specially-trained service animal. This year we placed three service dogs. The recipients included a graduating high school senior who hopes to attend college next year and a sophomore at Penn State University. A third recipient is also a graduating high school senior who hopes that having a service dog

will help him make plans to attend a training program or pursue business school.

### Support Groups

The past few years have been particularly challenging for many people with epilepsy who already struggled with isolation prior to the pandemic. This year we hosted a record 63 support group meetings. 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. This year all of our support groups were hosted virtually, which has significantly expanded the geographic reach of this program beyond what was possible when the groups met in-person at a single location.



Gianna

VNSTherapy® VNSTherapy®

I wear PURPLE for



EPILEPSY  
Awareness

## 1 in 26 Day & SUDEP Materials

# Expanding Awareness

The focus of our epilepsy awareness efforts centered on celebrating our everyday epilepsy heroes and honoring those we have lost to SUDEP and other epilepsy-related causes.

### 1 in 26 Day

On January 26th, we invented a new holiday that we called 1 in 26 Day, in honor of the 1 in 26 who will develop epilepsy in their lifetime. We invited people to share photos of the ones they love who are living with epilepsy and to describe them in three words or phrases. In total, we showcased 26 epilepsy warriors in social media posts throughout the day and our new holiday inspired nearly \$1,000 in donations to support programs and services for individuals and families impacted by epilepsy. These warriors are featured on the cover of this report. In addition, our social media reach increased by 200% in January.

### SUDEP Materials & Outreach

SUDEP stands for Sudden Unexpected Death in Epilepsy. For the past few years, a group of families that are linked by the tragedy of losing a loved one with

epilepsy have been meeting with each other and staff from the EAWCP to identify and address gaps in services for grieving families.

This year we created new printed materials for funeral directors and their staff. The first is a brochure that educates funeral home staff about SUDEP and prepares them to have a conversation about this difficult topic. The second resource is a rack card that can be given to families who have experienced loss. It includes information about all of the resources available through the EAWCP, including the Mason Langford Center for Support and Learning on SUDEP, a peer support network, and more. These materials have been distributed to all funeral homes in western and central Pennsylvania and are also available upon request.



## Epilepsy Alliance America & the CDC

# Together We Are Stronger

This year we continued to expand our impact through our partnership with Epilepsy Alliance America and a new grant that allows for collaboration with like-minded organizations based in Ohio.

### Epilepsy Alliance America

The EAWCP is a founding member of Epilepsy Alliance America, 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.

Our partnership with the Alliance gives us the ability to remain an independent organization but collaborate on a national level with other agencies dedicated to providing direct programs and services. Early this year, the *Epilepsy in the Age of COVID-19* first aid poster that was developed by EAWCP staff was distributed nationwide through the network of Epilepsy Alliance America member organizations.

### CDC Grant

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

The project will focus on two initiatives. We will be helping adults with epilepsy through a self-management program called SMART (Self-Management for People with Epilepsy and a History of Negative Health Events). And, we will be 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.



Walk for Epilepsy 2021

KINGS

DIONNE

DIONNE

#DoingitforDionne

Walk for Epilepsy 2021

## Run/Walks and Social Events

# Reuniting with Friends

With appropriate safety measures in place, we were able to host our annual run/walk fundraisers and some in-person social gatherings in Pittsburgh and Harrisburg.

### Run/Walk Events

We hosted our Epilepsy Awareness Walk in Pittsburgh and Senators Family Fun Run/Walk in Harrisburg as hybrid events, with options for participants to join us in-person or walk in their own community.

When making plans in March for the Epilepsy Awareness Walk in Pittsburgh, we were unsure what to expect for June so we built safety measures into the event. We staggered registrations times to avoid a large gathering. We only provided individual, prepackaged food items. Without a tailgate party, the bridge was available for photos and many participants posed with our #1in26 prop and the city skyline as the background.

The Harrisburg Senators Family Fun/Run Walk took place in August, and also offered a traditional and virtual option. With fewer restrictions in place, we were able to keep a regular schedule and over 200 people gathered at FNB Field for the event.

On the mornings of each event, we launched a kickoff video live on Facebook and YouTube to inspire

and energize the participants who planned to walk in their local communities.

Our dedicated walkers and donors raised well over \$150,000 in 2021, despite the pandemic and challenges with attending in-person gatherings.

### Social Events

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.

Since the beginning of the pandemic, many of our social events, like our annual Purple Party, have been held virtually. Toward the end of the year, however, we took advantage of outdoor spaces and reduced risk factors and held four in-person social events, which included a fall festival, a Halloween event, and two holiday movie screenings.



## 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.
- **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
- **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.
- **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, and encourage them to call us when drafting your charitable giving plans.



## Mardi Gras & Sponsorships

# Innovative Fundraising

We actively seek diverse sources of income to support our programs, which this year included a Mardi Gras campaign without the gala and new sponsorships for program events.

### Mardi Gras Campaign

With high coronavirus numbers, it became clear that hosting a gala would not be possible in 2021. Undeterred, Audrey Russo, our 2022 Mardi Gras King, and Joyce Bender, EAWCP Board Chair, personally reached out to the Pittsburgh corporate community to urge them to support the 2021 Mardi Gras Campaign. Although we could not be together to let the good times roll, the Pittsburgh companies rallied to ensure the funding necessary to continue supporting important epilepsy programs and services.

We anticipate returning to an in-person event next year, and we look forward to recognizing companies that participated this year as our Knights of the Purple Ribbon at the 2022 Mardi Gras Gala!

### Program Sponsorships

EAWCP programs are often made possible by grants or the generous support of contributors who establish dedicated funds.

We also receive several program sponsorships from the corporate community. These corporate donations often make social and educational events possible.

Support from program sponsors pays for the direct cost of individual social or educational programs including venue rental, food, entertainment, craft supplies, and other related materials. Program sponsorships also cover the cost of postage and mailing invitations or event flyers.

Restricted funds support several individual programs, including the Oscar Project, made possible by the *Michael R. Zupancic Seizure Response Dog Endowment*, which pays for service dogs. The *Emma Bursick Memorial Fund* pays for movement monitors provided by Emma's Gift. And, individual donors underwrite the expense of several of our high school scholarships (the *Golden-Rohr Family*, *Celeste DeFrank Memorial*, and *Hinds Family Scholarships*).

## Who We Are & Our Mission

# Our Epilepsy Community

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 and Harrisburg, 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.



**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.

# 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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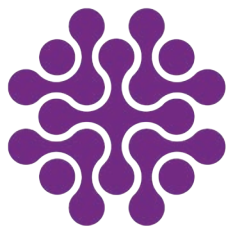
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**EPILEPSY**  
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