

SPRING / SUMMER NEWSLETTER 2019

# E CONNECTION

[WWW.EAWCP.ORG](http://WWW.EAWCP.ORG)





## In This Issue

- 3 A Note From the President  
& CEO
- 4 Spotlight on... Our New  
Coloring Book
- 5 Spotlight on...Advocacy
- 6/7 It's OK to Talk About SUDEP
- 8/9 Raising Awareness/  
Raising the Bar
- 10 Mardi Gras Wrap Up
- 11 Upcoming Events

*ON THE COVER: The Schnur family, part of Team Action for Jackson, participated in the Pittsburgh Family Fun Run/Walk for Epilepsy this summer.*



*Campers and EAWCP staff pause for a selfie in their Halloween costumes before the dance at Camp Firefly!*



*Families enjoyed another Zonne Fund movie - Wreck it Ralph 2: Ralph Breaks the Internet.*



*Individuals living with epilepsy and their families learned about a variety of topics and engaged in panel discussions at our Supporting Families Supporting You Conference.*



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 EAWCP hosted 4 holiday parties around the state this year with special visits from Santa. Other festivities included music, dancing, crafts, games, and gift exchanges.*



*Our Gateway Clipper Cruise sailed along Pittsburgh rivers with adults with epilepsy on board ready to learn about new treatment options and make new friends.*

Visit [www.eawcp.org](http://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

### Altoona Area

814-799-0345

### Erie Area

814-451-1135

### TDD EOP / AUX AID

800-855-2880

## A Note from the President and CEO...

Education can be described as an enlightening experience; one that facilitates learning, or the acquisition of knowledge, skills, values, beliefs, and habits. The Epilepsy Association Western and Central PA works to dispel the myths, stigmas, and misunderstandings associated with epilepsy by providing as much education as possible.

Living with epilepsy can feel limiting and isolating. Educating those around you can go a long way toward making you and everyone around you feel more empowered and more at ease. Meeting and talking to other people impacted by seizures can help you to feel less alone.

This spring the EAWCP brings new and exciting education programs that will reach some new audiences, and cover some topics that may be new as well. I am proud to announce that the EAWCP is setting out on an ambitious task of presenting epilepsy education and advocacy training in 26 separate local communities in our service territory. This is the perfect way for co-workers, family members, friends, and others to learn more about epilepsy. You can read more this exciting 1 in 26 Tour on page 5, and visit our 1 in 26 Tour webpage at [www.eawcp.org/1in26tour](http://www.eawcp.org/1in26tour) to see when we will be in your town.

And remember, the EAWCP Project School Alert trainings are not actually just for schools! Church groups, workplaces, grocery stores and restaurants, and summer camps have all benefitted from our trainings geared towards adult audiences. Of course, we offer our trainings for students from pre-K through college as well.

Training on how to advocate for your rights and for people with epilepsy can be life changing. Learning about SUDEP and likely risk factors can literally be life saving, and meeting other families affected by SUDEP can be impactful and helpful. This spring the EAWCP is offering trainings on advocacy at several conferences; and more in-depth information on SUDEP will be covered at an event in April as well as on our website.

I encourage you, and your circle of friends and family to join us at these events. Together we can break the stigma of epilepsy!

*Peggy*



**Peggy Beem-Jelley**  
President and CEO



Look for this ParentLink icon to find articles in our newsletter that may be especially helpful for parents of children with epilepsy.

## EAWCP Board and Staff

### Policy Board

Deb Rice-Johnson, Board Chair  
Russ Allen  
Joyce Bender  
Theresa Bone  
Patricia Crumrine, M.D.  
Eugene DeFrank  
Glen Goldbach  
Scott Heeter  
Brian Himmel, Esq.  
John Kreider  
Mark Kuczinski, CPA  
Barbara Kudis  
Carole Lane  
Edward Little  
Sandra McAnallen  
Anthony Musmanno  
Daniel Orie, Esq.  
Alan Shuckrow, Esq.  
James Valeriano, M.D.

### Advisory Board

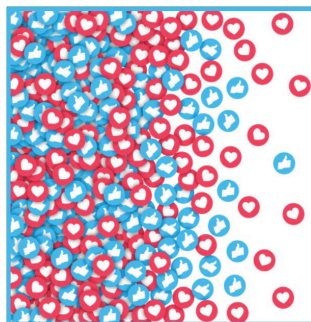
Miya Asato M.D.  
Jill Bischoff, CRNP  
Patricia Crumrine, M.D.  
Kevin Kelly, M.D., PhD  
Carole Lane  
Carol J. Schramke, PhD  
James Valeriano, M.D.  
Anne C. VanCott, M.D.  
Rajiv Varma, M.D.

### Emeritus Board

Dick Barton  
Louis Catalano, M.D.  
James D. Chiafullo  
Douglas Dick  
Jack Hinds  
Lawrence Leventon, Esq.  
Richard M. Ryan  
Thomas Trimm, Esq.

### Staff

Peggy Beem-Jelley  
President and CEO  
  
Annette Condeluci  
Development Officer  
  
Paige Devlin  
Children & Family Services Coordinator  
  
Francine Eden  
Adult Services Coordinator  
  
Colleen Fulkerson  
Special Events Coordinator  
  
Lynne Gensamer  
Financial & Benefits Administrator  
  
Jordan Hinds  
New Initiatives Coordinator  
  
Gretchen Knaub  
Regional Director, Harrisburg  
  
Greg McConnell  
Regional Coordinator, Altoona  
  
Laura Norris  
Executive Office Manager  
  
Yazmin Peña  
Community Education Coordinator  
  
Amanda Stein  
Marketing Coordinator  
  
Laura Woodward  
Community Education & Events Coordinator, Harrisburg  
  
Andrea Zonneveld  
Community Education & Events Coordinator



## WE'RE SOCIAL, ARE YOU?

Facebook.com/EAWCP

Instagram @EAWCP

Twitter @EAWCP

**FOLLOW  
LIKE  
TAG  
SHARE**



## Spotlight on... Our New Coloring Book

Explaining epilepsy and seizures to a young child can feel like an impossible task, but having the right tools can make all of the difference in the world.

### My Not-So-Secret Seizures

Starting this year, the Project School Alert program, which provides free epilepsy education to students of all ages, school staff, and other community organizations, has an updated coloring book program for young audiences. *My Not-So-Secret Seizures* is a story that was written by EAWCP staff to teach children that seizures are not as scary as they might seem and there are things they can do to help their friend if they have a seizure. In classrooms, the story is read aloud from a large format, full-color picture book, and all of the students are given a coloring book copy of the same story. The coloring book is available in English and Spanish.



*My Not-So-Secret Seizures* is narrated by Ezra, a young boy who has epilepsy. In the story, Ezra describes what seizures are and shares how each of his friends discovered that he has seizures. Ameena plays on a soccer team with Ezra and one day the coach explains to the team how to help if Ezra has a seizure. Matt sees Ezra taking medications during a sleepover and discovers that he sometimes has to miss school to go to the doctor. Sonya and Ezra went to the same summer camp, so when Ezra has a seizure at school, and Sonya knows exactly what to do to help him. The story also talks about service dogs, bullying, and medical alert bracelets.

*Project School Alert is a Free program that can provide education for children of all ages. If you would like to request*

*a presentation for your school or community organization, please contact your nearest Epilepsy Association office!*

### First Aid Posters

Are you looking for more resources to use in your classroom? Ezra and his friends return in a pair of first aid posters that explain what to do if someone has a tonic-clonic or focal seizure. Each poster (pictured below) provides tips on recognizing and responding to seizures, including some examples of things you should never do when someone has a seizure, and has English on one side and Spanish on the other.

*To request copies of this resource, contact the EAWCP at 800-361-5885.*

### Seizure Smart Schools

Each year, we recognize schools as *Seizure Smart* when they show that they are fully committed to epilepsy education by educating their entire staff and student body. *Seizure Smart* schools are awarded a framed certificate that can be displayed on the wall in their school.

Do you want your child's school to be *Seizure Smart*? Are you a school that would like to educate your entire staff and student body to join the *Seizure Smart* club yourself? Call your nearest EAWCP office to start scheduling presentations for your school so we can award you with your very own *Seizure Smart* certificate!



## It's Camp Season!

Registration is now open for Camp Frog and Spring Camp Firefly!

# CAMP FROG

**@Camp Conrad Weiser**  
(near Reading, PA)  
**June 16-22, 2019**

**@Camp Fitch**  
(near Erie, PA)  
**June 23-29, 2019**

**Call 800.361.5885**  
to learn more about this camp  
and register your camper!  
(Registration now open!)

# CAMP FIREFLY

Held at The Woodlands in Wexford, PA

**Spring Session**  
**April 13-14, 2019**

**Fall Session**  
**October 11-13, 2019**

**Call 800.361.5885**  
to learn more about this camp  
and register your camper!  
(Fall session not yet open.)

## Got what it takes to be a camp counselor?

We are now hiring camp counselors for both Camp Frog locations. Call 800.361.5885 or email [pdevlin@eawcp.org](mailto:pdevlin@eawcp.org) to learn more about what the job entails and how to apply!



## Spotlight on... Advocacy

"Do what you can, with what you have, where you are." - Theodore Roosevelt

Learning to advocate for yourself, or on behalf of someone living with epilepsy, can help you develop skills that are useful throughout your life. One of the key aspects of advocacy is becoming empowered by the rights that you learn that you have and using that power to effect positive change for yourself and others. Here are some ways you can learn to advocate for yourself and your loved ones.

### Advocacy at School

Every child is entitled to a Free Appropriate Public Education (FAPE) in the United States, as guaranteed by the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA). Children with epilepsy and other disabilities receive an educational program that is individualized to them, that meets their unique needs, provides access to the general curriculum, meets the grade-level standards established by the state, and that they receive educational benefit from.

If you feel that your child is not receiving the level of education that they should be getting, you can advocate for your child by requesting that the school do an evaluation to determine if an Individualized Education

Plan (IEP) or 504 Plan could benefit your child.

If you need help accomplishing this or navigating the special education system for your child, please reach out to Paige at pdevlin@eawcp.org.

### Advocacy at the Doctor's Office

Teens living with epilepsy can use health care transition as a way to begin developing advocacy skills. By taking small steps, you can slowly build your confidence until you are ready to go to medical appointments by yourself. Start by calling to make your next appointment, being responsible for carrying your medical insurance card, and preparing a list of questions for your doctor. Learn your medical history and ask questions to find out what other conditions run in your family. When you turn 18 years old, your parents will no longer have legal control over your health care decision, so it is a good idea to start thinking about health care transition long before that.

If you would like to work on your advocacy skills (or if you are a parent and want to learn how to support your teen's health care transition), join us at the **2019 Next STEPS**

**Transition Conference on August 9th-11th.** For more information about this conference, contact Jordan at jhinds@eawcp.org.

### Advocacy at the Capitol

There are many state and federal laws that affect people living with epilepsy, and the only way legislators can make informed decisions about these laws is to hear from those impacted by seizures. One of the easiest ways to become a legislative advocate is to learn how to tell your epilepsy story in a way that will resonate with lawmakers. Sometimes you only have 30 seconds to make an impression and other times you may be able to sit down with your legislator for a half hour, but the most important part is to always leave your audience empowered with something they can do to support you or your family.

If you would like to learn how to be a legislative advocate for all Pennsylvanians living with epilepsy, consider being a part of the **2019 Share Your Story/PA Public Policy Conference on April 28-30th** in Harrisburg. For more information about this conference, contact Andrea at azonneveld@eawcp.org.

## JOIN US FOR AN EDUCATION EVENT SERIES coming to a town near you!

# 1in26 Tour

Join us for a free two-part event in a town near you to **LEARN HOW TO RECOGNIZE AND RESPOND TO SEIZURES and BUILD YOUR SELF-ADVOCACY SKILLS!**

If you see our 1 in 26 Tour RV, snap a photo, and share it on social media for a chance to win a prize!

3.10.19 York	3.18.19 Towanda	3.29.19 State College
3.11.19 Chambersburg	3.19.19 Wellsboro	5.9.19 New Castle
3.12.19 Harrisburg	3.20.19 Saint Marys	5.10.19 Meadville
3.13.19 Lebanon	3.21.19 Clarion	5.11.19 Erie
3.14.19 Bloomsburg	3.24.19 Washington	5.12.19 Bradford
3.16.19 Lewisburg	3.27.19 Indiana	5.13.19 Oil City
3.17.19 Williamsport	3.28.19 Clearfield	5.14.19 Butler
		5.16.19 Somerset
		5.17.19 Altoona
		5.19.19 Greensburg
		5.21.19 Uniontown
		5.22.19 Pittsburgh

VISIT [eawcp.org/1in26tour](http://eawcp.org/1in26tour)  
FOR MORE INFORMATION AND TO REGISTER



# IT'S OKAY TO TALK



When you or someone you love is living with seizures, it is natural to have concerns about safety. Most people take steps to limit the

risk of injury from things like swimming by making sure they never swim alone or driving by following the law and waiting 6 months after a seizure to start driving again. [The law in Pennsylvania requires a 6-month wait, but if you live in another state you should check your local laws.] There is another mortality risk for people with epilepsy, and unfortunately it is one that often people hear about for the first time after losing a loved one. SUDEP stands for Sudden Unexpected Death in Epilepsy and occurs in 1 in every 1,000 people with epilepsy each year.

Although there are many people researching the causes, risk factors, and ways to prevent SUDEP, there is still a lot that we do not know for sure. According to the CDC, most, but not all, cases of SUDEP occur during or immediately after a seizure and possible factors that lead to death include breathing, heart rhythm, or a combination of both breathing and heart rhythm. The main risk factors for

SUDEP include uncontrolled or frequent seizures and generalized tonic-clonic seizures. Other risk factors may include seizures starting at a young age, having seizures for many years, missing doses of medication, and drinking alcohol. The suggested ways to prevent SUDEP include trying to control your seizures by taking your medications as prescribed by your doctor, avoiding seizure triggers, avoid excessive drinking of alcohol, and making sure you get enough sleep. In some studies, death was prevented in near-SUDEP cases with intervention from another person. Train your friends and family to recognize and provide first aid for seizures, and, if you have seizures that involve several seconds of sustained movement, you can research movement detection monitors that can alert your loved ones of a nocturnal seizure.

#### How can I learn more about SUDEP?

- The simplest way to learn more about SUDEP is to talk to your doctor. Ask your neurologist about your risk for SUDEP and what can you do to reduce that risk. If you do not have seizure control, discuss other medications or treatment options that may give you better control.

- Attend our upcoming SUDEP event on Tuesday, April 16th from 5:30pm-9pm to hear from a leading SUDEP expert. Dr. Jeffrey Buchhalter is a neurologist in Glendale, Arizona and is affiliated with St. Joseph's Hospital and Medical Center. He received his medical degree from David Geffen School of Medicine at UCLA and has been in practice for more than 20 years. Dr. Buchhalter has also been involved in the biannual Partners Against Mortality in Epilepsy (PAME) Conference, which brings together doctors, researchers, and families from around the world to discuss current research and SUDEP awareness. To register, or if you would like more information about this event, contact Francine at 412-322-5880.
- Visit our website at [www.eawcp.org](http://www.eawcp.org). This spring we are launching a new section to our website called the Mason Langford Memorial Learning Center on SUDEP, which will include resources about SUDEP, links to organizations who are dedicated to preventing SUDEP, and a place where families who have lost a loved one can create a memorial page.

## Leaving Behind a Legacy

Losing a loved one is never easy, but some families that we work with have been inspired by their loss to create legacies that will help other families impacted by epilepsy in the future.

### Emma's Gift: Movement Monitor Grants

**Does your child have nocturnal tonic-clonic seizures? Are you a teenager or an adult with tonic-clonic seizures that wants to continue living a safe, independent life? If so, you may be eligible for a movement monitor through our Emma's Gift grant program. These movement monitors alert loved ones to seizure activity by sensing several seconds of sustained, convulsive movement like that of a tonic-clonic seizure.**

**There are three types of monitors offered through this grant:**

**Emfit Monitor - A bed mat primarily for nocturnal seizures**

**SAMi Alert - A video camera that runs on Apple products**

**SmartMonitor - A smart watch that is worn day and night**

**To learn more about this grant and the monitor options available, please contact Amanda at 800-361-5885**

**This grant is generously made possible by the:**



**Emma Bursick**  
MEMORIAL FUND



# ABOUT SUDEP

## Emma Bursick

Emma Bursick was a happy and affectionate little girl who never let seizures define her. After she was diagnosed with epilepsy, her family assembled an army of care around Emma to make sure that epilepsy would not hold her back. Emma learned to crawl at 11 months, walked at 22 months, attended a typical preschool and eventually went to kindergarten with all of her peers. At the age of seven, Emma's journey abruptly ended on July 14, 2008. Her dad went to wake her for summer school and tragically discovered that Emma had died in her sleep.



**Emma's legacy is the Emma Bursick Memorial Fund and Emma's Gift Program.**

Emma's family started the Emma Bursick Memorial Fund (EBMF) to help raise awareness for SUDEP. The EBMF continues to search for information on non-invasive seizure detection and monitoring devices. These devices can be part of an epilepsy care plan that can help to improve safety during sleep and quality of life. Families can apply to receive a movement detection monitor through the Emma's Gift program by contacting the EAWCP at 800-361-5885. If you want to support Emma's legacy, please visit [www.emmabursick.com](http://www.emmabursick.com).

## Mason Langford

Mason Langford was a gentle soul who loved everyone and not a day that he spent on earth was wasted. He loved to go to the zoo and roar at the lions, and he loved to play with his trains and cars. At 7 months old, Mason had his first seizure. After many months of unexplained seizures, Mason was diagnosed with epilepsy and began a daily routine of medications in a desperate attempt to stop the seizures. The night before Mason's death, he had been seizure free for nearly 4 months. Mason died sometime in the middle of the night with no signs and no warning at the age of 21 months on Friday, February 13, 2015.



**Mason's legacy is the Mason Langford Learning Center on SUDEP.**

Each year, Mason's family hosts the Mason Langford Memorial Golf Outing to raise money that supports initiatives at the EAWCP, including a new section of our website dedicated to SUDEP. The new Mason Langford Learning Center on SUDEP, which is launching this spring, will include the latest information about SUDEP, links to resources, and a place where families can create memory pages to remember loved ones they have lost.

If you want to support Mason's legacy, contact Colleen at 412-322-5880 to learn more about participating in the Mason Langford Memorial Golf Outing on Sunday, May 19th. The registration fee is \$100 per golfer and includes 18 holes of golf, a cart, and dinner.

## Mark Zonneveld

Mark Zonneveld started having seizures when he was in middle school. Although living with seizures presented many challenges, Mark always managed to bounce back from those hardships and find the fun in life. He was a computer engineer who worked as a website system manager for a financial services company. He loved geeking out with his colleagues at work and playing on the company's softball and tennis team in his spare time. Mark did not show up to work one morning and his colleagues were immediately alarmed. Mark passed away at his apartment on May 16, 2010.



**Mark's legacy is the Zonne Fund.**

To honor Mark's spirit of always looking for the fun in life, his family started the Zonne Fund at the EAWCP. The purpose of the Zonne Fund is to provide fun experiences for families affected by epilepsy which can help balance the drawbacks of living life with seizures. Some of the fun things that the Zonne Fund has accomplished include: hosting 40 people in the World Series Suite at PNC Park for a Pirates game and hosting an annual free private showing of a movie with free popcorn, sodas, and door prizes.

If you want to support Mark's legacy, join the Mark's Pack team for the Pittsburgh Family Fun Run/Walk on Saturday, July 13 or make a donation to the Zonne Fund through the EAWCP website at [www.eawcp.org/donate](http://www.eawcp.org/donate).





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](mailto:staff@eawcp.org).

Mackenzie Rummings (an 8th grader at North East Middle School), hosted a fundraiser and movie event to benefit the EAWCP. The school had a Purple Day on March 26th and encouraged teachers and students to wear purple and make a donation. The school collected over \$150. Mackenzie also organized an after-school viewing of the movie, Wonder, on April 13th which was free to attend, where they accepted donations and sold purple gear and purple baked goods.

Mackenzie's older sister has epilepsy and their family has benefited from our services in the past. Thank you for being so awesome, Mackenzie!

Ana Humphreys held a lemonade stand during a garage sale and raised \$145 in support of the EAWCP. Ana's brother, Sam, has been a Camp Frog camper and also recently received a service dog through our Oscar Project.



The Wyke Family were our 2nd Place Individual Fund Raising Winners for the Pittsburgh Family Fun Run/Walk for Epilepsy. They traveled to Bradenton, FL to cheer on the Pittsburgh Pirates at Spring Training Camp.



Sarah Ciancarelli was diagnosed with seizures at age 18. After many years of struggling with seizures, they were under control for almost 2 years. Unfortunately, they have just recently started back. Sarah now works as a stay at home mom with her two wonderful daughters.

Sarah and her husband Joseph planned a fundraiser at B&L Wine Cellars in Johnstown, and raised about \$1,000!

The Bulldog Pub, located in Morningside, has a strong community presence. They regularly raise funds and awareness for the epilepsy community by way of their Pittsburgh Family Fun Run/Walk for Epilepsy team, Stephen's Hulksters.



In November, Shenango High School Senior, Haley Earl, hosted the Run to Fight Epilepsy, a 5k to benefit the EAWCP for her senior project. Held in Pearson Park in New Castle, she successfully raised over \$1,900! Way to go Haley!



## SEND US YOUR VIDEOS!

**Have you recorded your loved ones' seizure activity?**

**Are you willing to share the video with us?**

We are looking for real-life seizure scenarios to show during our seizure recognition and first aid presentations.



**Contact Paige or Yazmin  
at 412-322-5880 for details.**

## CALL 800-361-5885 TO UPDATE YOUR MAILING STATUS WITH US!

**Are you getting the mail from us that you want?**

Everyone on our mailing list receives our Newsletter, but our event mailings are more targeted. If you are not receiving invitations to events near you that you are interested in attending, or if you think you are receiving mail that doesn't apply to you, or if you have moved and need to update your address, please let us know!



Heather and Hannah are a mom and daughter duo from Pittsburgh, Pennsylvania. Hannah is 15 years old and suffers from severe intractable epilepsy in the form of Lennox Gastaut Syndrome. She has suffered from over 100,000 seizures which has resulted in a variety of issues and developmental delays. Traveling through this remarkably challenging journey has led Heather on a mission to bring happiness to others suffering from medical challenges. She knows first-hand what children and parents could use to help give them a happy boost and feeling of comfort, which is why she created Hannahtopia™.

Hannahtopia™ is an online unique boutique specializing in products that are colorful, comfy, fun, and functional. Their boutique is a place for families and friends to shop for birthdays, holidays, thinking-of-you days, or just-because-you-care days. Children that suffer from medical challenges are often offered products that are very medically sterile and colorless. Also, oftentimes, family and friends are unsure of what to purchase for these awesome children and as a result, they receive gifts they are unable to use. Hannahtopia™ offers a variety

of products and will continue to add amazing products as they grow!

One of their exclusive products is the NillyNoggin™ which is a cap specially designed to be worn while getting an EEG. This cap is colorful, snug, comfy, breathable, and functional. Heather created the NillyNoggin™ after seeing her daughter and other children go through many EEG's. Nothing looks as medically sterile and scary as an EEG, especially to a child. Hannahtopia™ is helping to take the 'scary' out of the EEG. Children, families, Neurologists, and EEG technicians love the look, feel, comfort, and functionality of the NillyNoggin™.

Hannahtopia™ gives family and friends an option when they say, "If there is anything I can do, let me know." A

gift of happy, colorful comfort from Hannahtopia™ would go a long way.

Heather recalls Hannah being at the hospital for weeks at a time and spending many sleepless nights at home during medically challenging times, receiving gifts of comfort during these most vulnerable times meant the world. These gifts took them mentally away, if even for a moment, from these emotionally challenging times. Now, they want to share these comforts with all of you. Join the journey at hannahtopia.com.

Instagram: @hannahtopia\_llc  
Facebook: @hannahtopia  
Website: [www.hannahtopia.com](http://www.hannahtopia.com)





## 25th Annual Mardi Gras Gala



The 25th Annual Mardi Gras Gala was held on Fat Tuesday, March 5, 2019 at the Westin Convention Center Pittsburgh. Deborah L. Rice-Johnson, President of Highmark Health Plan and Diversified Business, was crowned King of the Mardi Gras in front of over 700 guests. Through the support of our corporate community, and generous individual donors, the event raised \$510,000.

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 premier social gatherings, and has been sold to capacity since its inception. If you would like to confirm your table to celebrate Fat Tuesday with us next year on February 25, 2020, please contact Colleen Fulkerson at [cfulkerson@eawcp.org](mailto:cfulkerson@eawcp.org) or 412-322-5880.



Deb Rice Johnson, King of the Mardi Gras (center), flanked by her Dinner Chairs: Jerry MacCleary, Audrey Russo, Dan Onorato, Thomas VanKirk, Stefani Pashman, and Louis R Cestello.

## Thank you to our 2019 Mardi Gras Sponsors

\$25,000 FLEUR DE LIS SPONSORS



\$15,000 FRENCH QUARTER SPONSORS

Allegheny Health  
Network

Express Scripts

UPMC Health Plan

\$10,000 BOURBON STREET SPONSORS

Accenture

Anderson & Kime Employee Benefits

Arthur J. Gallagher Co.

Buchanan Ingersoll & Rooney

Covestro

Gateway Financial Group

Gateway Health

ProspHire

Reed Smith

UPMC



Guest Speaker, Logan Devlin

*"There are many reasons that I wished we had found the Epilepsy Association before 2010 – right before my first surgery. I would have loved to have the support this community provides, I would have been so grateful for a Project School Alert presentation for my teachers and peers, or to attend camp, or to come to a holiday party. These everyday things are what could have made my life – and my family's lives – just a little bit easier. To interact with others who were going through similar hardships would have been so comforting and to go somewhere without my parents would have been a dream. I have become a successful young adult, not despite my epilepsy, but because of it. I chose to not allow my circumstances and my diagnosis to define me. Instead, I learned how to fight."*





## Upcoming Events

### March

**28-30** Attending the EMS Conference  
Seven Springs

**29-31** Attending the PASNAP Conference  
State College

### April

**10-12** Attending the Head Start Conference  
State College

**12-14** Camp Firefly  
The Woodlands, Wexford

**16** SUDEP Symposium  
Pittsburgh

**16** First Responders Training  
Lebanon County

**27-28** Youth Leadership Summit  
Harrisburg

**28-30** Share Your Story Conference  
Harrisburg

**30** Legislative Hill Visits  
State Capitol, Harrisburg

### May

**1-4** Attending the HRSA Grantee Annual Meeting  
Washington DC

**9** Challenges in Treating Epilepsy - An Educational Workshop for Adults  
Pittsburgh

**18** Highmark Walk for a Healthy Community - Altoona  
Altoona Curve Stadium

**19** Mason Langford Memorial Golf Outing  
Export

### June

**1** Highmark Walk for a Healthy Community - Erie  
Presque Isle, Erie

**14** Dr. Valeriano Seminar  
Pittsburgh Zoo

**16-22** Camp Frog  
Camp Conrad Weiser

**23-29** Camp Frog  
Camp Fitch

**27-28** Para-Medicine Conference  
Harrisburg

### July

**12** Harrisburg Senators Community Day - First Pitch  
FNB Park, City Island

**13** Pittsburgh Family Fun Run/Walk for Epilepsy  
PNC Park



Be sure to check our calendar for upcoming family events near you!

**17-19** Attending the PATTAN Conference  
State College

**23** Harrisburg Run Volunteer Meeting  
Camp Hill Giant

### August

**3** Harrisburg Senators Family Fun Run/Walk for Epilepsy  
FNB Park, City Island

**9-11** Transition Conference  
TBD

### September

**22** Family Picnic  
Pittsburgh

### October

**TBD** Halloween Spooktacular  
York

**11-13** Camp Firefly  
The Woodlands

### November

**National Epilepsy Awareness Month**

**TBD** York Mini-Conference  
York

## EAWCP OFFICE CLOSURES

In observation of the holidays, our offices will be closed the following days:

**MAY 27**

Memorial Day

**JULY 4-5**

Independence Day

**SEPTEMBER 2**

Labor Day

**NOVEMBER 28-29**

Thanksgiving

**DECEMBER 24-25**

Christmas Holiday

## Support Groups

We host several monthly support groups for adults living with epilepsy.

(Meetings may vary each month. Please call the contact person for your group to confirm the date and time.)

### York

1st Thursday of each month | 6:00-7:00pm  
WellSpan Surgery & Rehab. Hospital  
Call Gretchen for details | 717-730-6779

### Hershey

1st Tuesday of each month | 6:00-7:30pm  
Hershey Medical Center, Dept. of Neurology  
Call Laura for details | 717-730-6779

### Johnstown

4th Wednesday of each month | 4:00-5:00pm  
Conemaugh East Hills Center  
Call Greg for details | 814-799-0345

## CALLING

EPILEPSY ADVOCATES!



Share Your Story  
PA PUBLIC POLICY CONFERENCE

**SUNDAY-TUESDAY, APRIL 28-30, 2019**

**THE BEST WESTERN PREMIER  
HARRISBURG, PA**

*This conference will help you learn to share your epilepsy story and advocate for yourself and all Pennsylvanians living with epilepsy. This program begins with dinner on Sunday and culminates in a visit to the State Capitol to share your story with legislators.*

TO LEARN MORE, CONTACT ANDREA AT  
412-322-5880 • AZONNEVELD@EAWCP.ORG





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

1501 Reedsdale Street, Suite 3002  
Pittsburgh, PA 15233

Non-Profit Org.  
U.S. Postage  
**PAID**  
Pittsburgh, PA  
Permit No. 1390

# IT'S RUN/WALK SEASON!

## ALTOONA

HIGHMARK WALK FOR A HEALTHY COMMUNITY

**SATURDAY, MAY 18**

<http://hcf.convio.net/epilepsyaltoona>

## ERIE

HIGHMARK WALK FOR A HEALTHY COMMUNITY

**SATURDAY, JUNE 1**

<http://hcf.convio.net/epilepsyerie>

## PITTSBURGH

PITTSBURGH FAMILY FUN  
RUN/WALK FOR EPILEPSY

**SATURDAY, JULY 13**

<http://tiny.cc/epilepsywalk>

## HARRISBURG

HARRISBURG SENATORS FAMILY  
FUN RUN/WALK FOR EPILEPSY

**SATURDAY, AUGUST 3**

<http://tiny.cc/epilepsy-walk-harrisburg>