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ON THE COVER: Colston, member of the run/walk team Colston's Corral, found fun places to walk while participating in the run/walk virtually this year.



The EAWCP participated in a Christmas in July event, hosted by the Mall at Robinson, with an interactive tree display.



Ronit, a camper, paints a creative design onto a birdhouse during Virtual Camp Frog.



By providing supports and services, the Epilepsy Association of Western and Central PA (EAWCP) endeavors to improve the quality of life for persons with epilepsy/seizure disorders and to dispel the myths, stigmas, and misunderstandings associated with epilepsy.



Tesia poses with Atlas, her new service dog that she received through the Oscar Project.



Participants in Harrisburg were excited that the Harrisburg Senators Run/Walk for Epilepsy was held in-person this year.



Families who participated in the Virtual Holiday Party received a gingerbread house kit to build as a family.

Visit **www.eawcp.org** or contact one of our offices:

Pittsburgh Office

1501 Reedsdale Street Suite 3002 Pittsburgh, PA 15233

> 412-322-5880 800-361-5885

Harrisburg Office

3507 Market Street Suite 203 Camp Hill, PA 17011

> 717-730-6779 800-336-0301

TDD EOP / AUX AID 800-855-2880

A Note from the President and CEO...

Dear Friends,

I have been reflecting on the things most important to our success. Optimism, the ability to stay hopeful and have confidence about the future, keeps surfacing in my thoughts. As individuals and as an organization, I think our ability to remain optimistic is key to moving beyond difficulties and managing the challenges that confront us.



Peggy Beem-Jelley
President and CEO

In 2020, no one would have predicted the work environment we have today. When we pivoted to online programs, we never expected to be continuing to work on expanding virtual programs. The idea of not hosting in-person fundraising events would have been scandalous. Yet, in each of these cases, all of our leaders, volunteers, the people that we serve, their families, our donors, and everyone associated with our organization quickly stepped forward to say, "We can make this happen. Tell me how I can help."

Our community responded with optimism. And that optimism has paid off. Our virtual and hybrid fundraising events have not only survived, but they have also raised nearly as much as our traditional events. This support has allowed the EAWCP to maintain important programs, including the Oscar Project, Emma's Gift, the emergency medication assistance program, Project School Alert, patient education (Everything Epilepsy Webinar Series), and Virtual Camp Frog, to name just a few. We are slowly beginning to reintroduce in-person events, when circumstances allow, and we look forward to seeing you face-to-face.

I cannot thank you enough for your optimism. Your donations, leadership, time, and assistance as volunteers and contributors are appreciated and very much needed. Your optimism sustains us and propels us into the future.

Yes, the last 20 months have been a challenge. COVID-19 has been devastating for many families. The EAWCP has experienced the heartbreaking loss of friends and benefactors that we love, miss, and who will continue to influence our lives and organization for generations. There is no denying things have been tough.

Leaning upon one another and our optimism, we will look to the future with hope and confidence.





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Spotlight on... Epilepsy Awareness Month Education

November is National Epilepsy Awareness Month, and this year we are celebrating by educating as many school staff and students about epilepsy as possible. We are excited to announce our calendar of pre-scheduled virtual presentations. Schools and classrooms can sign up for these presentations by contacting us. As a thank you for making epilepsy education a priority in your school, we will have a drawing for prizes that will include a gift card for classroom supplies and surprises for students.

In addition to the presentations, we have developed a National Epilepsy Awareness Month (NEAM) kit for schools. Contact us for your free digital kit, which includes awareness posters, facts and figures that can be included in morning announcements, and more!

If you would like your child's classroom to participate in these activities, we encourage you to share this information with your child's teacher so they can contact us to receive their NEAM kit or register for one of our education programs! If you are unable to participate in our November events, we will be planning another education day that will take place around March 26th, in recognition of Epilepsy Awareness Day. If you contact us now, we will add you to a mailing list so you are the first to know about our March event.

Although we are encouraging more presentations be scheduled in



Megan and Axel, her service dog, will be our special guest speakers for the Seizures and Service Dogs presentations this November.

November, the EAWCP provides free seizure recognition and first aid training throughout the year. If you are interested in requesting a presentation for your child's school or another local organization, you can contact us for more information. Virtual presentations allow for more flexibility than ever, giving us the ability to work around your schedule and tailor the content to fit your needs.

For more information or to schedule a free training, contact us at 800-361-5885 or azonneveld@eawcp.org.

November Schedule

PROGRAMS FOR STUDENTS

My Not-So-Secret Seizures 30 minutes

11/3 @ 10am and 2pm 11/12 @ 10am and 2pm

For our youngest audiences, this program is based on a picture book that will be read aloud, and each student will receive a coloring book of the story. We will ship coloring books to your classroom.

1 in 26

45 minutes

11/3 @ 9am and 1pm

11/12 @ 9am and 1pm

For 4th grade and up, this program talks about epilepsy and seizures and how to support your peers. It also includes a series of short videos featuring kids from western Pennsylvania who have epilepsy.

Seizures and Service Dogs 30 minutes

11/9 @ 9am and 10am

This program includes a special guest speaker - one of our Oscar Project recipients. We will talk about seizure first aid and how service dogs are trained to help their humans. Future availability of this program depends on the availability of our guest speaker.

PROGRAMS FOR STAFF

Epilepsy and Seizures 60 minutes

11/1 @ 4pm and 5:30pm

11/10 @ 4pm and 5:30pm

For faculty and staff, this presentation provides an overview of epilepsy and seizures. Topics that are covered include seizure recognition and first aid, treatments for epilepsy, and how to manage seizures in a school setting.

For more information or to schedule a free training, contact us at azonneveld@eawcp.org.



Consider an End of the Year Gift to the EAWCP!

The EAWCP feels blessed to have loyal and generous contributions from across the state and all communities.

Did you know that there will be new and extended tax incentives for charitable giving in 2021?

The CARES Act, for example, includes provisions that allow individual taxpayers who take the standard deduction to claim an additional \$300 for cash contributions; married couples filing joint returns can claim an additional \$600 in 2021.

Donors can maximize end-of-year gifts to the EAWCP in a few different ways.

Give appreciated non-cash assets like stocks. Instead of a cash gift, one way to contribute to the EAWCP with a tax-smart strategy for you as the donor is donating appreciated non-cash assets that you have held for more than one year. You can generally lower or eliminate the capital gains tax that otherwise incurs when these assets are sold, if they are donated directly to the charity.

Consider donating retirement assets. If you are in or near retirement, in the process of doing estate planning or reviewing your estate plans, you can consider donating funds from your retirement assets.

A **Oualified Charitable** Distribution (QCD) of **Individual Retirement** Account (IRA) may help to reduce your tax burden and will certainly help the EAWCP. Individuals age 701/2 and older can direct up to \$100,000 per year tax-free from their IRAs to charities through QCDs. This is true if you itemize deductions or if you claim a standard deduction. You could reduce your future tax liability on that IRA when you reduce the IRA

balance via a QCD. These donations must be completed by the end of the year so getting started by early December is a good idea.

Donors should always consult with their investment advisors and estate planning professionals when making decisions that could affect their retirement and investment portfolios.

The EAWCP is happy to talk with our donors about these and other opportunities to include the EAWCP in your estate planning and end-of-year gift-giving decisions.

To learn more about ways to give to the EAWCP, contact Peggy at 412-322-5880.



Scan the QR Code below or visit www.eawcp.org/donate to make a donation today!





for supporting the 1 in 26 who will develop epilepsy in their lifetime!

SUDEP Outreach



For the past few years, a group of families that are linked by tragedy - the loss of 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.

One of our projects that was inspired by the work of this group includes new printed materials for funeral directors and their staff. These materials have been distributed to all funeral homes in western and central Pennsylvania and are also available upon request.

The first of these new materials is a trifold brochure that will educate funeral directors and their staff about Sudden Unexpected Death in Epilepsy (SUDEP). Many people know what epilepsy and seizures are, but most, even those who live with seizures every day, have never heard about SUDEP. It is possible that funeral directors working with families who have lost a loved one to epilepsy will be the first ones to mention SUDEP. This brochure can help prepare them to have a conversation about SUDEP.

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, peer support network, memorial pages, and more.

If you or someone you know has lost a loved one to SUDEP or another epilepsyrelated cause, we encourage you to visit www.eawcp.org/Langford or contact us at 412-322-5880 or 800-361-5885 for support.

PARTNERING

INDIVIDUALLY WE ARE $one\ drop$, together, we are an ocean.

- RYUNOSUKE SATORO

Epilepsy is a condition that impacts millions of people across the world. We want to help the epilepsy movement grow as much as possible, so we partner with other organizations to share what we have learned, learn from them, and help improve programs and services for individuals with epilepsy and their support systems. Here is a highlight of some of our recent partnerships.

National Partner

Epilepsy Alliance America

The EAWCP is a founding member of the 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. The Alliance was founded in 2018 by eight leading grassroots epilepsy organizations who have unified in their mission to provide direct support to people with epilepsy, and the people who care for them.

Members of Epilepsy Alliance America have been collectively supporting people with epilepsy for decades through support services, information, education, advocacy, and public awareness. As a result, the Alliance provides real epilepsy help to approximately 1 million Americans living with seizures.

Our partnership with the Alliance gives us the ability to remain an independent organization but still collaborate on a national level with other organizations that are dedicated to providing direct programs and services. Here are some things that we have been able to be a part of as a member of the Alliance:

 Start a new scholarship for students with Psychogenic Non-Epileptic Seizures (PNES)

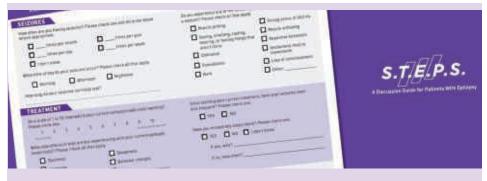


To learn more about the Alliance, visit www.epilepsyallianceamerica.org.

- Develop and distribute posters to address epilepsy first aid in the age of COVID-19
- Share information about programs and services at the Epilepsy Awareness Day and Expo at Disneyland
- Participate in annual conferences hosted by the American Epilepsy Society



In addition to sending staff to Epilepsy Awareness Day and Expo at Disneyland, we also sponsored a family to attend the expo and enjoy Disneyland through our Zonne Fund.



Epilepsy Alliance America also partners on a national level with companies that support individuals living with epilepsy. **SK Life Science, Inc.** is a marquee sponsor of the Alliance and through this partnership is providing a new tool that is available on the Alliance's website in English and Spanish.

The S.T.E.P.S. discussion guide was developed by SK Life Science to help individuals with epilepsy talk to their health care professional about:

- Seizures
- Treatment
- Emotional Impact
- Personal Goals
- Safety



SK Life Science hosted a resource table at the 2021 Harrisburg Senators Run/Walk for Epilepsy.

Visit www.epilepsyallianceamerica.org/steps-tool for a copy of this tool today!

WITH A PURPOSE

Regional Partners

Epilepsy Alliance Ohio, Epilepsy Association in Cleveland, and Case Western Reserve University

The Centers for Disease Control (CDC) has provided a grant that supports epilepsy programs on a national level for decades. This year, for the first time, the CDC is also providing grants to support regional epilepsy projects. The title of the five-year grant is Improving Epilepsy Education, Systems of Care, and Health Outcomes through National and Community Partnerships.

The EAWCP, in partnership with the Epilepsy Alliance Ohio, Epilepsy Association in Cleveland, and Case Western Reserve University, has received a five-year grant to support epilepsy programs in Pennsylvania, Ohio, Kentucky, and West Virginia. Our project will focus on two initiatives: helping adults with epilepsy selfmanage their condition and increasing the connections of those impacted by epilepsy to available resources in their community.

Over the next five years, the EAWCP will offer self-management programs for adults with epilepsy, using SMART (Self-Management for People with Epilepsy and a History of Negative Health Events). SMART is based upon the idea that people learn by observing

others, gaining knowledge, skills, and experience, and acquiring the self-confidence to put their new-found knowledge into practice in ways that are practical and self-sustaining. SMART uses peer support to promote connection, understanding, and acceptance.

The EAWCP will also be working to increase access to community programs and resources, which include both epilepsy-specific programs and other resources that impact social determinants of health, such as food security, housing, and more.

Local Partners

Paige Nagy Memorial Golf Outing

The Paige Nagy Memorial Golf Outing is an annual golf event that is hosted by the Nagy family in memory of Paige Nagy.

This year, the golf outing was held on Saturday, August 28th at the Duck Hollow Golf Club. This event raised over \$12,000 to support EAWCP programs and services.

Paige Nagy was 21 years old when she passed away on May 12, 2015 from SUDEP. Paige did not let epilepsy stop her from living a full and beautiful life, and her legacy lives on in all of the



In addition to hosting the golf outing, Paige's family raises money for the Pittsburgh run/walk event with their team Paige's Platoon.

programs and services that are supported by the money raised at the golf event.

Local Communities

As an organization that provides programs and services to 49 counties, we often rely on our partnerships in local communities to help increase epilepsy awareness. We work with individuals and families to support local fundraisers and awareness events, providing handouts and, when we can, being there in person to help educate

people about epilepsy. If you would like to plan something in your community, here are some ideas that have been successful in western and central Pennsylvania:

- Get a local landmark, like a building or a bridge, turned purple for Epilepsy Awareness Month (November) or Epilepsy Awareness Day (March 26th)
- Organize a day at your office or school where everyone wears purple for epilepsy awareness



The American Legion Riders Charleroi Post 22, hosted a ride which raised money to support the EAWCP in memory of Tammy Lee, a past officer and member of the organization.

- Contact your local newspaper, radio, or TV station and ask them to run a story about epilepsy - you may even get the chance to share your own epilepsy story!
- Use your social media platforms to post information about epilepsy and share the posts from the EAWCP accounts
- Work with a group of people you are close with to organize a fundraiser to benefit the EAWCP

To learn more about hosting a local fundraiser, contact Colleen at cfulkerson@eawcp.org or 412-322-5880.



On March 26th, we hosted a virtual Epilepsy Education Day, teaching 860 students how to recognize seizures and what they can do to help. One lucky teacher won our raffle prize - a \$100 gift card for school supplies for the classroom and purple EAWCP sunglasses and teddy bears for her students.



Kylie Jayne - "Being at Wilkes University has been amazing! I love the new people I am meeting and I really enjoy all the new things I'm learning. I'm already getting an outstanding education in the short time I have been here. I am so grateful for all of your help!"



Alan Faneca, epilepsy warrior and former Pittsburgh Steeler, was inducted into the Pro Football Hall of Fame, Class of 2021. During the Enshrinement Ceremony, Alan handed out goodie bags to over 500 attendees, which included brochures about epilepsy. Alan has been a longtime friend of the EAWCP. This photo was from Steelers Training Camp in 2007, when he took time to meet with several families from the epilepsy community.



Catching up with our Scholarship Recipients

Gavin Hunt - "What has stood out most to me about my school is the community. I am constantly learning, even outside of the classroom, by meeting new people with vastly different experiences. But at the same time I have also found people whose lives were similar to mine and others with common interests, and I have made amazing friendships."

Gavin Krebs - "What I like most about Kettering is the unique opportunity to obtain a co-op as a college freshman. Because of this opportunity, I will be working as an Engine Performance and Emissions Intern at MAHLE Powertrain this fall."





Jill Bischoff, formerly a Certified Nurse Practitioner at the UPMC Comprehensive Epilepsy Center, has been a friend of the EAWCP and the Pittsburgh epilepsy community for many years. We want to wish her a happy retirement!

Jill was hired in December 1985 for the University of Pittsburgh Epilepsy Center, which formally opened in January 1986. When she retired, Jill was the only staff member left from the original crew. Over her 35 year career, she saw multiple medications, surgeries, and medical devices, like the VNS and RNS, developed.

"Epilepsy anchored my career and I found it fulfilling and gratifying," Jill shared. "I loved my patients - watched them grow, hone families and careers. I am so proud of them and miss them."

Jill has been involved with the EAWCP for many years. She came in costume to the EAWCP's first Mardi Gras in 1995. She has also attended all of the Pittsburgh Family Fun Run/Walks for Epilepsy. Jill also served on the EAWCP's Professional Advisory Board.

This section of our newsletter focuses on you - people who persevere with their epilepsy, who raise money, and who raise awareness. Send your stories and photos to staff@eawcp.org.

In Memoriam

The loss of a life is never easy and is always devastating for the family and friends left to grieve. Like all families, the EAWCP experiences this loss, and over the last few months, we have lost some dear friends, passionate advocates, and beloved epilepsy leaders. The impact of their lives will live on in their legacies, the work they've entrusted to us, and the lives they have touched. We extend our most sincere sympathies to their families and friends.

Rudolph F. "Rudy" Zupancic, 88, of Nevillewood, passed away on May 30, 2021. He had a heart of gold, a broad smile, and always a word of encouragement. Imagine leaving a legacy that helps individuals with uncontrolled seizures to live more independently. Rudy Zupancic and his family established the Michael R. Zupancic Seizure Response Dog Endowment with the EAWCP. Rudy was a big part of the Oscar Project, and recipients loved meeting Rudy when they received their seizure response dogs. Rudy was the sort of man who made you feel like anything was possible.



Rudy Zupancic posing with Avex, an Oscar Project dog who was trained to help his human during a seizure

And with his help, anything was possible. The EAWCP staff will miss our annual luncheons with Rudy and his wonderfully lively stories.

Ronald L. Violi, 81, of Pittsburgh, passed away on August 4, 2021. Ron was the former President and CEO of Children's Hospital of Pittsburgh. Before becoming the CEO at Children's Hospital of Pittsburgh, Ron raised millions of dollars to get the hospital out of debt before moving it to its new home in Lawrenceville. In 2004, Ron served as the Honorary King of the Mardi



Ronald L. Violi

Gras Gala. He
was just the 6th Pittsburgh
corporate leader to take
on the responsibility of
helping to raise funds
and awareness of
epilepsy through what
is now the largest
EAWCP fundraiser
each year.

Mary L. Brougher, 57, of Moon Township, passed away on August 10, 2021. Mary was an International Disability Rights Leader, President & CEO of Bender Consulting Services, Inc., a strong advocate for youth with disabilities, a ferocious fundraiser for the EAWCP, and friend to every person she ever met. She had an infectious laugh and was perhaps the most optimistic person on planet earth. Mary was a founding force behind the Bender Leadership Academy,

preparing youth with disabilities to transition from school to work. Mary has been an ever-present force at EAWCP events and programs for 25 years or more. She has been a top fundraiser at the Pittsburgh Run/Walk for Epilepsy for many years. We already miss Mary, her smile,



Mary Brougher (left) with close friends Joyce Bender and Paula Ballog at the Pittsburgh Family Fun Run/Walk for Epilepsy

crazy antics, and endless energy.

Dr. Freddie Fu, 70, of Pittsburgh, passed away on September 24, 2021. Dr. Freddie Fu was an internationally known and world-renowned sports medicine orthopedic surgeon at UPMC. To the EAWCP, Dr. Fu and his wife, Hilda Pang Fu, are the 2011 King and Queen of the Mardi Gras. Dr. and Mrs. Fu have been

frequent contributors to the Mardi Gras Gala, and Dr. Fu has been well known for his fashion-forward Mardi Gras garb. He always had a smile for everyone, and he was every bit as much fun as he was brilliant. Our hearts are heavy with the recent loss of Dr. Fu.



Dr. Fu and his wife, Hilda Pang Fu at the 2011 Mardi Gras Gala

Your presence we miss. Your memory we treasure. Honoring you always. Forgetting you never.

Ghanks you for your support!



Audrey Russo, President and CEO of the Pittsburgh Technology Council, will be honored as our 2022 Mardi Gras King on Fat Tuesday, March 1, 2022.

2021 MARDI GRAS CAMPAIGN

When it became clear that a gala would not be possible in 2021, Audrey Russo, our 2022 Mardi Gras King, really stepped up! She and Joyce Bender, EAWCP Board Chair, personally reached out to the Pittsburgh corporate community to urge them to support the 2021 Mardi Gras Campaign, ensuring that the EAWCP would have the funding it needs to support important programs and services. Pittsburgh came through and despite the fact that there was no party, Audrey Russo and Joyce Bender secured significant sponsorships for the EAWCP.

Thank you to these companies for their dedication to the epilepsy community - we look forward to recognizing you as our Knights of the Purple Ribbon at the 2022 Mardi Gras Gala!

FLEUR DE LIS SPONSORS Highmark/AHN PNC UPMC/UPMC Health Plan

FRENCH QUARTER SPONSOR

Gateway Health

BOURBON STREET SPONSOR

Gateway Financial

TABLE SPONSOR

Bender Consulting Services, Inc. Eat'n Park Hospitality Group Federated Investors Foundation, Inc. Strassberger, McKenna, Gutnick and Gefsky

EVERYTHING EPILEPSY SPONSORS

Starting in the fall of 2020, we began offering a series of webinars called Everything Epilepsy to share information on a variety of epilepsy-related topics.

We want to give a huge **THANK YOU to all of our** speakers who volunteered their time and expertise and also the companies who have sponsored our webinars:

PhRMA Aquestive

Eisai SK Life Science

Greenwich Biosciences **UCB** LivaNova Zogenix

Neurelis

2021 Epilepsy Awareness Run/Walk Sponsors

Hall of Fame

Greenwich Biosciences Penn State Hershey Medical Center

Golden Glove

Eisai Neurelis SK Life Science **UCB** Wellspan

Most valuable Player

Baver Healthcare Bender Leadership Academy LivaNova PhRMA

Prasco Laboratories Stratus

UPMC Pinnacle Zogenix

In Kind

Alco Parking Clown Around Town Dunkin'

Filson Water Herr's Potato Chips

Martin's Potato Chips

Pepsi Sheetz Target

Tyler Mountain

Utz

Waste Management Weamans

Weis



Colby, from the run/walk team Cruising for Colby, made sure everyone in his community knew why he participated in the virtual walk this year

Celebrating 20 Years of Service

Over the last year we have celebrated the 20th anniversary of three employees – now half of our staff has been with our organization for at least 20 years!



Francine

Adult Services Coordinator

When Francine started working at the EAWCP over 20 years ago, it was hard to imagine that some of the individuals she worked with that first year would still be in touch with her today. Francine spends hours each day helping adults navigate the challenges of living with seizures. Her experience has helped her create and grow social programs like our annual Holiday Party, which started as a small gathering of adults from a support group and has now grown to a social event for over 150 people. She has coordinated programs that educated people about epilepsy aboard the Gateway Clipper, provided scholarships to high school seniors, and introduced individuals to their new service dogs.



Lynne (right) with her daughter, Laura

Lynne

Financial and Benefits Administrator

For the last 20 years, Lynne has been behind the scenes making everything we do possible. She spends her days surrounded by numbers and spreadsheets, deciphering contracts, and making sure that all of the money we raise goes to support programs and services for people with epilepsy. She often jokes that no one else would want her job, but we contend that is because she is incredible at what she does and we could not imagine working with anyone else!



Gretchen

Regional Director, Harrisburg

Gretchen started working for the EAWCP because she has epilepsy and knows firsthand how much of a struggle life can be with seizures. She can distinctly remember a counselor who sat in on her doctor's appointments when she was young and who helped her feel like someone truly understood what she was going through. When the opportunity came to pay it forward and join the EAWCP and be that support system for other individuals with epilepsy, Gretchen leaped at the chance. Gretchen works in the central region of the state in the Camp Hill office, and she is proud of the relationships she has formed over the last 20 years with the entire epilepsy community, including patients and doctors, and the increased epilepsy awareness in central PA.









1501 Reedsdale Street, Suite 3002 Pittsburgh, PA 15233

Giving Tuesday is November 30, 2021



Americans will develop epilepsy in their lifetime www.givebigpittsburgh.com/organizations/epilepsy-association-of-western-and-central-pa
Set yourself a reminder to make a donation on Giving Tuesday in support of the 1 you love!