

# Four Decades of Distinguished Service:

## Significant Dates in the History of the EFWCP

**1972** A group of parents and friends concerned about the lack of services for people with epilepsy, who began meeting in 1971, establish the beginnings of what will become the EFWCP. On May 30th, the group is officially incorporated as the Allegheny Plateau Chapter of the Epilepsy Foundation of America.

**1979** Polly Phillips gets involved with the Foundation because her son, John Phillips, begins experiencing epilepsy at age four. She recognizes a need for the Foundation to be better organized so it can better reach and serve people who have epilepsy. Polly, along with Foundation board members, calls on her sister-in-law, Lee Phillips, to take the helm as executive director.



*The foundation has been honored over the years by the presence of community-minded board members. Included, from left, back row: Steve Greenberg, George Whitmer, Tom Chakurda, Dan Koch, Bob Moorehead, Peter Rockwell, Chuck Voelker, David Koch, and Larry Leventon. Front row, from left: Julie Klym, Douglas Dick, Dave Taylor, Tom Trimm, and Rich Ryan.*

**1981** Lee Phillips is hired as the EFWCP's first paid executive director. She takes the Foundation from a loosely tied group of interested social workers and doctors to a finely knit board of directors made up of outstanding community leaders.

In Phillips' first year, she has no staff and relies heavily on volunteers. While attending one health fair, she is inspired by her interaction with the Arthritis

Foundation at a neighboring booth; dealing with arthritis herself, she finds it helpful to talk with people who understand what she is going through. This experience fuels her passion to arrange several support groups and classes featuring local experts for adults with epilepsy and parents of children with epilepsy; the groups number in the 20s on a regular basis.

**1982** The Foundation hosts its first-ever fundraiser, honoring new University of Pittsburgh Football Coach Foge Fazio. The event puts the EFWCP on the map in the larger corporate community, as local nonprofits are just beginning to go out on their own with Fundraising events.

EFWCP's first major annual fundraiser, Froggy's Golf Classic, is created by Steve "Froggy" Morris, Peter Rockwell, John Phillips, and other Foundation board members to raise funds for epilepsy services.



*Early camp photo*

**1984** The EFWCP creates and facilitates a summer camp program for children with epilepsy to enjoy. Volunteers begin trucking 25 kids in a donated van each summer to various camps. With help from Dr. Patricia Crumrine and medical staff on hand from Children's Hospital of Pittsburgh, many children with epilepsy experience the magic and fun of summer camp for the first time. The annual camp becomes known as *Camp Frog* in honor of Steve "Froggy" Morris.



*Lee Phillips and Bobbie Martha*

**1985** Through the help of board member Bobbie Martha, the EFWCP secures a 2-year grant from the Junior League of Pittsburgh and hires the Foundation's first paid program staff member, Linda Otto, to formally develop a loosely existing school and community education program that she had been supporting on a volunteer basis. A person who lives with epilepsy herself, Otto begins writing letters to schools in August, and is flooded with responses of requests for presentations to teachers, students, and the workplace. From September through May, she gives presentations four days a week and reaches more than 6,000 people.

**1988** Judith K. Painter is hired as the next executive director, and continues to grow the EFWCP. After raising new funds, she hires a program director.

**1989** An adult employment program, funded by a grant from the National Epilepsy Foundation office, is initiated to help adults with epilepsy secure permanent employment by providing job seeking skill training, a job club, and individual vocational counseling.

EFWCP receives an Epilepsy Family Action Services 2-year contract from the Epilepsy Foundation National.

The first Pirates Family Fun/Run Walk is held to raise awareness and funds for the Foundation; more than 1,000 people participate.



**1991** EFWCP is recognized by the Epilepsy Foundation National office with the *Affiliate of the Year* award.



Staff including Judy Painter and Rick Boyle, and board members Rich Ryan, Dr. Patricia Crumrine and Peter Rockwell accept the *Affiliate of the Year* award.

**1992** EFWCP hires a full-time community education specialist to make *Project School Alert* presentations to teachers, students, and other organizations interested in learning about epilepsy, seizure recognition, and first aid training.

**1993** Partnering with the Epilepsy Foundation Eastern Pennsylvania, the EFWCP leads the way in stepping up efforts with legislative affairs. In addition to maintaining contact with local members of the General Assembly, meetings are held with staff from the Governor's office, the Office of the Budget, the Department of Health, and the Department of Public Welfare; and a representative is sent to testify about health care reform at public hearings held by then First Lady Hillary Clinton and Senator Harris Wofford.

*Project School Alert* program designs two giant story books *Lee the Rabbit* and *Because You are My Friend*.

First *Meet the Employer* event is launched as a part of the employment program.

First legislation for epilepsy services in Pennsylvania history, H.B. 2371, is introduced into the Pennsylvania House of Representatives in December.

**1994** First state funding in Pennsylvania's history to finance epilepsy programs and services begins. This enables the EFWCP to expand services in local territories, and establish the first Epilepsy Foundation affiliate services ever available in central Pennsylvania.

EFWCP participates in the National Foundation's *Public Policy Institute*, and sends two representatives to Washington, D.C.

**1995** EFWCP establishes epilepsy support services in 17 counties in the south central region of Pennsylvania, increasing the total number of counties served to 32.

Doors open to the Epilepsy Resource Center in the central Pennsylvania region in January, and services are provided to 261 individuals, 96 families, and 165 adults during this first year. In addition, 37 professionals and social service agencies in the area receive information and training.



Jane Duffy (far right) accepts the award for *Employer of the Year*.

EFWCP receives an unprecedented three awards from the National Foundation: *Board Member of the Year*, *Employer of the Year*, and *Executive Director of the Year*.

Dr. Louis Catalano coordinates the Westmoreland County Sports Dinner and Auction; it is the first fundraiser held outside Allegheny County for the Foundation.



The first *Mardi Gras Gala*

The first *Mardi Gras Gala* is held, which honors a prominent community/business leader. *Mardi Gras* quickly becomes the Foundation's largest fundraiser.

**1996** Volunteers receive the Epilepsy Foundation National *Family Service Award* and the Allegheny County Medical Society *Benjamin Rush Organization Award*.

The first *Regional Family Conference on Epilepsy* is held in Pittsburgh to offer an in-depth look at the issues that affect people with epilepsy; more than 250 people attended.

Annual Budget grows from a negative balance in the early 1980s to approximately \$500,000.

**1997** A communications director is hired to improve public relations in territories served by the EFWCP.

A website, [www.efwp.org](http://www.efwp.org), is developed to facilitate access to information on epilepsy and EFWCP services, and provides links to other resources.

**1998** EFWCP receives three more awards from the Epilepsy Foundation National: a *Special Recognition Award*, *Volunteer of the Year*, and an *Advocacy award*.

A major restructuring organizes the Foundation's board of directors into three entities, and adds a number of new staff to effectively deliver programs and services in western and central Pennsylvania.



Tom Trimm, Judy Painter, Melissa Hart, Annette Chelius, George Harakal, and Bill Adolph

The Pennsylvania General Assembly and the Governor's office double the appropriation for epilepsy services in the 1998-1999 state budget, which ensures continual full-time status of *Project School Alert* in western Pennsylvania, and enables the creation of such services in central Pennsylvania. The funds also allow the Foundation to hire staff to



deliver employment services in central Pennsylvania.

A new and improved newsletter, *Interaction*, is unveiled. Published quarterly and mailed to over 6,300 residences, it puts a face on epilepsy by telling the stories of people's experiences with the disorder throughout the EFWCP service area.

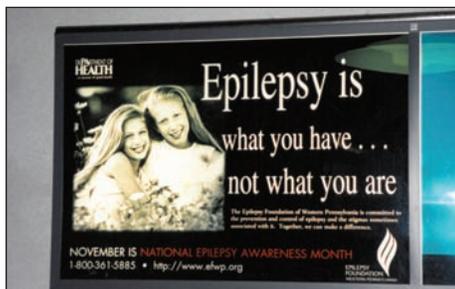
The Foundation creates a glossy, 16-page information book, publishes a number of new educational and special event brochures and posters, and successfully bridges the gap with media outlets to bring epilepsy/seizure disorders into the public eye.

First *Teen Getaway* offers teens that have epilepsy the opportunity to share experiences and feelings about living with the disorder, while also building friendships and having fun.

**1999** EFWCP's Mardi Gras Gala receives the first and only Epilepsy Foundation *National Fund Raising Award*.

First full year of operating *Project School Alert* and *Adult/Employment projects* in the central region of the state.

A parent Advisory Committee is established to aid the Foundation in promoting epilepsy awareness and advocacy, and to create a corps of volunteers; the group also develops a quarterly newsletter, *ParentLink*, written by, for, and about parents of children with epilepsy.



*The billboard at the Allegheny County International Airport*

A billboard campaign is launched in Pittsburgh during National Epilepsy Awareness Month, which increases

awareness and donations with the slogan: *Epilepsy is What You Have, Not What You Are*.

**2000** Mardi Gras is recognized among the top annual social events in Pittsburgh by local society newspaper editors.

The first Family Picnic is held in Pittsburgh to provide the opportunity to socialize with other individuals and families affected by epilepsy in a fun, relaxed atmosphere; 40 families attend.

**2001** A public relations campaign launches the distribution of four display boards, each targeting specific audiences in an effort to connect individuals experiencing epilepsy with the EFWCP to benefit from its existing services. The display boards are distributed to doctor's offices, epilepsy medical clinics, pharmacies, and libraries throughout western Pennsylvania.

In June the Epilepsy Foundation National approves the addition of another 17 counties located in west and central regions of the northern part of the state, bringing a total of 49 counties into the EFWCP service territory.

Pennsylvania's state budget increases by \$50,000 to help the Foundation serve its new territories; \$25,000 is allotted for reaching the northwest part of the state.

The *Annual Regional Conference on Epilepsy* takes place in Harrisburg, marking the first time it is held outside of Pittsburgh.

Pittsburgh Police Training Academy invites EFWCP to provide seizure recognition and first aid training for academy recruits.

A scholarship program is created, and five \$1000 scholarships are awarded to teens with seizure disorders to attend a secondary school.

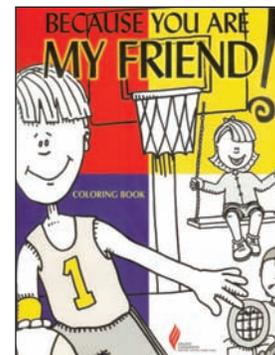
First ever *Gateway Clipper cruise* socialization and education event held in Pittsburgh sees nearly 100 adults in attendance.

During National Epilepsy Awareness Month in November, the EFWCP

participates in National's youth research and awareness campaign, *Entitled to Respect*, which teams up with pop music stars ★NSYNC.

**2002** The EFWCP is named *Affiliate of the Year* by the Epilepsy Foundation National, and Associate Director Peggy Beem-Jelley is honored as *Affiliate Staff Person of the Year*.

The *Annual Regional Conference on Epilepsy* is held in Erie, with more than 120 people in attendance.



*The Because You Are My Friend coloring book is used for school presentations and given to families with children newly-diagnosed with epilepsy*

The *Because You Are My Friend* book is turned into a coloring book for Project School Alert presentations for pre-K and elementary schools.

The *School Nurse Update* is published. The newsletter is sent to 1,600 nurses and provides updates on newer treatments for children who have epilepsy.

EFWCP holds a regional conference for school nurses in State College in November, with 20 school districts participating in the one-day event.

**2003** The annual Mardi Gras Gala receives the *Golden Circle Award* from the Epilepsy Foundation National. This recognition is reserved for events that raise more than \$100,000 in net proceeds, and the EFWCP is the only affiliate to receive such an honor. Dr. Lou Catalano, EFWCP board member, received the *Excellence in Fundraising* award in recognition of his work on the annual Westmoreland County Sports Dinner and Auction.

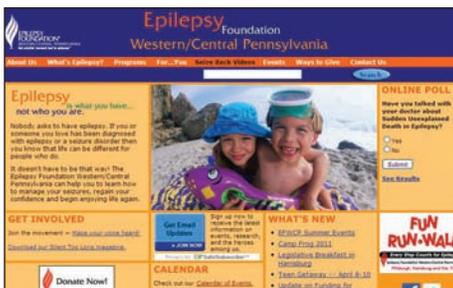


EFWCP leads a branding initiative in conjunction with six other major markets across the country and the National Office. The EFWCP coordinates efforts which delve into the needs of persons with epilepsy/seizure disorders so that all affiliates can be ready to address the specific challenges associated with the condition. A tag line is developed by MARC Advertising, and is adopted and trademarked by the National Office.

Two new fundraising initiatives, the Erie and Harrisburg Fun Run/Walks, are launched in conjunction with each city's minor league baseball team.

**2004** Judy Painter is named *Executive Director of the Year* for the second time by the Epilepsy Foundation National, and Louis Testoni, president of the EFWCP Board of Directors, is named *Volunteer of the Year*.

Offices in Erie and Johnstown are opened. These new offices allow the organization to better serve individuals and families affected by epilepsy in the northwest and central areas of the state.



The new face of the EFWCP website

A redesigned website is launched in February. The site has a brand-new look and very comprehensive information; from the diagnosis & treatment of epilepsy, to the programs & services offered by the EFWCP, to news about the Foundation's achievements, events, and noteworthy happenings.

An interactive CD-ROM is developed. This technological tool is a resource for educators and healthcare professionals who can help others learn more about epilepsy, and can be a way for families affected by epilepsy to share information about seizure disorders with other family members and friends.

A symposium for professionals working with individuals with developmental disabilities was held in November in Pittsburgh. More than 80 attendees hear a presentation from an area neurologist on new treatment options for epilepsy patients and learn about EFWCP programs and services.

**2005** The Pittsburgh, Erie and Harrisburg Fun Run/Walks for Epilepsy receive a *Golden Circle Award* from National, and the Mardi Gras Gala is the *Top Golden Circle Award* winner, having netted more than \$204,000 – more than any other affiliate in the country. The EFWCP is again named *Affiliate of the Year*.

A *Saturday Spring Spectacular* takes place at the Community College of Allegheny County Boyce campus. At this expanded version of the EFWCP's annual conference format, more than 70 attendees hear from experts on a variety of epilepsy-related topics while children enjoy games, crafts, activities, and the basketball showmanship of Mighty Mike Simmel.

Research projects are launched during the summer in Erie and Pittsburgh to determine how best to serve both African American and Hispanic families living with epilepsy. The results of these projects serve as guiding forces in the development and implementation of new outreach initiatives to these communities, including a *Soul Food Luncheon* for human service professionals serving African Americans and a direct mail outreach campaign addressing issues of stigma and misconceptions about epilepsy in black communities.

*Family Conferences on Epilepsy* are held in Erie and Johnstown in November. More than 40 attendees in each location hear from experts on topics ranging from healthy living with a chronic condition to treatment options and available community resources.

EFWCP staff work with staff from the University of Pittsburgh's Office of Child Development to design program evaluation tools. The measurement instruments are piloted in the spring. Results from the data collected indicate

that *Project School Alert* is highly effective in increasing the public's understanding of epilepsy and appropriate first aid steps.

The EFWCP is named *Affiliate of the Year* for an unprecedented third time.

**2006** EFWCP Board of Directors member Joyce Bender is named *Volunteer of the Year* by the Epilepsy Foundation National.

The *Steve "Froggy" Morris – G. Peter Rockwell Endowment Fund* is established. The endowment will provide scholarships to young people with epilepsy so that they can attend Camp Frog.

For the first time, *Camp Frog* is offered for a week at two different locations in the state. The first week of camp is at Camp Conrad Weiser in Wernersville, and the second is at Camp Fitch in North Springfield.

The EFWCP holds its first *Women and Epilepsy* conference in November in Pittsburgh. Seventy-seven women and their loved ones attend the conference to hear from experts on topics including hormones and epilepsy, social concerns, and issues affecting pregnancy.

The Pittsburgh Steelers, and Steelers offensive lineman Alan Faneca, invite families to training camp in August at St. Vincent College in Latrobe. Forty-one 'Faneca Fans' watch the Steelers practice from the sidelines, and meet Alan Faneca and several other players after practice for autographs and pictures. Alan offers many words of encouragement to all the kids and talks openly about growing up with epilepsy. He also speaks with news crews from two local TV stations to promote epilepsy awareness and the services available through the EFWCP.

**2007** The EFWCP receives three *Golden Circle Awards* from National. The 13th Annual Mardi Gras Gala grosses \$400,000 for epilepsy support services and programs. The Pittsburgh Pirates Annual Fun Run/Walk grosses over \$100,000 for the first time. The third *Golden Circle* is for Froggy's Golf Classic.



A video is created by EFWCP to raise awareness about the impacts epilepsy/seizure disorders have on families and how the EFWCP can help them to improve their quality of life. The video is released during Mardi Gras 2007.

The EFWCP moves from its longtime home in the Vocational Rehabilitation Center on Forbes Avenue to its current home in the Cardello Building on the North Shore.

Grants are received from National to provide a Women in Epilepsy Conference in Harrisburg, attended by 60 people, and to create Employer Training programs.

**2008** The EFWCP receives two *Golden Circle Awards* from National.

The EFWCP receives the *John H. Harris Award* from Variety the Children's Charity of Pittsburgh. This award recognizes outstanding service to children with disabilities in southwestern Pennsylvania.

EFWCP receives a grant and staff provides educational presentations to almost 450 seniors and their caregivers at senior centers, nursing homes, and assisted living facilities in Allegheny County.

The EFWCP meets the Epilepsy Foundation National's Affiliate Standards, one of the first affiliates in the country to do so.

**2009** The EFWCP receives three *Golden Circle Awards* from National. The 15th Annual Mardi Gras Gala breaks fundraising and attendance records, with 900 guests bringing in more than \$423,000 in support of EFWCP programs and services.

Long-time EFWCP board of director's member Joyce Bender becomes chair of the Epilepsy Foundation National's board.



*The helmet safety program encourages children to stay safe while riding their bicycles*

Staff in the Johnstown office partner with the Johnstown Chiefs minor league hockey team to present seizure awareness, helmet safety, and head injury prevention programs to area elementary school students. Staff also collaborates with the Johnstown Rotary to distribute bike helmets to participating schools.

The EFWCP is certified as an affiliate meeting the National Standards of Excellence created by the Epilepsy Foundation National. The EFWCP is one of only five affiliates in the country to achieve this distinction.



*Andrew Stockey, Jim Krenn, and Tony Watson, co-chairs of the 2011 Pittsburgh Fun/Run with Andrew McCallion, one of 6 scholarship winners.*

**2010** The EFWCP receives two *Golden Circle Awards* from National.

In partnership with the UPMC Health Plan, the EFWCP develops a model program for families raising children with seizures. The Start SMART (Seizure Management Awareness & Recognition Training) program provides parents with support and help in developing seizure self-management skills to minimize the negative impact of seizures upon the life of their child and family.

The EFWCP receives a federal grant under the US Department of Health & Human Services, Maternal and Child Health Services Division's Innovative Strategies in Serving Children & Youth with Epilepsy Project Access Program. This project creates an opportunity for the EFWCP to work with quality improvement programs within both primary pediatrics and specialty care. Children's Hospital of

Pittsburgh, Division of Child Neurology and three office locations of the Pediatric Alliance group participate in this program to replicate a model of care coordination developed at Dartmouth Hitchcock University Hospital.



*EFWCP supporters in the Erie area gathered at Presque Isle State Park for the 2011 Highmark Walk for a Healthy Community*

**2011** The EFWCP participates in the Highmark Walk for a Healthy Community for the first time in Erie. The Highmark Walk for a Healthy Community is underwritten by Highmark Blue Cross Blue Shield, which covers the cost of the walk and allows all of the money raised by participants to go to the organization they are supporting.

The EFWCP partners with the PA Medical Home Project to provide a statewide training conference on epilepsy in Harrisburg as part of the annual *EPIC-IC Conference*. The conference provides an opportunity for over 150 primary pediatric care providers to learn more about managing epilepsy and seizures in their patients.

Lundbeck, Inc. awards the EFWCP with a \$10,000 grant to start a new program, called Studio E: The Epilepsy Art Therapy Program. Studio E will encourage individuals living with epilepsy to find their voice through art. This program is expected to launch in the summer of 2012.

The 17th Annual Mardi Gras Gala is recognized by local papers; rated the #9 Best Event in Pittsburgh by the Post-Gazette's Marylynn Uricchio of Seen and the #4 Best Event in Pittsburgh by Tribune Review's Kate Benz of Fanfare.

