Since I started having seizures later in life, I’ve learned that there are three secrets to living with epilepsy: finding the right doctor, finding the right medication, and having the right attitude. Be persistent – ask others who’ve been through it. And it doesn’t matter how old you are, epilepsy is manageable.

— Judy, age 70, with five of her 23 grandchildren

Epilepsy is what you have, not who you are.

Seizures can happen to anyone, at any age. Seniors are being diagnosed with epilepsy/seizure disorder now more than ever. The Epilepsy Foundation Western/Central Pennsylvania offers information and support to older adults who are living with seizures and their caregivers. We can address the special concerns seniors with seizures have – together.

For more information, visit www.efwp.org or call 1-800-361-5885.
A Note of Welcome
from the Executive Director

Dear Friends,

Summer is just around the corner, and with it comes warm weather, outdoor fun, and EFWCP events perfect for the whole family.

You don’t have to be a fitness fanatic to be a part of our Pittsburgh and Harrisburg 5K run/walks. In fact, these events give people of all abilities the chance to raise awareness of epilepsy/seizure disorders, raise funds to support EFWCP programs and services, and raise their spirits at a morning full of friends, food, and fun.

Families affected by epilepsy can also attend our social events taking place around our service territory over the next few months. Folks in the northwestern region of the state can look forward to a Zoo Adventure, while families in the Johnstown area can attend a picnic in July. Family events are also planned for the Pittsburgh and Harrisburg regions – look for more information to arrive in your mailboxes over the next few weeks.

Camp Frog is leaping into action in July. We are thrilled to once again offer two weeks of camp – the first will take place at Camp Fitch on the shores of Lake Erie and the second will be held at Camp Conrad Weiser near Reading. Young people with epilepsy/seizure disorders and families can look forward to a great time at both camps, enjoying everything from rock climbing walls to horseback riding to waterskiing.

We hope that you and your family are able to join us at one of our many summer activities this summer. These events give you a chance to get to know us and to meet others who understand what it means to live with seizures. Our programs and family events are the bedrock of this organization – without your participation, we simply wouldn’t exist. So come on out to one of our great summer happenings to show your support for the EFWCP and everyone living with seizures. We look forward to seeing you soon!

Best wishes,

Judy K. Painter
Executive Director

EFWCP Run/Walks are fun for the whole family

The Epilepsy Foundation Western/Central Pennsylvania (EFWCP) is gearing up for two great summer events the whole family can enjoy, and you’re invited to join in the fun! The Pittsburgh and Harrisburg Fun Run/Walks for EFWCP bring together families and adults affected by epilepsy, community members, and local celebrities to have a great day in support of a great cause.

Teens and individuals can raise funds for EFWCP programs and compete to win fantastic prizes like Spring Training getaways, private boxes at a baseball game, and shopping sprees. Everyone who participates goes home a winner – walkers and runners receive t-shirts, tickets to an upcoming baseball game, and entrance to a tasty tailgate party.

Saturday, June 16
19th Annual Pittsburgh Pirates Fun Run/Walk
PNC Park, Pittsburgh
Registration begins at 8 a.m. Race begins 9:30 a.m.

Saturday, August 4
5th Annual Harrisburg Senators Fun Run/Walk
City Island, Harrisburg
Registration begins at 8:30 a.m. Race begins 9:30 a.m.

For more information or to register for a fun/walk, visit www.epilepsyfoundationrunwalk.hInterested.org or call 1-800-361-5885. So bring your who friends, family members and neighbors to one of the EFWCP run/walks this summer and make every step count for epilepsy!

Save the Date
Oktoberfest Clay Shoot coming to Nemacolin Woodlands

The EFWCP is proud to announce its first-ever Oktoberfest Clay Shoot event! Perfect for both experienced shooters and new to the sport, the event will include lunch and an auction of some great sporting gear. So make plans now to join us at Nemacolin Woodlands Shooting Academy on October 19th – you won’t want to miss the fun! Call 1-800-361-5885 or email kbrickell@efwp.org for more information.

Inside this issue
4 How I grow in Nowhere Land
Cassie Hall, a teen living with absence seizures, shares her story of coping with epilepsy.

6 Exercise Benefits and Epilepsy
Information about the positive effects exercise can have for people living with seizures.

Erie Zoo Adventure
A great summer get-together for families affected by epilepsy.

Teen Getaway
Young people have a fun weekend at Camp Allegheny.

7 Seniors and Seizures Initiative
The EFWCP launches an outreach program for elders and their caregivers.

8 Sudden Unexplained Death in Epilepsy
What patients need to know.

Local Woman Joins Epilepsy Foundation Youth Council
Bridget Green is chosen as a member of a national advocacy group.

9 Calendar of Events
Expressions of Courage
Art contest for anyone diagnosed with epilepsy/seizure disorders announces the entry deadline.

10 Oh, What a Night!
The annual Monte Carlo Gala lets the good times roll.
The first place I could ever formally name my odd reaction to light was in an office at the local neurological center. The words petit mal epilepsy were almost comforting because they sounded so official, despite the fact that it was an affliction and, yes, it affected me. At least my vocabulary for the seizures expanded beyond: crazy trips to Nowhere Land I take while riding a bus, while flipping on the trampoline, etc. I also knew that in older novels, characters with epilepsy were considered possession.

I remember watching my mother sitting quietly in the corner of the office that day, two years ago. I could see her face vanishing and reappearing as the doctor’s white-sleeved arm bent and extended over my head. He must have caught on to my mother’s hyperventilating and my lack of breathing because he blurted, “Oh, no, you’re not disabled! That’s why it’s so strange that you have this kind of epilepsy!”

Misunderstandings like this, with general people and professionals alike, have always been a part of dealing with petit mal epilepsy. I mean - consider what the characters in those novels had to put up with! A lot of misinterpretations are unavoidable, even in an open-minded society free of harsh labels like possession. Following that adrenaline rush of diagnosis, however, the effort to make people understand became tiresome, especially when many people would mistake it for a mental instability. It was like wearing a cast on a broken leg and being plopped helplessly into a room full of people who want to know what happened before they sign it, because that would make their signature more real. My story tapered down from a grand, elaborate explanation of the affliction that would make any neurologist swoon from my knowledge of scientific terms, to a curt “It’s what happens when the sunlight hits my eyes.” Developing patience was part of growing up, despite how difficult, but it will not hinder me from boarding that bus and getting to where I need to be. I move on, farther and farther in my life, despite the recurrent trips to Nowhere Land on the way. The closest I can come to describing the act of passing one’s own test would be to use the words of Edward Estlin Cummings. Strengths of determination are those “which I cannot touch because they are too near!”

I want to go to college to write and study psychology. It is ironic that I yearn for insight on the mind because I suffer from a condition that can prevent mental functioning or focus. To counter my neurological adversity, I’ve doubled-up on a prescription medication and wear polarized blue sunglasses, made especially for seizure prevention.

When I threw my pills away on Christmas day, as a little gift to myself, I did not implode at the thought of stringing tinsel and making cookies, something needed to approach your doctor if you don’t agree with the medicine he/she prescribes. I remember my mother pulling her hands through my hair month after month, and seeing her face, turning more and more worried. When I first met the doctor he blurted, “Oh, no, you’re not disabled! That’s why it’s so strange that you have this kind of epilepsy!” I did not realize that I was putting myself at risk of a grand mal seizure, the type of seizure I’ve been fortunate enough never to experience naturally. It may seem this warning is obvious but a person is willing to do anything to get rid of something they don’t want in their systems. Us Neuro-Turtles understand.

I think that the two years of my being diagnosed with epilepsy brought me closer to the people who do understand the person, even if they cannot understand the condition. I still get questions like “Can you babysit tomorrow night or would your seizures make that difficult?” from my mother, but I don’t take it so personally. I’ve learned that another way to define petit mal epilepsy is that it is not me.

Despite all social misunderstandings and inconveniences involved with having epilepsy, I am stronger than my condition; it will not bind me down. Epilepsy complicates vehicle transportation for me, and it makes conversations aboard the bus difficult, but it will not hinder me from boarding that bus and getting to where I need to be. I move on, farther and farther in my life, despite the recurrent trips to Nowhere Land on the way. The closest I can come to describing the act of passing one’s own test would be to use the words of Edward Estlin Cummings. Strengths of determination are those “which I cannot touch because they are too near!”

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Kowabunga, dude.
**Exercise Benefits**

By Lori Murphy, MSPT

Nearly everyone can benefit from exercise, but certain gains may be especially important to those with epilepsy. Long-term use of anti-epileptic drugs can lead to osteoporosis, which weakens bones and increases the risk of fractures. Teens with epilepsy tend to be less active and participate less in group or sports-related activities. This creates a greater tendency to become overweight. Also, many persons with epilepsy experience mood disorders, often involving depression. Exercise can have a positive impact on all these issues and lead to other health benefits as well.

There are different ways to exercise. These include working out in a gym, swimming, playing sports, or even taking a walk around the block. Contact sports, which were once discouraged among persons with epilepsy, are now encouraged, especially if sensible guidelines are in place. Other popular methods of exercise include Yoga and Tai Chi. Such activities can be done either in a group or a more private setting. The type of exercise chosen should depend on what one’s goals are. Strenuous exercises are good to improve flexibility. Working with weights or against some other form of resistance increases strength. Exercises that increase the heart rate for a sustained amount of time can improve endurance and facilitate weight loss or weight-bearing exercises can also promote bone health. Exercises that incorporate controlled breathing, such as Yoga and Tai Chi, can lower the heart rate, reduce blood pressure, and improve stress levels.

Some individuals prefer to exercise alone, whereas others prefer group-related activity. No matter what is chosen, it is important to select something that is enjoyable. This may help in making exercise a part of one’s regular routine. Daily exercise is usually encouraged, but it may not be possible. However, exercising even for just a few days a week can promote positive changes in one’s health.

**Seniors and Seizures**

EFWCP INITIATIVE LAUNCHING THIS SUMMER

In addition to these trainings, a symposium on seniors and seizures will be held on Friday, October 5th at the Sheraton Station Square. This half day informational session will feature a presentation on the topic by Dr. Anne Van Cott, a neurologist with the Veteran’s Administration Health System and a member of the EFWCP’s Professional Advisory Board. Healthcare professionals, social workers, staff at senior care facilities, and other caregivers are invited to attend the event and learn more about this important topic.

As a large portion of our country’s population ages and baby boomer advance in years, the issue of seniors and seizures will continue to be a growing one. The good news is that work is underway to raise the public’s awareness of the condition and its impacts. The EFWCP stands ready to bring the latest information about seizures in the elder community to our constituents and to work with seniors and their caregivers to address any seizure-related concerns they have.

For more information about the EFWCP’s “Seniors and Seizures” initiative, please contact Francine Rehyer at feden@efwp.org or 1-800-361-5885.

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**Family Fun in Erie! EFWCP gears up for a great summer get-together**

Families in northwestern Pennsylvania are invited to a fantastic family outing this summer.

Join us for a Zoo Adventure on Wednesday, June 20th. Pre-registered families and individuals will receive admission tickets to enjoy all the Erie Zoo has to offer from 3 – 5 p.m. Then, join EFWCP staff at a pavilion in Glenwood Park (adjacent to the zoo) from 5 – 7 p.m. for a tasty potluck dinner. We’ll provide the fixed dishes, drinks, and utensils. Bring your favorite dishes to share with and enjoy good food and great company. Games and crafts will be provided for kids of all ages.

Pre-registration is required for the event. The registration deadline for the Zoo Adventure is Friday, June 8th. Contact Sue Edmonds at sedmonds@efwp.org or 814-44-1135 for more information or to register.

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**Teen Getaway**

Eighteen young people and four counselors attended the EFWCP’s annual Teen Getaway weekend, held at Camp Allegheny April 27 – 29. The teens enjoyed all the camp had to offer, including hiking, challenge courses, zip lines, wall climbing, sports, crafts, camp fires, and movies. The young people also got a chance to talk with other teens who understand what it’s like to live with seizures. Kate Wilson, EFWCP children and family services coordinator, said, “The getaway was a lot of fun! Everyone had a great time, and for some of the kids, it was the first time they’d ever met someone else who had seizures. It was really great to see a lot of friendships forming over the weekend.”

Many thanks to Jenny Ferko, RN, who provided onsite medical supervision for the weekend.

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**Seniors & Seizures**

Persons of all ages with epilepsy should be encouraged to exercise, as negative effects rarely occur. Exercise-induced seizure activity has been reported in some situations. One theory is that rigorous exercise could possibly trigger a seizure, either directly from hyperventilation or indirectly by impacting anticonvulsant levels in the body. It is also thought that repetitive mild head trauma during contact sports may lead to increased seizure frequency. These scenarios, however, are rare and evidence does not support any relationship between such physical activity and seizure frequency.

Nonetheless, it is important to consult with your health care provider for additional guidance if there are concerns regarding a particular exercise activity and seizure frequency.
Sudden Unexplained Death in Epilepsy – What Patients Need to Know

by Paul L. Schraeder, Professor of Neurology, Drexel University College of Medicine

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The SUDEP (Sudden Unexplained Death in Epilepsy) phenomenon has been known to exist for many years, but only in the past two or three decades have neurologists in the United States acknowledged it as a common cause of death in association with epilepsy.

In the United States, the educational effort about SUDEP for patients and families has been minimal. Reluctance to discuss the possibility of SUDEP when a seizure disorder is diagnosed seems to be based upon the presumption that such information would be too stressful or too difficult for the patient and family to handle. This attitude has been manifested both by medical professionals and lay organizations that support persons with epilepsy. The fear that such information may have a negative impact is not borne out by the responses of patients and families when presented with the facts.

Indeed, there seems to be some change in the wind regarding the desire to know more about SUDEP. Recently, because of requests for information from persons with epilepsy and their families, a first ever regional symposium about SUDEP was presented through the auspices of an Epilepsy Foundation affiliate. Evaluations from the more than 100 attendees indicated that they were grateful to have been presented, for the first time, with in-depth information about SUDEP. It seemed that having this information was far more helpful than not knowing. Responses to this symposium indicate that patients and their families seem more comfortable discussing SUDEP than are the medical professionals.

The most frustrating aspect of SUDEP is our lack of knowledge about why it occurs and how it may be prevented. While there is data indicating that optimal seizure control lowers the probability of occurrence, it does not remove the chance entirely. The only intervention that is associated with an ablation of risk is that of complete cure of seizures consequent to temporal lobe surgery. The implication of this observation is that having any seizures, no matter how infrequent, is still associated with some risk of SUDEP.

The association of SUDEP with sleep has raised the question of whether monitoring of respiratory function during sleep allows for intervention by care-givers to prevent a fatal apnea (brief pauses in breathing). Nonetheless, we still have a large group at risk of fatal cardiac arrhythmias for which we do not have any preventive measures.

Above and beyond the need for more scientific investigation into this accomplishment and is proud to be chosen as a member of the first-ever Youth Council of the Epilepsy Foundation. The focus of the group for the next two years is to create a strategic action plan for the Foundation’s youth programming and how the Foundation will reach out to young people.

The Youth Council comprises 10 young adults, ages 18 to 24, from across the country who have demonstrated exceptional leadership in the epilepsy community. Members serve as ambassadors and public spokespersons for the Epilepsy Foundation mission, as state and national advocacy representatives, and as epilepsy community leaders at the local level. Council members include youth with and without epilepsy.

Bridget Green, a recent graduate of St. Mary’s College in Indiana with her bachelor’s degree in communications and a minor in sociology, Bridget orchestrated an Americans with Disabilities Act compliance audit of her college to ensure that all students with disabilities had access to the college environment. Locally, Bridget has worked as both an intern for the EFWCP and as a Camp Frog counselor. The EFWCP congratulates Bridget on this accomplishment and is proud to have her represent Pennsylvania’s young people on the council.

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Bridget Green (far left) with members of the Youth Council and Epilepsy Foundation National board president Tony Coelho (far right).

Art Contest for People with Epilepsy

“Expressions of Courage” contest showcases creativity of people living with seizures

Art can provide an escape from the daily day experiences of living with any disease or illness, and may be a way for people to express how they feel about hope, strength, courage and freedom. Many more investigators are involved in SUDEP related research than there were even a few years ago. We can be hopeful that some answers to the mystery of this disorder will be forthcoming.

Sudden Unexplained Death in Epilepsy (con’t)

mechanism and prevention, we also need to determine the prevalence of SUDEP. A recent survey of medical examiners and coroners in the United States found a reluctance to use the diagnosis of SUDEP even when post mortem examination finds no other cause of death. Inappropriate diagnoses such as seizure related death, status epilepticus (a continuous state of seizure activity), or respiratory failure may be used instead. Consequently the accurate prevalence of this disorder is underestimated when compiling statistics about causes of death in epilepsy.

Expressions of Courage, c/o Ortho-McNeil Neurologics, Inc., 389 Pottstown Road, Pottstown, NJ 08867. For more information and to download entry forms, please visit www.expressionsofcourage.com.
More than 800 revelers joined in the Fat Tuesday fun at the EFWCP’s 13th Annual Mardi Gras Gala. The Westin Convention Center Pittsburgh was transformed into The Big Easy with beads, masks, balloons, entertainers, and a Dixieland band. Guests danced the night away to the John Parker Band after enjoying a sumptuous dinner and the coronation of the King of the Mardi Gras. James E. Rohr, Chairman and Chief Executive Officer of The PNC Financial Services Group, reigned as the 2007 King, while King’s Court members Jim Broadhurst from Eat’n Park Hospitality Group, Jack Brooks from the Greater Pennsylvania Regional Council of Carpenters, Pat Hassey from Allegheny Technologies and John Surma from United States Steel Corporation joined in the festivities.

Through the generosity of Gala guests, $400,000 was raised to support the EFWCP’s programs and services. Thank you to all of our donors for making this Mardi Gras Gala our most successful ever!

Mardi Gras Gala a tremendous success

Oh, What a Night!

Epilepsy Foundation staff and friends “let the good times roll!”

Thank you to all of our donors for making this Mardi Gras Gala our most successful ever!