The Greater Chicago Epilepsy 2011 5K

Proceeds Benefit the Epilepsy Foundation of Greater Chicago

Saturday, May 14 • 5K Walk/Fun Run
Danada Forest Preserve • Wheaton

Saturday, May 21 • 5K Walk/Timed Run
NEW LOCATION! Montrose Harbor • Chicago

www.epilepsychicago.org • 1-800-273-6027

Epilepsy and Traumatic Brain Injury

FOR SOME RETURNING SOLDIERS, ONCE THE FIGHTING IS OVER... THE BATTLE BEGINS.

Aging’s Impact on Epilepsy
Making Sense of Individualized Education Plans

epilepsy琉璃hicago.org
Everyone who helped make Purple Day (Weekend!) such a success! Thanks to radio host Steve Cochran, and comedienne Patti Vasquez. Thanks to a percentage of profits to EFGC. The weekend culminated with “Stand up with epilepsy awareness canisters, while businesses such as dozens of schools, businesses, and other organizations in our efforts.

See our cover story (starting on pg. 6) for more on TBI and epilepsy, along with an interview with Dr. Rutecki.

Ilegal TEAM USES TOY BLOCKS TO HELP BUILD THE FUTURE OF EPILEPSY CARE
On January 15, the LEG0 Pr0m0ject won the Illinois State - FIRST®LEGO®League (FLL) Championship. The team worked on a bio-medical project focusing on providing an early warning of epileptic seizures. Early detection of seizures can improve a patient's quality of life as well as prevent many seizure-related accidents. The ILEGAL team researched how seizures start, and then researched various medical sensors. The team consulted with Dr. Marvin Rossi M.D., PhD, Neurologist at Rush Memorial Hospital, and Phil Gattone, President & CEO of the Epilepsy Foundation of Greater Chicago for guidance in creating a wearable seizure detection device. The ILEGAL team is currently creating a prototype that will be featured at the international World FIRST®LEGO®League Championship on April 27-30 in St. Louis, MO. Team updates will be posted at www.SchoolofStreetRobotics.org.

ADULT EpILEPSY program looks at TBI, other epilepsy issues for veterans
Over four dozen US military veterans, along with an equal number of Veterans Administration staff members, took part in “Operation Epilepsy,” a half-day educational session at the Jesse Brown VA Center in Chicago, on February 23. Paul Rutecki, MD (pictured at left), Director of the Veterans Association’s Northwest Center of Excellence, addressed a variety of epilepsy-related topics which specifically impact veterans, their families, and friends. Special attention was paid to the issue of traumatic brain injury (TBI), which affects a large number of veterans returning from combat in Iraq and Afghanistan. Fifteen percent of all incidence of TBI will lead to epilepsy, and an astounding 47% of veterans who experience TBI in conjunction with a penetrating head wound will develop epilepsy.

See our cover story (starting on pg. 6) for more on TBI and epilepsy, along with an interview with Dr. Rutecki.

IEP (continued from pg. 4)
The Epilepsy Foundation of Greater Chicago offers the following guidelines that parents may consider when preparing for their child’s IEP meeting:
• Obtain a copy of your school district’s IEP form before the evaluation.
• Become an expert about your child’s educational performance and needs.
• Put together your child’s ideal IEP so that you are prepared to discuss the educational program and services that you prefer for your child.
• Obtain relevant statements from your child’s neuropsychologist concerning appropriate modifications or accommodations that need to be in the IEP.

• Familiarize yourself with special education terminology.
• Understand your child’s legal rights to special education. Become familiar with the 2004 Individuals with Disabilities Education Act (IDEA) laws and regulations.
• Be prepared to speak directly about your child’s seizure type. How will the seizure activity affect your child’s academic performance?
• Develop a seizure action plan. How should your child’s teacher and other staff respond to your child if she or he has a seizure in school?
• Invite appropriate advocates to speak at the IEP meeting on your child’s behalf.

EFGC case managers are trained and available to advocate at your child’s IEP meeting. EFGC case managers are also available to assist you in preparing for the IEP meeting. In addition, EFGC’s community educator is available to provide presentations on epilepsy education to school staff and students.

Parents with concerns or questions regarding IEPs should contact our Case Management team at 312-939-8822.

For additional information on legal issues surrounding education, visit www.epilepsyfoundation.org/living/children/education/Education.cfm

TBI (continued from pg. 7)
With Davies’ newly found knowledge, he was beginning to find the care he needed. The VA’s mental health department referred him to the Epilepsy Foundation of Greater Chicago, which he claims was “the best thing anyone could have ever done.” When Davies went to his first appointment with an Epilepsy Foundation social worker it had been seven years since his Traumatic Brain Injury. “I had gotten lost in the system,” Davies real- izes, “but eventually found the resources I needed.”

When the Epilepsy Foundation was given a demonstration grant, Davies was offered a job to initiate self-help groups. “I wanted to be there for others,” he says. “If you don’t have information about epilepsy, how can you react to having epilepsy? I learned that you have to ask questions, and that you cannot accept ‘non-answers.’ It was my goal to get that across.”

Davies believes it is the responsibility of the military and the Veterans Association to educate veterans on the possibilities of what might happen as a consequence of a Traumatic Brain Injury. Look- ing back, he feels that his epilepsy made him more “secretive” because he didn’t know what was happening and therefore, didn’t feel comfortable telling others about it. “It can be hard to admit that you have epilepsy if you don’t understand what it is.”

Recently, Dr. Rutecki spoke at “Operation Epilepsy,” an educational program at the Jesse Brown VA Medical Center in Chicago. He presented on Post Traumatic Epilepsy to veterans, as well as to staff of the organization.

“The educational program at the VA was a great step after years and years of lack of information,” Davies says. “Community outreach is so important to meeting the needs of veterans with epilepsy.”

Dr. Rutecki is interested in the studies being developed by the Epilepsy Centers of Excellence. Providing appropriate care to veterans is a crucial step, just as it is the research that is being put in place.

“The neurology community is coming together,” he says, “and the veterans will be supported.”
Wrigley View Rooftop, 1050 W. Waveland, hosting an extravaganza at Chord On Blues in St. Charles. His event raising over $500 for the Epilepsy Foundation of Greater Chicago. Epilepsy Awareness month, Crystal raised over $300 for the foundation by sharing her story with schools and churches and selling epilepsy awareness pins in November for National Epilepsy Awareness Month. New features such as an online press room allow immediate access to past and current news releases from the Foundation, and an archive of back issues of Epilepsy Connections magazine is now always available. People are also now invited to share their photos and personal stories of living with epilepsy with other web site visitors. The new site also has comprehensive epilepsy information for those seeking answers, along with details on all EFGC services.

An online shop will allow visitors to order Epilepsy Foundation of Greater Chicago products such as shirts, mugs, and mouse pads, with all net proceeds coming directly to our affiliate. All funds donated via the site remain in the Greater Chicago area to support our local programs and services.

We will continue to build and expand the new web site, and we look forward to hearing your input. Drop us a line at info@epilepsychicago.org.

For more information visit us online at www.epilepsychicago.org.

A Little Effort Can Help a Lot: Ask These Folks!

All throughout the year, scores of individuals and families develop creative “third party” events aimed at supporting our local programs and services. Here are just a couple of the things our friends did over the past few months:

Crystal Williams, a school nurse who has epilepsy, wrote her own story about living with epilepsy and the ways in which she is now helping students with epilepsy and others in her community. By sharing her story with schools and churches and selling epilepsy awareness pins in November for National Epilepsy Awareness month, Crystal raised over $300 for the Epilepsy Foundation of Greater Chicago.

That same month, west suburban resident Ben Stach decided to host a party to watch the Cubs take on the Pirates from home plate style seating, views of home plate and the scoreboard, open bar, and food. Call Jen at 847-560-0788 or email her at jerelyden10@gmail.com.

Finally, our annual 5K Walk is coming up in May. This is a great time for you and your friends to find local businesses who are willing to donate raffle items in support of our organization and to help you fundraise at a local establishment.

From jewelry parties and make-up parties, to video arcade nights or pub trivia events—there are as many good ideas as there are amazing people willing to go the extra mile to turn these ideas into something truly special for the Foundation. If you have an idea for a third party fundraiser but don’t know where to begin, call our Development office at 312-939-8622. Together, we’ll turn your idea into something special!

Your gift can be your legacy to people with epilepsy. Contact Erin Leyden at 312-939-8622, x208 to discuss planned giving options.
Epilepsy in the Classroom

Taking an IEP to School

Epilepsy in the Classroom

To School

Information compiled and edited by the EFGE Case Management Team

Everyone deserves the opportunity to realize the maximum benefit from his or her education. For a child with epilepsy who has special needs, an Individualized Education Plan (IEP) provides a structured approach to reaching this goal. As a parent with a child with epilepsy, the process of developing an IEP may seem overwhelming and difficult to understand at first, however, once completed it is an invaluable asset, and we can help.

An IEP is a process which produces a written description of the optimal educational program of a child with special needs. All disabled children are entitled to a free appropriate public education and the child’s home school district must provide special education and related services at no cost to the child or his or her parents.

A student with epilepsy is eligible for an IEP if they are deemed by a designated IEP team. This team will consist of, but is not limited to, the parents, the student when appropriate, a general education teacher, special education teachers, a school social worker and a school psychologist.

When it is decided that a student is eligible for special education services, the team will convene to collaboratively develop the IEP. Using the assessment results, the team determines the least restrictive placement for the student. The least restrictive placement is achieved by the assessment results, the team determines the least restrictive placement for the student. The least restrictive placement is achieved by the assessment results, the team determines the least restrictive placement for the student. The least restrictive placement is achieved by the assessment results, the team determines the least restrictive placement for the student.

**Eleventh Annual Greater Chicago Epilepsy 5K**

Saturday, May 29, 2010

This fun golf event will benefit the Epilepsy Foundation of Greater Chicago. To order tickets, contact Linda Dresser at 312-994-3980 or ldresser@chicagosky.net. Tickets may also be purchased online at www.epilepsychicago.org.

**Epilepsy Support Group Network**

**ADULT GROUPS**

Chicago, Loop
25th Thursday at Noon
Epilepsy Foundation Office
17 N. State St., #1300, Chicago

Chicago, South (Spanish)
1st Saturday at 7
Shirley Road
1915 S. Mayfair, Chicago

**PARENT GROUPS**

Chicago, South (Spanish)
1st Saturday at 6:30 pm
St. Luke’s Hospital
2635 S. Maryland Ave., Chicago

**SENIOR GROUP**

Chicago, Downtown
3rd Tuesday at 10 am
Epilepsy Foundation Office
17 N. State St., #1300, Chicago

**YOUNG ADULT GROUP**

Chicago, Downtown
3rd Saturday at 7
Central DuPage Hospital
939-8622, x224 for location information.

**TEEN GROUP**

Chicago and suburbs
Fri. and Sat. evenings
11th Street Club, Chicago
(For more info, call Kimberly Taylor at 773-471-0299)

**Upcoming Events**

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Mara Goldman is clearly a dedicated member of the EFGC community. Her dedication is key to its success and we are very fortunate to have her as such. Mara’s willingness to give back is such an important part of the Foundation. Her dedication is key to its success and we are very fortunate to have her as such.

Gwen Ramirez

“Mara and Tony both get to experience the joy that comes with being able to make a difference in the lives of others. It’s so exciting to advocate for EFGC,” Gwen says. “After all they’ve done for Jonathan and for everything they have taught me, I feel so empowered and want to do everything I can.”

MARA GOLDMAN

“I work hard because EFGC works so hard.” Chicago-native Mara Goldman is clearly a dedicated member of the EFGC community. Every growing success of her annual walk team, “Seizure Free,” continues to be a highlight of the event each year.

Mara does a lot more than just raise thousands of dollars for the Foundation, however. As someone with epilepsy, she understands how important it is for EFGC to continue to provide its programs and services to the Greater Chicago area.

Whether it’s distributing epilepsy awareness material in her community, hosting three separate Talk About It @ Dinner events within one week, volunteering at the Foundation’s annual Consumer Conference, or mentoring a person with epilepsy, Mara is always finding a way to help give back, just as the Epilepsy Foundation of Greater Chicago has given to her.

“I work hard because EFGC works so hard,” Mara says. “It has helped me in so many ways and I feel very lucky to be a part of something so wonderful.”

Gwen Ramirez

“As a Greater Chicago Epilepsy Walk poster at her doctor’s appointment and knew she had to get involved. Each year since then, the ‘Journey for Jonathan’ team has been a huge success as Gwen has been able to rally hundreds of friends and family to support the Epilepsy Foundation of Greater Chicago. It’s not Jonathan’s team, or my team,” Gwen explains. “It’s our team and we reach out to everyone to help.”

In 2009, Gwen learned about the Foundation’s Community Advisory Boards at the Camp Blackhawk orientation. CABs are an all volunteer board committed to acting as a liaison between EFGC and their local communities. Gwen jumped on the chance to take part.

“I am so excited by how things are progressing,” Gwen says. “We have a great team of people who are all dedicated and want to do good.”

Gwen’s CAB was instrumental in making the Foundation’s “Purple Day,” epilepsy awareness initiative, a success.

“I am just trying to get the word out and do what I can,” Gwen explains. While meeting with their politicians and vocalizing their opinions.

“arly on, I will briefly review the function of age (and treatment). However, individual experiences can vary dramatically. As always, patients and families should strive for an expert assessment with a neurologist highly experienced in epilepsy.

Aging is a critical factor for epilepsies that begin in infancy and childhood as would be expected. Identifying the presence of a defined epilepsy syndrome will not only allow some predictor concerning the seizures over time but also the response to treatment that can be expected.

The question of age remains relevant so long as a person has to contend with the specter of seizures and has not either experienced a spontaneous remission or been cured. In this case, the seizure disorder itself can be affected by the aging process that includes acquired comorbidities and other medications that may be prescribed.

The prognosis of some of the so called idiopathic epilepsies that begin in infancy and childhood is favorable. This means that most people will either enter a remission as they exit childhood or they can expect a good response to treatment. These include benign neonatal convulsions, benign myoclonic epilepsy, childhood epilepsy with occipital paroxysms, benign childhood epilepsy with centrotemporal spikes, childhood absence epilepsy, juvenile myoclonic epilepsy, and generalized epilepsy with febrile seizures plus (but not be confused with simple febrile seizures).

Unfortunately, in many of the symptomatic epilepsies, the prognosis is not good and seizures can be resistant to treatment. These include Dravet syndrome, Lennox-Gastaut syndrome, and progressive myoclonic epilepsy. However, some of the symptomatic epilepsies can have mixed outcomes such as Rasmussen encephalitis. Here treatment with immunotherapy may not be successful but surgery with a hemispherectomy can have a surprisingly good outcome. Landau-kleffner syndrome can vary tremendously respond to treatment but regardless, the EEG abnormalities can resolve as the child gets older but be left with some degree of language impairment.

Overall, it is said that approximately 50% of children with epilepsy will grow out it by young adulthood. However, this obviously means that 50% will not. It is in this 50% that the concerns about aging is shared with those whose epilepsy begins after youth. For most people, the best predictor of the future of their epilepsy is the past.

If one is predating from a standpoint of a young adult, then there is not much past to draw from. But, if the epilepsy has remained under control for a significant period of time (years), then it would be expected to continue to remain so. I do not caution all of the patients who have seizures that have been under control to understand that medication efficacy is far from all not. Rather, medications have a continuum of effect that only time can clarify. This means that when a treatment is begun, it will not be known if it will be effective for a very long time; perhaps years. Some people can experience a breakthrough seizure after years of control. Assuming that the level of the drug has been stable, this would suggest the efficacy of the treatment is not 100% but slightly less. Hence, epilepsy can be thought of as a chronic disorder that, like many other medical problems, require dosage adjustments or a change in a drug.

For both men and women, aging affects a number of factors that impact epilepsy. Key among them is metabolism. As people age into their senior years...
Traumatic Brain Injuries have been a common and devastating consequence of war throughout time. Today, as troops return from Iraq and Afghanistan, their experiences enforce the fact that TBIs continue to be a major risk for those who serve in the military. In fact, Traumatic Brain Injury is being labeled as the “signature wound” of modern day combat.

Whether the injury is from a land mine blast, improvised explosive device, or a gunshot wound, it can have a significant impact on the soldier’s daily life, including the development of Post Traumatic Epilepsy. Of the 1.64 million soldiers who have served in Operation Enduring Freedom and Operation Iraqi Freedom, 19% (320,000) will experience a Traumatic Brain Injury. As many as 34% of veterans with moderate to severe cases of TBI will develop Post Traumatic Epilepsy, with rates as high as 55% for those with penetrating skull injuries.

Dr. Paul Rutecki, Director of the Veterans Association’s Northwest Epilepsy Center of Excellence, one of the six national centers established in 2009 by the VA to address the needs of returning servicemen who have suffered a TBI, sees the importance of having a game plan in place. “We need a better infrastructure for veterans returning with Traumatic Brain Injury,” Dr. Rutecki explains. “The Epilepsy Centers of Excellence have been created to not only improve the quality and availability of care for veterans with TBI, but also to anticipate the needs for Post Traumatic Epilepsy care.”

Studies have been done in the past on the correlation between epilepsy and veterans who have experienced a TBI. The decades long Vietnam Head Injury Study has shown that 44% of veterans who experienced a penetrating brain injury at least 25 years earlier developed Post Traumatic Epilepsy. Inexplicably, thirteen percent of study participants showed no sign of PTE until more than 14 years after the injury.

“The nurse told me I had a seizure. And it was the first time I had even heard of epilepsy.” - Jim Davies, Veteran

Jim Davies, a Vietnam veteran who served as a Lance Corporal in the Marine Corps, understands the importance of Post Traumatic Epilepsy care all too well. His last memory of November 16, 1968, was getting into a small truck off his base that later “went off the side of a mountain.”

“When they saw me wake up again, they’d just give me another.”

Davies was taken to the Great Lakes Naval Hospital in the Philippines, strapped down with my head wrapped up,” Davies recalls. “And I didn’t know what was going on.”

This was the beginning of a long and arduous recovery process for Davies who had suffered from a Traumatic Brain Injury. The following day on a plane transport heading for the U.S., Davies hadn’t received any answers as to what had happened. “I would wake up and they would give me a shot,” Davies says. “When they saw me wake up again, they’d just give me another.”

Davies was discharged and the VA thought that the military had already taken care of the issue. Davies was discharged and the VA thought that the military had already taken care of the issue. Months later, when Davies woke up in the High Land Park Hospital Emergency Room and asked the nurse what had happened, he finally got a straight answer. “She told me I had a seizure,” Davies vividly remembers when a student in his high school had a seizure. “At the time, I didn’t know what was going on, all I knew was that he never came back to class. Being able to understand what had happened all those years before, helped me to continue to have a life.”

Currently, Dr. Rutecki and his colleagues of the Epilepsy Centers of Excellence are working with the Veterans Association to create a solid system that will effectively serve veterans who have experienced a Traumatic Brain Injury.

“The VA is the largest healthcare system in the United States,” Rutecki says. “We can utilize each other’s resources, such as military records, to create a meaningful database that will keep track of veterans who have had a TBI. Over time, our studies will show how it impacted them and then enable us to provide them with the best possible care.”

The Epilepsy Centers of Excellence’s goal, to improve the quality and availability of care for veterans with epilepsy, means a great deal to Davies. “I have to admit, I wasn’t asking good questions,” Davies says, “but that was because I didn’t know what to ask.”

Davies believes that miscommunication was the key component to the lack of adequate care he received. “Everyone assumed that someone else was explaining to me what was going on. The military thought that the VA would handle it because I had been discharged and the VA thought that the military had already taken care of the issue.”

Months later, when Davies woke up in the High Land Park Hospital Emergency Room and asked the nurse what had happened, he finally got a straight answer. “She told me I had a seizure,” Davies vividly recalls. “And it was the first time I had even heard of epilepsy.”

“(The nurse) told me I had a seizure. And it was the first time I had even heard of epilepsy.” - Jim Davies, Veteran

“Where Sacrifice and Courage Unite Generations of Veterans”

June 17-19, 2011 ★ Chicago, Illinois

All veterans, their families & all supporters of our Armed Forces are invited to this very special event of the 25th Anniversary of the Chicago Vietnam Veterans Welcome Home Parade

It will be a full weekend of events that includes:

- Veterans Art and Photo Exhibit at the Chicago Cultural Arts Center.
- Presentation by Veteran authors.
- "Moving Wall" on display at Navy Pier.
- Saturday morning kick-off rally at Navy Pier – opening ceremony followed by entertainment.
- Saturday banquet with Bill Kurtis as the Master of Ceremonies, acknowledging the City of Chicago and honoring all veterans with Medal of Honor Recipients as special guests.
- Sunday morning inter-faith ceremony featuring Reverend John Steer.
- Information booth, vendors, variety of seminars and hospitality suites for mini-reunions.
- Sunday afternoon of music at Millennium Park featuring Dennis DeYoung and the music of Styx, ARRA, Joe Cantafio and the 101st Rock Division, Kimotion, and more.

www.ServiceandHonor.org
Traumatic Brain Injuries have been a common and devastating consequence of war throughout time. Today, as troops return from Iraq and Afghanistan, their experiences enforce the fact that TBIs continue to be a major risk for those who serve in the military. In fact, Traumatic Brain Injury is being labeled as the "signature wound" of modern day combat.

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“I would wake up and they would give me a shot,” Davies says. “When they say I wake up again, they’d just give me another.”

Davies was taken to the Great Lakes Naval Hospital in Chicago and was put on anti-epileptic medication, although he didn’t know what it was.

“No one gave me any kind of explanation. More worrisome than anything else was not being aware of my situation. Not only did I not know what was happening, I also didn’t know what was going to happen,” Davies says.

Davies was discharged from the military for medical reasons that he didn’t understand. When he had his first seizure, he was referred to the Veterans Association where he was told he had Post Traumatic Brain Syndrome, something he had never heard of before.

He was discharged and the VA thought that the military had already taken care of the issue.

Davies saw an epilepsy center, which didn’t make any sense to him. “I have to admit, I wasn’t asking good questions,” Davies says. “But that was because I didn’t know what to ask.”

Davies believes that miscommunication was the key component to the lack of adequate care he received. “Everyone assumed that someone else was explaining to me what was going on. The military thought that the VA would handle it because I had been discharged and the VA thought that the military had already taken care of the issue.”

Months later, when Davies woke up in the Highland Park Hospital Emergency Room and asked the nurse what had happened, he finally got a straight answer.

“She told me I had a seizure,” Davies vividly recalls. “And it was the first time I had even heard of epilepsy.”

“I decided I was going to learn everything I could about Post Traumatic Epilepsy,” he says. “I had a seizure… At the time, I didn’t know what was going on, remember when a student in my high school had a seizure… At the time, I didn’t know what was going on, all I knew was that he never came back to class. Being able to understand what had happened all those years before, helped me to continue to have a life.”

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The Epilepsy Centers of Excellence’s goal, to improve the quality and availability of care for veterans with epilepsy, means a great deal to Davies.

“It is so important for veterans with epilepsy to have educational programs and services that are understandable and easily available,” he states. “No body should have to go through what I did. The lack of information I received caused as much trouble as my epilepsy itself.”

Davies sees his experience with the nurse at Highland Park Hospital as a “starting point.”

“I began to put the pieces together,” he says. “I remembered when a student in my high school had a seizure… At the time, I didn’t know what was going on, all I knew was that he never came back to class. Being able to understand what had happened all those years before, helped me to continue to have a life.”

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**Welcome Home 2011**

“Where Sacrifice and Courage Unite Generations of Veterans”

June 17-19, 2011 ★ Chicago, Illinois

All veterans, their families & all supporters of our Armed Forces are invited to this very special event of the 25th Anniversary of the Chicago Vietnam Veterans Welcome Home Parade

It will be a full weekend of events that includes:

- Veterans Art and Photo Exhibit at the Chicago Cultural Arts Center.
- Presentation by Veteran authors.
- “Moving Wall” on display at Navy Pier.
- Saturday morning kick-off rally at Navy Pier – opening ceremony followed by entertainment.
- Saturday banquet with Bill Kurtis as the Master of Ceremonies, acknowledging the City of Chicago and honoring all veterans with Medal of Honor Recipients as special guests.
- Sunday morning inter-faith ceremony featuring Reverend John Steer.
- Information booth, vendors, variety of seminars and hospitality suites for mini-reunions.
- Sunday afternoon of music at Millennium Park featuring Dennis DeYoung and the music of Styx, ARRA, Joe Cantafio and the 101st Rock Division. Kimotion, and more.

www.ServiceandHonor.org
"I'm just trying to get the word out and do what I can," Gwen explains. While Gwen's CAB was instrumental in making the Foundation's “Purple Day” event a success at the Camp Blackhawk orientation, CABs are an all-volunteer board committed to offering support for Purple Day or answering the phone at the office's front desk, her dedication has been invaluable.

"The staff are very knowledgeable here and I have gotten very useful vocational assistance, along with help figuring out my Social Security benefits," Tony says. "That's why it is so important to me to offer my help. I want to give back." Tony continues to give back each week as he regularly volunteers at the organization. His friendly demeanor and bright smile are a welcome addition to the organization and the perfect way to greet clients and guests as they come in. We're happy to have Tony as part of our team!

"Mara's willingness to give back is such an important part of the Foundation. We are so happy to have her as such a close friend!" Mara's dedication is key to its success and we are very fortunate to have her as a member of the Community Advisory Boards, she and Jonathan also participated in this year's annual Public Policy Institute in March (see page 2 for more on their trip). At PPI, families came together in Washington, D.C. and advocate for people with epilepsy by meeting with their politicians and vocalizing their opinions.

"It's so exciting to advocate for EFGC," Mara says. "After all they've done for Jonathan and for everything they have taught me, I feel so empowered and want to do everything I can."

MARA GOLDMAN: "I work hard because EFGC works so hard." Chicago native Mara Goldman is clearly a dedicated member of the EFGC community. The ever growing success of her annual walk team, "Seizure Free," continues to be a highlight of the event each year. Mara does a lot more than just raise thousands of dollars for the Foundation, however. As someone with epilepsy, she understands how important it is for others to receive appropriate counseling about this topic. Of course, the prognosis of some of the so-called idiopathic epilepsy syndromes that are problematic. It is not clear that these patients will not encounter significant surprises specific to aging and epilepsy.

"Mara is always finding a way to help give back," what the Epilepsy Foundation of Greater Chicago has given to her. "I work hard because EFGC works so hard." Mara says. It has helped her in so many ways and I feel like I'm back on track by how things are progressing," Gwen says. "We have a great group of people who are all dedicated and want to do good." Gwen's CAB was instrumental in making the Foundation's "Purple Day," epilepsy awareness initiatives, a success. "I'm just trying to get the word out and do what I can," Gwen explains. White meeting with their politicians and vocalizing their opinions.

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EPILEPSY ANSWERS
By Roy Soucholiki, MD

Q: Should I be concerned about my epilepsy as I age?
A: This is a common question that is asked in my practice. Unfortunately, many people with epilepsy will not encounter significant surprises specific to aging and their epilepsy. However, for some patients this is not the case and hence people with epilepsy should receive appropriate counseling about this topic. Of course, the concerns regarding aging and epilepsy is highly dependent not only on the type or cause of epilepsy but age of onset of seizures, gender, comorbid medical problems, other medications and psychosocial circumstances. These can all contribute to marked differences in the experiences from person to person.

Surprisingly, there is not a lot of animal or human research data to draw from. Regardless, there is an understanding that as our bodies change with age, so can an illness within that body. For all of us, when we are born, our brains are not fully matured. The physical maturation of the brain is a process that takes a long time and does not fully occur until approximately 30 years of age. Puberty is a relatively rapid phase of growth mediated in part by dramatic hormone changes. The brain changes less after age 30 until advanced age, which varies from person to person. As such, epilepsy being a disorder of neurons and their connections can be affected by these changes. First, I will briefly review the diagnosis of some specific epilepsy syndromes that begin in infancy and childhood and then I will review issues in relation to aging in general. The information here serves to provide a perspective and brief overview of the concept of prognosis as function of age (and treatment). However, individual experiences can vary dramatically. As always, patients and families should strive for an expert assessment with a neurologist highly experienced in epilepsy.

Aging is a critical factor for epilepsy and drug response. Treatment may be expected to improve in some people. For both men and women, aging affects a number of factors that impact drug response. For example, the drug blood levels may change with age, which can affect how the drug is metabolized in the body. Additionally, older people may be more sensitive to the side effects of medication, which can affect how well the drug works.

In summary, it is important to understand that medication efficacy is not all or none. Rather, medications with some continuation of effect that only time can clarify. This means that when a treatment is begun, it is not known if it will be effective for a very long time; perhaps years. Some people can experience a breakthrough seizure after years of control. Assuming that the level of the drug has been stable, this would suggest the efficacy of the treatment is not 100% but slightly less. Hence, epilepsy can be thought of as a chronic disorder that, like many other medical problems, require dosage adjustments or a change in a drug. For both men and women, aging affects a number of factors that impact epilepsy. Key among them is metabolism. As people age into their senior years, epilepsy symptoms can change. It is important to monitor these changes and adjust treatment as necessary.
**Epilepsy in the Classroom**

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When it is decided that a student is eligible for special education services, the team will convene to collaboratively develop the IEP. Usually, the team will consist of, but is not limited to, the parents, the student when appropriate, a general education teacher, special education teachers, the child’s school social worker and a school psychologist.

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**Night Out With the Chicago Sky**

Saturday, February 20, 2016

Allstate Arena • Rosemont

Join the Chicago Sky for a night of world-class WNBA basketball and family fun on June 25, when the Sky take on the Phoenix Mercury. A portion of the proceeds from your $10 or $30 ticket purchase will be donated back to the Epilepsy Foundation of Greater Chicago. To order tickets, contact Linda Dresser at 312-994-5080 or ldresser@chicagoknights.net. Tickets may also be purchased online at www.epilepsycc.org.

**11th Annual “Day for Zach” Golf Outing**

Monday, June 22, 2015

Seven Bridges Golf Club • Woodridge, IL

On Monday, June 27, the family of Zach Pflingston will be hosting a golf outing at the Seven Bridges Golf Club in Woodridge. All net proceeds from the event will be used to support Camp Blackhawk, the camp Zach loved to attend. The cost is $125 per person, which includes golf and lunch with an auction. Those wishing to attend the luncheon only may do so for $30. Tee-off time is 12:30 pm for 18 holes of scramble format golf. For more information, or to RSVP, call Jack or Manjula Pflingston at 224-785-1590.

**Camp Blackhawk**

Sunday, July 17 to Friday, July 22, 2011

Camp Blackhawk, located in north suburban Illinois, is a great opportunity for kids ages 6-18 to experience the fun of camp activities, all designed to be accessible and adapted to individual needs and abilities, and all in a safe, medically-monitored setting. Download camp applications at www.epilepsycc.org or call Meredith Taylor at 312-695-2202.

**Epilepsy Foundation Golf Outing**

Tuesday, August 30, 2011

Ruffled Feathers Golf Club • Lemont, IL

The Epilepsy Foundation of Greater Chicago’s eleventh annual Golf Outing will take place on Tuesday, August 30, at Ruffled Feathers Golf Club in Lemont. The cost per golfer is $250, which includes 18 holes of scramble format golf with cart, lunch, post-cycling cocktails, and dinner. Tee-off is at 1:30 pm, with registration and lunch starting at 12:30 pm. For more information, or to reserve a place, call Lauren McGlone at 312-939-4622, x209.

**Upcoming Events**

**Epilepsy Support Group Network**

**ADULT GROUPS**

Chicago, Loop

2nd Thursday at 10 am

Epilepsy Foundation Office

17 N. State St., #1300, Chicago

Chicago, Loop (Spanish)

1st Friday at 10 am

Epilepsy Foundation Office

17 N. State St., #1300, Chicago

Chicago, North Side (Spanish)

3rd Wednesday at 2 pm

Little Company of Mary Hospital

2650 W. Oakton, Chicago

Chicago, Northwest Side

1st Wednesday at 7 pm

Our Lady of the Assumption Med. Ctr.

5045 W. Ashland, Chicago

Chicago, South Side

3rd Monday at 10 am

Pius V Church

1913 S. Central, Chicago

Chicago, West Loop (Eng/Span)

4th Friday at 10 am

Brunner Hospital, 180 W. Park St.,

River West, Chicago

(Comp will be held in English on even months and Spanish on odd months)

Elgin

4th Thursday at 7 pm

St. Joseph’s Hospital

7 N. Afton, St. Lake Elgin, Elgin

Evanston

2nd Thursday at 7 pm

Evanston Hospital

2614 Ridge Rd., Evanston, IL

Green Park

2nd Saturday at 8 pm

Little Fountains of Mary Hospital

2560 W. 39th St., Tonet, IL

9th Floor, Evergreen Park

Oak Park

1st & 3rd Sunday at 5:30 pm

Oak Park Hospital

520 S. Maple, Oak Park

St. Charles

1st Thursday at 7 pm

Huggins Lutheran Church

305052 Ridge Oak Rd.

St. Charles

Plainfield

Worldwide Cruise

2nd Thursday at 7 pm

Central DuPage Hospital

221 W. Wendell Rd., Winfield

Chicago, Adult Social Club

1st & 3rd Sunday at 1 pm

Epilepsy Foundation Office

17 N. State St., #1300, Chicago

Chicago, Adult Job Club

2nd & 4th Thursday at 10 am

Alderman Building

17 N. State St., #1300, Chicago

**PARENT GROUPS**

Chicago, South

1st Thursday at 5 pm

University of Chicago

Cermak, Comer Children’s Hospital

4155 S. Maryland Ave., Chicago

Elgin

2nd Thursday at 7 pm

Evanston Hospital

2600 Ridge Rd., Evanston, IL

West Suburban Mothers Group

3rd Monday at 1 pm

Meeting location varies. Call Peg Fadde (312-939-5022, x224) for location information.

**Senior Group**

Chicago, Downtown

3rd Friday at 10 am

Epilepsy Foundation Office

17 N. State St., #1300, Chicago

**Youth Group**

Chicago, Downtown

2nd Saturday at 1 pm

Barnes and Noble

111 S. Michigan Ave., Chicago

For more info, call Kimberly Taylor at 312-939-8622.

**Teen Group**

Chicago and Suburbs

1st Saturday each month

Time and location vary due to special outings. Call Tracy (312-939-8622, x202) for info.

**Other**

Epilepsy Support Group Network Chicago, South

3rd Thursday at 7 pm

University of Chicago

Cermak, Comer Children’s Hospital

4155 S. Maryland Ave., Chicago

Elgin

2nd Thursday at 7 pm

Evanston Hospital

2600 Ridge Rd., Evanston, IL

West Suburban Mothers Group

3rd Monday at 1 pm

Meeting location varies. Call Peg Fadde (312-939-5022, x224) for location information.

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(decided on pg.11)
New Web Site Brings Increased Interactivity

With the start of spring, the Epilepsy Foundation of Greater Chicago launched a complete overhaul of its online presence. Our new web site, offering increased functionality and opportunities for interactivity, made its online debut at the end of March.

The focal point of the new front page is a photo cycle, highlighting four main feature stories, each of which links to further information. Other news stories of interest appear below the photos.

Videos, such as our public service announcements and event highlights can now be embedded directly on the front page for easy access, as can links to our social media pages.

New features such as an online press room allow immediate access to past and current news releases from the Foundation, and an archive of back issues of Epilepsy Connections magazine is now always available. People are also now invited to share their stories and personal stories of living with epilepsy with other web site visitors.

For the first time, individuals will be able to directly donate to EFGC through a secure web interface directly on our site. All funds donated via the site remain in the Greater Chicago area to support our local programs and services.

An online shop will allow visitors to order Epilepsy Foundation products such as shirts, mugs, and mouse pads, with all net proceeds coming directly to our affiliate.

The new site also features a comprehensive interactive calendar. Visitors can view each month at a glance, and receive an overview of all fundraisers, educational programs, support groups, and other community events. Details on each event are then just a click away.

The new site also has comprehensive epilepsy information for those seeking answers, along with details on all EFGC services.

We will continue to build and expand the new web site, and we look forward to hearing your input. Drop us a line at info@epilepsychicago.org.

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For more information visit us online at www.epilepsychicago.org.

A Little Effort Can Help a Lot: Ask These Folks!

All throughout the year, scores of individuals and families develop creative “third party” events aimed at supporting our local programs and services.

Here are just a couple of the things our friends did over the past few months:

Crystal Williams, a school nurse who has epilepsy, wrote her own story about living with epilepsy and the ways in which she is now helping students with epilepsy and others in her community. By sharing her story with schools and churches and selling epilepsy awareness pins in November for National Epilepsy Awareness month, Crystal raised over $300 for the Epilepsy Foundation of Greater Chicago.

That same month, west suburban resident Ben Stach assembled a cadre of comedians and musicians for an evening of mariachi at Chord On Blues in St. Charles. His event raised over $500.

But there’s more to come! Supporter Jennifer Leyden is hosting a party to watch the Cubs take on the Pirates at the Wrigley View Rooftop, 1050 W. Waveland, on Sunday, May 29.

Tickets are $150 per person, and are ALL INCLUSIVE—with stadium style seating, views of home plate and the scoreboard, open bar, and food. Call Jen at 847-560-0788 or email her at jenleyden@ymail.com.

Finally, our annual 5K Walk is coming up in May. This is a great time for you and your friends to find local businesses who are willing to donate raffle items in support of your team and to help you host a fundraising party at a local establishment.

From jewelry parties and make up parties, to video arcade nights or karaoke events—there are as many good ideas as there are amazing people willing to go the extra mile to turn these ideas into something truly special for the Foundation. If you have an idea for a third party fundraiser but don’t know where to begin, call our Development office at 312-939-8622. Together, we’ll turn your idea into something special!

For a free donation pick-up Call Toll-free 1-855-986-3662 or visit our drop-off location in Lombard - 1051 N. Garfield.
FOUNDATION

FOCUS

EDUCATION PROGRAM LOOKS AT TBI, OTHER EPILEPSY ISSUES FOR VETS

Over four dozen US military veterans, along with an equal number of Veterans Administration staff members, took part in "Operation Epilepsy," a half-day educational session at the Jesse Brown VA Center in Chicago. On February 23, Paul Rutecki, MD (pictured at left), Director of the Veterans Association’s Northwest Center of Excellence, addressed a variety of epilepsy-related topics which specifically impact veterans, their families, and friends.

Special attention was paid to the issue of traumatic brain injury (TBI), which affects a large number of veterans returning from combat in Iraq and Afghanistan. Fifteen percent of all incidences of TBI will lead to epilepsy, and an astounding 47% of veterans who experience TBI in conjunction with a penetrating head wound will develop epilepsy.

See our cover story (starting on pg. 6) for more on TBI and epilepsy, along with an interview with Dr. Rutecki.

GREATER CHICAGO TURNS “PURPLE” IN THE NAME OF EPILEPSY AWARENESS

Friends, supporters, and volunteers of Epilepsy Foundation of Greater Chicago helped turn the region purple in honor of "Purple Day," the international epilepsy awareness initiative, which is recognized each year on March 26. Since the 26th fell on a Saturday this year, EFGrC celebrated Purple Day on March 25 as well, engaging dozens of schools, businesses, and other organizations in our efforts.

Volunteers braved the chilly late March temps to stand on street corners with epilepsy awareness canisters, while businesses such as Culver’s, Potbelly Sandwich Shops, and Jersey Mike’s Subs donated a percentage of profits to EFGrC. The weekend culminated with “Stand Up for Epilepsy,” a comedy revue featuring WGN-TV’s Ana Belaval, radio host Steve Cochran, and comedienne Patti Vasquez. Thanks to everyone who helped make Purple Day (Weekend) a success!

I.LEGO TEAM USES TOY BLOCKS TO HELP BUILD THE FUTURE OF EPILEPSY CARE

On January 15, the FIRST®LEGO® League (FLL) Championship on at the International World FIRST®LEGO®League Championship on April 27-30 in St. Louis, MO. Team updates will be posted at www.SchoolsInRobots.org.

AGING

(continued from pg. 5)

A discussion about aging and epilepsy cannot be had without understanding that epilepsy can start due to illnesses that have higher incidences at certain ages. Although strokes can occur in young individuals, it is most likely to occur at older ages. In fact, 10% of people that experience a stroke will develop epilepsy. This is also the case with Alzheimer’s disease. As in other people who have epilepsy as a cause of some other neurological illness, quality of life can be driven as much by that disease as with the symptom of epilepsy. Finally, people with epilepsy need to update their neurologist with any changes in health even if they might not think it is relevant.

TBI

(continued from pg. 7)

With Davies’ newly found knowledge, he was beginning to find the care he needed. The VA’s mental health department referred him to the Epilepsy Foundation of Greater Chicago, which he claims was “the best thing anyone could ever have done.” When Davies went to his first appointment with an Epilepsy Foundation social worker it had been seven years since his Traumatic Brain Injury. “It had gotten lost in the system,” Davies realizes, “but eventually found the resources I needed.”

When the Epilepsy Foundation was given a demonstration grant, Davies was offered a job to initiate self-help groups. “I wanted to be there for others,” he says. “If you don’t have information about epilepsy, how can you react to having epilepsy?” “I learned that you have to ask questions, and that you cannot accept ‘non-answers.’ It was my goal to get that across.”

Davies believes that it is the responsibility of the military and the Veterans Association to educate veterans on the possibilities of what might happen as a consequence of a Traumatic Brain Injury. Looking back, he feels that his epilepsy made him “more secretive” because he didn’t know what was happening and therefore, didn’t feel comfortable telling others about it. “It can be hard to admit that you have epilepsy if you don’t understand what it is.”

Recently, Dr. Rutecki spoke at “Operation Epilepsy,” an educational program at the Jesse Brown VA Medical Center in Chicago. He presented on Post Traumatic Epilepsy to veterans, as well as staff of the organization.

“The educational program at the VA was a great step after years and years of lack of information,” says Davies. “Community outreach is so important to meeting the needs of veterans with epilepsy.”

Dr. Rutecki is interested in the studies being developed by the Epilepsy Centers of Excellence. Providing appropriate care to veterans is a crucial step, just as it is the research that is being put in place.

“The neurology community is coming together,” he says, “and the veterans will be supported.”

The Epilepsy Foundation of Greater Chicago offers the following guidelines that parents may consider when preparing for their child’s IEP meeting:

• Obtain a copy of your school district’s IEP form before the evaluation.

• Become an expert about your child’s educational performance and needs.

• Put together your child’s ideal IEP so that you are prepared to discuss the educational program and services that you prefer for your child.

• Obtain relevant statements from your child’s neuropsychologist concerning appropriate modifications or accommodations that need to be in the IEP.

• Familiarize yourself with special education terminology.

• Understand your child’s legal rights to special education. Become familiar with the 2004 Individuals with Disabilities Education Act (IDEA) laws and regulations.

• Be prepared to speak directly about your child’s seizure type. How will the seizure activity affect your child’s academic performance?

• Develop a seizure action plan. How should your child’s teacher and other staff respond to your child is or she has a seizure in school?

• Invite appropriate advocates to speak at the IEP meeting on your child’s behalf. EFGrC case manager are trained and available to advocate at your child’s IEP meeting. EFGrC case managers are also available to assist you in preparing for the IEP meeting. In addition, EFGrC’s community educator is available to provide presentations on epilepsy education to school staff and students.

Parents with concerns or questions regarding IEPs should contact our Case Management team at 312-939-8822.

For additional information on legal issues surrounding education, visit www.epilepsyfoundation.org/living/children/education/Education.cfm
The Greater Chicago Epilepsy 2011

Proceeds Benefit the Epilepsy Foundation of Greater Chicago

Saturday, May 14 • 5K Walk/Fun Run
Danada Forest Preserve • Wheaton

Saturday, May 21 • 5K Walk/Timed Run
NEW LOCATION! Montrose Harbor • Chicago

For some returning soldiers, once the fighting is over... the battle begins.

Epilepsy and Traumatic Brain Injury

Making Sense of Individualized Education Plans