E CONNECTION NEWSLETTER 2020 WWW.EAWCP.ORG



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ON THE COVER: In March we hosted a contest as part of our virtual Purple Party. This photo, submitted by Jessica Plants, is one of our honorable mentions!



The 1 in 26 Tour RV made its final appearance at the 2019 Pittsburgh Run/Walk.



An attendee at the 2019 Purple Party shows the craft she completed.



Dr. Todd Barron works with a patient during filming for a transition video series.



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.



The Diamond and Eyth families had a great time Boo-ling at Zone 28 in Harmarville in October.



Oscar recipients, new and old, met to enjoy the day at a picnic at Settlers Cabin in September.

Visit www.eawcp.org, email staff@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

Altoona Area

814-799-0345

Erie Area 814-451-1135

TDD EOP / AUX AID 800-855-2880

A Note from the President and CEO...

I want you to know that the Epilepsy Association of Western and Central PA (EAWCP) is here for you and your family! On behalf of our Board of Directors and staff, we want you to know that your health and safety is our highest priority. We certainly hope that you all remain safe, and we extend our best wishes to you during these stressful times.

Our staff has been working from home and is now busy planning new ways to reach out and support you with programs that maintain social distancing, protect your health, and continue



Peggy Beem Jelley President and CEO

to support those in need. As we transition to reopening our offices, please do not hesitate to continue to call us for help or send an email to let us know how we can help. If the office is not open, leave a message for us at 412-322-5880 or 1-800-361-5885, or send us an email at staff@eawcp.org. We check these messages throughout the day, every day, and we will get back to you as guickly as possible.

I also encourage you to check us out online at www.eawcp.org. We post new information about programs and events regularly on the EAWCP website. You can also find other fun ways to connect with the EAWCP and friends via the EAWCP Facebook, Instagram, and Twitter accounts – search for @EAWCP.

The coronavirus and COVID-19 are likely to be with us for the remainder of 2020. If you are looking for the most current information and guidance on the coronavirus, visit the Centers for Disease Control website at https://www.cdc.gov/, the PA Department of Health at https://www.health.pa.gov/Pages/AlertDetails.aspx, or your county website.

Tough times never last, tough people do. People with epilepsy and other disabilities are tough, resilient, optimistic, and spirited. The coronavirus has totally changed the way we live, do business, work, worship, and play. We all feel anxiety right now, every day. If you find you need help, please reach out to us or someone else. The state has created a new toll-free support line if you are feeling anxiety. The number to call is 1-855-284-2494, for TTY dial 724-631-5600, and is staffed around the clock. Page 6 includes a text box with a list of other resources available if you need help.

Remember, physical isolation does not mean social isolation. If you are feeling lonely, call a friend. Reach out – join us online, call us, email us, or drop us a note. We are here, as we have been for decades, and as we will be in the future.

Practice social distancing, stay healthy, and we will look forward to seeing you again as soon as possible!





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Epilepsy and the Coronavirus

Many things about our lives have changed as a direct result of the coronavirus and COVID-19. As reported by the World Health Organization (WHO), people with disabilites may be at higher risk of contracting COVID-19 because of barriers to implementing basic hygiene measures, difficulty in enacting social distancing because of additional support needs, the need to touch things for physical support, and barriers to accessing public health information. Individuals with disabilities may be at greater risk of developing a severe disease if they become infected because of the pre-existing health condition underlying their disability and barriers to accessing health care. Individuals with disabilites may also be disproportionately impacted by the outbreak because of serious disruptions to the services they rely on. If you are struggling during this pandemic, please contact us and we will help connect you with support services available in your community.

Recently, the American Epilepsy Society (AES) released some guidance on treating COVID-19 for people with epilepsy:

- You should always check with your pharmacist or physician regarding the selection and use of nonprescription medications.
- There has been controversy around the use of ibuprofen and possibly other nonsteroidal anti-inflammatory drugs (NSAID) and worsening of COVID-19 disease. Acetaminophen is the preferred drug for treating fever, muscle pain, and other COVID-19 symptoms.
- It is generally best for you to limit use of products that contain decongestants. Oral decongestants should be used for a short duration, as effectiveness will wane over a few days. Nasal decongestant products should be avoided.
- In some places, herbal products that contain various constituents, such as Ma Huang (ephedra), have been used in treating COVID-19. These

- products should be avoided in patients with epilepsy as they may interact with antiseizure medications and could exacerbate seizures.
- Several different drugs are being studied for treating COVID-19.
 While some of these medications may be effective, they all have adverse effects and some have potential drug interactions.
 Some of the adverse effects can include seizures. You should never take these medications outside of the care and management of a physician knowledgeable in their use. You should never use products that may contain these medications but are not intended for human use.

For more detailed guidance from the Task Force of the AES Council on Clinical Activities, visit https://www.aesnet.org/about_aes/position_statements/covid-19/delivery-of-care/covid-pharmacotherapy-epilepsy.

ADA30: Inspiring Words from our Board Chair

In the words of President George H. W. Bush when he signed the ADA in 1990,

"Let the shameful wall of exclusion finally come tumbling down."

This year we are celebrating the 30th Anniversary of the signing of the Americans with Disabilities Act! This is the most significant civil rights law for Americans living with disabilities. One of the most powerful forces who worked to get the ADA passed, Tony Coelho is still fighting the fight for people living with disabilities to gain freedom, through competitive employment in this country. He is a person who changed the world for

ADA30 ****

Americans with Disabilities Act

Celebrate the ADA! July 26, 2020

Learn more about the celebration at ADA National Network (adata.org)

those of us living with disabilities; he is the author of the ADA...and this powerful man lives with epilepsy!

There is no doubt, everyone who meets me learns something about me immediately: I am living with epilepsy and I am not ashamed that I am living with epilepsy. I am an advocate for all people living with disabilities to gain quality of life, with a personal interest in people living with

epilepsy. Two years ago, I spoke at the National Korean Epilepsy Congress about the fierce stigma associated with epilepsy and how that stigma sometimes destroys the confidence in our ability to live independently. While stigma toward epilepsy is not as horrific in the US as it is in Asia and in many other countries, we too have to breakthrough obstacles built by stigma.



Joyce Bender (on right), our EAWCP Board Chair. with Mary Brougher, EVP, Operations for Bender Consulting Services, Inc. Photo by Mary Jane Bent

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.

-Jøyce Bender, EAWCP Board Chair

Join Us (Virtually) for an Upcoming Run/Walk!

REAL people
bringing REAL awareness and
raising REAL money to
support REAL challenges
faced by REAL families
affected by epilepsy.

That's what is **REAL** about a virtual walk.[©]

Fighting the coronavirus has forced people across the world to change things about how we live our lives. The Centers for Disease Control (CDC) and our PA Department of Health continue to recommend staying home and maintaining physical distance from other people to slow the spread of the virus.

In order to keep the epilepsy community safe, we have made the difficult decision to turn the 2020 Pittsburgh Family Fun Run/Walk for Epilepsy and Harrisburg Senators Family Fun Run/Walk for Epilepsy into virtual walks. Highmark has also decided to convert its Highmark Walks for a Healthy Community into virtual walks.

We encourage you to get creative this year - it's your chance to bring awareness to your community! Will you walk through the streets of your neighborhood with an epilepsy awareness sign? Will you use social media as a way to encourage friends and family to not only donate, but join your team and raise money to support epilepsy programs and services too?

Share with us how you are coming together to support epilepsy awareness by sending photos and video to staff@eawcp.org. We would love to showcase all of your incredible efforts on our social media pages!

REGISTER TODAY

ERIE - MAY 30TH

Highmark Walk for a Healthy Community http://tiny.cc/ErieWalk

ALTOONA - JUNE 6TH

Highmark Walk for a Healthy Community http://tiny.cc/AltoonaWalk

PITTSBURGH - JUNE 20TH

32nd Annual Family Fun Run/Walk for Epilepsy http://tiny.cc/epilepsywalk

HARRISBURG - AUGUST 1ST

18th Annual Senators Family
Fun Run/Walk for Epilepsy
http://tiny.cc/epilepsy-walk-harrisburg







The Epilepsy Association of Western and Central PA (EAWCP) is committed to doing its part to prevent, stop, and control the spread of the novel coronavirus COVID-19. In response to growing concerns about the community transmission of COVID-19:

- Our office locations in Pittsburgh and Camp Hill are closed. Our staff will continue to be available to assist you via phone and email. You can call the EAWCP at 800-361-5885 or email the Association at staff@eawcp.org.
- Programs that involve face-toface, group, or personal contact have been canceled, moved online, or postponed. For the latest information about our upcoming events, visit our Upcoming Events calendar: https://www.eawcp.org/ Module/Calendar/UpcomingEvents.
- We are developing virtual alternatives to some of our programs. We know that these virtual programs can not completely replace the sense of community that we all feel when we see each other in person, and we look forward to getting back to our regular programs once it is safe to do so!

Information and Referral

If you have questions, need help accessing a service, or just need to talk, all of our staff are available from 8:30am-4:30pm on Monday-Friday. You can reach us by phone at 800-361-5885 or by email. Please note that our turnaround time may be a little longer

than usual, but rest assured we will reply to your emails and return your phone calls as quickly as we can.

Emergency Medication

Our emergency medication assistance program can provide a 30-day supply of all of an individual's epilepsy medications. If you have lost health insurance coverage or can not afford your medication, please contact us to learn more about this program. When possible, we work with your pharmacy to fill your current prescription to make it as convenient as possible. We will also work with the pharmacy to arrange for delivery of the medications, if that is a service they offer.

Please do not wait until you are out of medication to call. The entire process can take a few days, especially if the pharmacy is out of the medications that you need.

If you have questions about your application, contact Francine at feden@eawcp.org.

Health Care Transition

THEN: Throughout the year, we offer programs to help teens prepare for the transition from pediatric to adult healthcare.

NOW: We are hosting a series of webinars for teens, their parents, and professionals who would like to learn more about health care transition:

Thursday, April 23, 2020, 12:00pm ET Getting Started on Transition –

Discovering and Tracking

Presenters: Dr. Miya Asato & Dr. Patricia Crumrine

Thursday, May 14, 2020 , 12:00pm ET

Building Bridges – Preparing and Planning

Presenter: Dr. Andrew McCormick Friday June 19, 2020, 12:00pm ET

From Takeoff To Landing – Transferring and Completing

Presenter: Dr. Anto Bagić

If you missed one of our webinars, recordings will be available on our YouTube channel.

If you would like to join us for these webinars, contact Jordan at jhinds@eawcp.org.

One-on-One School Advocacy

THEN: We provide one-on-one consulting for parents to teach them about their child's rights in school, which are protected by special education laws. We also attend IEP and 504 meetings upon request.

NOW: We are still available by phone and email if you have questions about your child's rights in school, how to incorporate epilepsy-related accomodations into IEPs and 504 Plans, and more. We can also attend virtual IEP and 504 meetings.

As this school year winds down, remember that it's never too early to start thinking about IEPs and 504 Plans. If you are just starting the process, it will take time to complete the evaluations and work with your child's school to develop a plan. You can call the school and see who on the staff is the right person to work with and check their availability. In some school districts there may be people available over the summer, but even if there won't be, you can work with the school now to develop a timeline for the process when school resumes in the fall.

If you have any questions about school advocacy, contact Paige at pdevlin@eawcp.org.

Other resources are available for anyone who needs help:

- National Suicide Prevention Lifeline: 1-800-273-TALK (8255)
- Línea Nacional de Prevención del Suicidio: 1-888-628-9454
- Crisis Text Line: Text "PA" to 741-741
- Safe2Say: 1-844-723-2729 or www.safe2saypa.org
- Veteran Crisis Line: 1-800-273-TALK (8255)
 Disaster Distress Helpline: 1-800-985-5990
- Get Help Now Hotline (for substance use disorders): 1-800-662-4357



Project School Alert

THEN: Each year we train thousands of students and school personnel how to recognize and respond to seizures, most often through in-person programs.

NOW: With schools remaining closed through the end of the academic year, we are here to help teachers who are looking for something new to add to their virtual lesson plans. All of our programs for students are available virtually and our staff is excited for the opportunity to join your virtual classroom and teach your students about epilepsy and seizures.

My Not-So-Secret Seizures (30 min)

For the youngest audiences, this program is based on a picture book called "My Not-So-Secret Seizures." The story is read aloud to the children, and each child receives pages from our coloring book. This book is also available in Spanish.

1in 26 (45 min)

For 4th-8th grades, this program has a PowerPoint presentation and series of short videos featuring kids from western Pennsylvania who have epilepsy.

The Truth About Epilepsy (45 min)

For high school students, this program features a PowerPoint presentation and short video introducing epilepsy from the points of views of individuals impacted by epilepsy.

We can also provide training to school staff, hosted on our Zoom platform or by joining you virtually on the school's meeting platform.

If you would like to schedule a virtual presentation, contact Yazmin at ypena@eawcp.org.

Parent Education Workshop

THEN: We had a series of in-person parent workshops scheduled for May which had to be canceled due to the coronavirus.

NOW: We are hosting a series of three virtual parent education workshops:

Wednesday, June 3, 2020, 6:00pm ET

Special Education: Before and After COVID-19

Presenter: Mike Connolly, from McAndrews, Mehalick, Connolly, Hulse and Ryan, P.C.

The other two virtual parent education workshops will be held on June 10th and June 17th at 6pm. Topics for these sessions will be announced at a later time.

If you miss any of these workshops, recordings will be available on our YouTube channel.

If you would like to register for a workshop, contact Gretchen at gknaub@eawcp.org.

Support Groups

THEN: We offer monthly, in-person support groups in York, Hershey, Mechanicsburg, and Johnstown.

NOW: All in-person support group meetings have been canceled and support groups are being offered as virtual events until further notice.

Our support groups meet once a month and you can join us virtually for a support group meeting, through Zoom or Google Meet.

If you would like to be part of the next support group call, please contact:

- Laura at lwoodward@eawcp.org (Hershey and Mechanicsburg)
- Greg at gmcconnell@eawcp.org (Johnstown)
- Gretchen at gknaub@eawcp.org (York)

Other EAWCP Program Updates

OSCAR PROJECT:

Applications for this year's recipients of our seizure response dog program are being processed now. The service dogs will be placed later than usual this year, when it is safe to do so.

Any applications received now will be considered for the Oscar class of 2021.

If you have questions about your application, contact Francine at feden@eawcp.org.

EMMA'S GIFT:

Applications for our program that provides movement detection monitors (which send an alert when movement occurs that indicates a seizure might be happening) are being accepted and processed as usual.

If you have questions about applying for this program, contact Jordan at jhinds@eawcp.org.

CARESHARE RESPITE CARE:

Many respite care providers are not currently offering in-home services.

In order to use the CareShare Respite Care program and receive 25 hours per year of free, skilled nursing care, you must apply for the program and be approved. You can apply for the program now and once providers resume in-home services, you can begin to receive the care.

If you have questions about applying for this program, contact Jordan at jhinds@eawcp.org.

SCHOLARSHIP PROGRAM:

The application window for our high school scholarship program is closed. We will contact applicants to follow-up once our office reopens.

If you have questions about our scholarship program, contact Francine at feden@eawcp.org.



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.

Oscar dog recipient
Ricky D'Auria and his
service dog, Charlie,
have been attending
school presentations
to help teach children
about service dogs and
epilepsy. His t-shirt
helps to remind people
that they should not
distract a working
service dog by trying to
pet or interact with it.





EAWCP staff member Yazmin teaches young children about seizures at Dorseyville CoTRAIC. Six schools including this one were recognized as a Seizure Smart School in 2019 by educating all students and staff about epilepsy.



The Humphreys family hosted a dress down day at Central Penn College in support of their son.



Maggie and DJ Garsteck sold bracelets for 2019 Purple Day at Ramsay Elementary in Mt. Pleasant.



Students at Robert Morris University held a 3-on-3 basketball tournament to help raise funds and epilpesy awareness in their local community.

This group of young ladies represented the EAWCP during this year's Children's Actions that Create Hope presentation at Sewickley Academy Middle School. The core of the program is the time spent talking about their ideas and the research they do to learn more about how different philanthropic



organizations work. These amazing young ladies not only chose to talk about the work that we do here at the EAWCP, but their class decided that we should be the recipient of this year's funds!



This group of stellar advocates shared their epilepsy stories at the Capitol last spring. Due to the coronavirus, this year we had to advocate for epilepsy support virtually.

VIRTUAL PURPLE PARTY

We could not host our annual Purple Party this year, but we could not let the day go by without celebrating with you through a social media photo contest so we could still crown our Purplest People! Thank you to everyone who participated and helped raise epilepsy awareness!

HONORABLE MENTIONS



Amy Selders



Jenn Baer



Jennifer Cribari won our contest,

receiving \$50 to the food delivery

service of her choice!

Greta Garsteck

ONGRATULATION



Jessica Plants



Amanda Kuehmichel



Kelly Mellquist Myers

showing our support from Ridgway Medical Center you RoCk Zaleena!!

Thank you to the healthcare professionals and all of the rest of the essential workers who are keeping all of us safe! #stayathome

RIDGWAY MEDICAL CENTER

The staff at Ridgway Medical Center took time out of their busy day to let the epilepsy community know that they are thinking about us! This photo was submitted as part of our social media photo contest. Rather than consider it for the contest, we wanted to thank them all for everything they are doing to care for people during this pandemic, so we sent them lunch instead!

WTAE Channel 4

THANK YOU TO OUR 2019 SPONSORS

Pepsi Cellone's

Pepsi
Guardian
UPMC Pinnacle
Wellspan Neurosciences
Alco Parking
Aramark
Bimbo Bakeries
Best Western Premier, The
Central Hotel and Conference
Center

Delaware North Sportservice
Dunkin' Donuts
Eat'n Park
Filson Water LLC
IQ Escape
Monte Cello's
Clown Around Town
Outside the Box Escape Room

2019 Run Walk Wrap-Up

Our 2019 Run/Walks were a huge success. Thank you to everyone who

participated. We are excited to have you join us again this year.

Giant Eagle Pharmacy
Pride of the Susquehanna
Sam's Club
Sheetz
Sports Emporium
Tyler Mountain
Utz
Waste Management



Mardi Gras King Jeff Broadhurst, with special guest Mardi Gras Smiley Cookie!

26th Annual Mardi Gras Gala

Jeff Broadhurst of Eat'n Park Hospitality Group was crowned King of the Mardi Gras on Fat Tuesday, February 25. Jeff and his dinner chairs, Toni Murphy of Comcast, Tim O'Brien of PJ Dick, Laura Karet of Giant Eagle, Mike Lyons of PNC, and Dave Malone of Gateway Financial helped us to raise almost \$500,000!

The Mardi Gras Gala is a fundraising event that honors a community leader for their commitment and dedication to the Pittsburgh region. The event is traditionally supported by the corporate community through table sponsorships. The event has become one of Pittsburgh's premiere social gatherings, and has been sold to capacity since its inception. Consider joining us next year on Fat Tuesday, February 16, 2021. Reserve your table with Colleen at 412-322-5880.

The Humphrey family were our special guest speakers at Mardi Gras this year. Mom, Katherine, did an excellent job speaking for the family. Here is an excerpt from her speech:

"Shortly after Sam was diagnosed with epilepsy, we received a friendly phone call from the Epilepsy Association, followed by an invaluable amount of information arriving in the mail, explaining epilepsy and many resources available to us. Initially what was most helpful was information on epilepsy as we tried to make sense of what was happening in the family. Invitations from the Epilepsy Association began arriving in the mail ... It was amazing to meet people with a shared experience ... Without the support of the Epilepsy Association, I am really not sure how my family would have survived the last six years. We are incredibly grateful."



Sam Humphrey and his service dog, Colt.

Thanks you to our 2020 Mardi Gras
Sponsors

\$25,000 FLEUR DE LIS SPONSORS







\$15,000 FRENCH QUARTER SPONSOR UPMC Health Plan \$10,000 BOURBON STREET SPONSORS

Accenture
Dentons Cohen & Grigsby
Gateway Financial Services
Gateway Health
Giant Eagle
PJ Dick-Trumbull-Lindy Paving

UPMC

2019 Snapshot

These are some highlights of our accomplishments from last year. For a more detailed summary, visit our website to read our 2019 Annual Report.



trained to recognize seizures and provide first aid



families assisted with individual consultations



respite care hours covered



campers at Camp Frog & Camp Firefly



advocates sharing their stories with legislators



support group meetings



emergency medications provided



education events



movement monitors granted



scholarships awarded



Oscar dogs placed

Make Sure that You Count in the 2020 Census

Article below is from www.pa.gov/ census/

The U.S. Constitution requires a census of all residents in the entire country every 10 years. The census counts every person living in the U.S. once (and only once) in the right place. You are counted based on where you are living on April 1, 2020.

Everyone Counts

You might be living in an apartment, a house, or a group housing situation (like a dorm or nursing home). Or you might be experiencing homelessness. Regardless of your living situation, you count as a Pennsylvanian. It also doesn't matter what your citizenship status is, how old you are, or your gender. If you live here, you matter to us and the census.

Fair Representation

Neighborhoods change over time. The census makes note of these demographic changes and reports the statistics. This information is then used to determine how many seats each state gets in the U.S. House of Representatives. Pennsylvania

currently has 18 Congressional representatives. We used to have 19 but lost a seat after the 2010 Census.

Additionally, state officials use the statistics produced by the decennial census to redraw U.S. congressional and state legislative districts.

Federal Spending & Programs

Census data is used to decide how \$675 billion in federal public funding is spent every year. Pennsylvania gets \$26.8 billion annually through our 16 largest federally-funded programs. That's about \$2,000 per Pennsylvanian each

These numbers may change based on our 2020 Census data. Federal funding supports many important programs and services for Pennsylvanians, including healthcare, food security, education, transportation, housing, community development, support for families, and

Learn more about making sure you are represented in the decisions that are made as a result of the census by visiting www.pa.gov/census/.

DIGITAL Resources Available at www.eawcp.org



Transition with Ease Video Series

Healthcare transition is the process of moving from your childhood (pediatric) doctor to the doctor you will see as a young adult. Our new video series introduced the three E's that will help you transition with ease.

Find these videos on our website at www.eawcp.org/ HealthcareTransition.xml.

Resource Library

We maintain a library of helpful resources for people with epilepsy and their families.

Find these resources on our website at www. eawcp.org/programs/ resourcelibrary/

Information Sheets as Printable PDFs

A chart of different seizure types and the appropriate first aid response

Reconocimiento de Ataques Epilépticos y Primeros Auxilios 11x17 (Spanish) Tabla de los distintos tipo de ataques epilépticos y los procedimientos de primeros auxilios apropiados para cada uno.

<u>First Aid Poster — Tonic-Clonic Seizure</u> First Aid steps for a tonic-clonic seizure

First Aid steps for a focal seizure

Primeros Auxilios en Caso de Convulsiones — Crisis Tonico-Clonicas (Spanish)

First Aid Poster — Focal Seizure

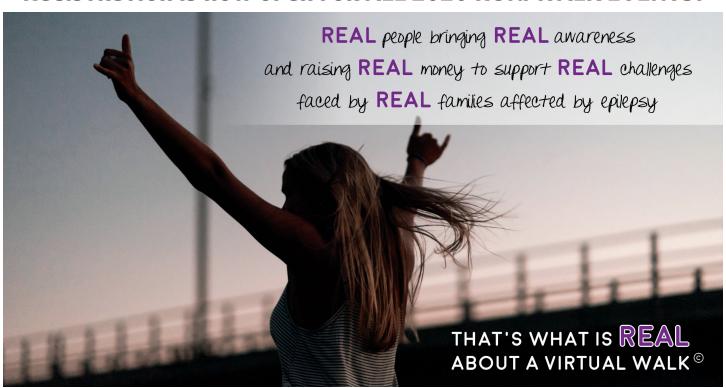


Primeros Auxilios en Caso de Convulsiones — Crisis Parciales (Spanish)



1501 Reedsdale Street, Suite 3002 Pittsburgh, PA 15233 Non-Profit Org. U.S. Postage **PAID** Pittsburgh, PA Permit No. 1390

Registration is now open for ALL 2020 RUN/WALK EVENTS!



Turn to page 5 for more information about our run/walk events and how to register. Thank you for your support!