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Spring/Summer 2009



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An independently incorporated affiliate of the Epilepsy Foundation

A member agency of the Epilepsy Coalition of New York State, Inc.

A member agency of the United Way of Greater Rochester



## Support Groups

### Binghamton Adult Support Group

Wilson Memorial Hospital, Johnson City, NY  
Wilson Conference Room 5A, 4th Floor, Piccano Building  
7:00 - 8:00 pm  
**July 15, August 19** at 6 pm, Summer Picnic at Highland Park, **September 16**  
Call (877) 214-7715 to confirm.

### Rochester Parent & Family Network

1650 South Ave, Suite 300, Rochester, NY 14620  
6:00 pm pizza, 6:30 - 7:30 meeting  
No meetings **June, July or August**  
Next meeting **September 10**  
Call (800) 724-7930 to confirm.

### Rochester Adult Support Group

1650 South Ave, Suite 300, Rochester, NY 14620  
6:00 pm pizza, 6:30 - 7:30 pm meeting  
**August 6, September 3, October 1**  
Call (800) 724-7930 to confirm.

### Syracuse PFN/Adult Support Groups

1045 James Street, Suite 270, Syracuse, NY 13203  
6:00 pm pizza, 6:30 - 7:30 pm meeting  
No meetings **July or August**  
Next meeting **September 29**  
Call (877) 214-7715 to confirm.

## Other Events

### 12th Annual Epilepsy Foundation Golf Tournament

Brook-Lea Country Club  
**September 28, 2009**  
**11:00 am to 7:00 pm**  
Join us on Monday, September 28 for a beautiful fall day of golf at the renowned course at Brook-Lea Country Club outside of Rochester. To register, call us at (585) 442-4430 x2707.

### Camp EAGR

For kids with epilepsy, aged 8 to 17.  
**August 16 to August 22**  
Call (800) 724-7930 for more information and to register.

### The AI Sigi Center Campus has gone Smoke Free!

For everyone's health, the AI Sigi Center campus, on which our main office, 1650 South Ave, Rochester, is located, went smoke free inside and out on April 1, 2009.

Interested in an epilepsy support group, but there isn't one in your area?  
Please call Mike Radell at (800) 724-7930 to get things started.

## Walk for Epilepsy in Oswego

Carrie Gibbs is very familiar with the disorder of epilepsy and the need for awareness about epilepsy and seizures in Oswego County. Carrie was diagnosed with epilepsy following a tonic-clonic seizure (see page 5 for a description of seizure types) on her 16th birthday, but she has diary entries describing seizure events going back to when she was 9 years old.

Before her diagnosis, Carrie would often get into trouble for not paying attention in class or not listening to her parents. She also would often have what she described as "the shakes," where one part of her body would jerk unexpectedly.

Turns out that Carrie had been experiencing both absence and myoclonic seizures that went undiagnosed until she had a seizure (the tonic-clonic on her 16th birthday) that was more recognizable as a seizure. Carrie takes two anti-seizure medications and considers her seizures fairly well controlled now.

Carrie has lived in Oswego County her whole life and has to travel to Syracuse for her epilepsy care. There are no services for people with epilepsy in Oswego County and there is a distinct need *continued on page 5*

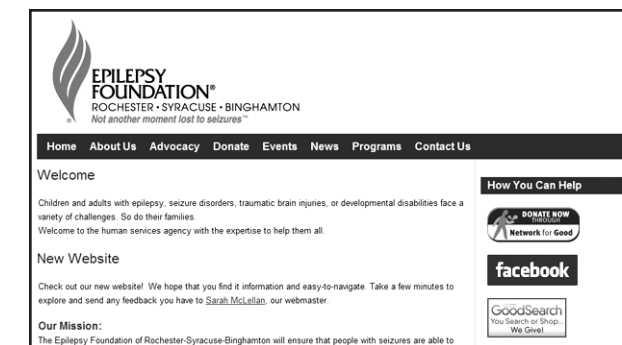


Walk for Epilepsy committee members Linda Lum and Jeanne Jackson pose with walk organizer Carrie Gibbs (left to right).

## New EF of RSB Website

The Epilepsy Foundation of Rochester-Syracuse-Binghamton will be unveiling a new website in July.

Check it out at [www.epilepsy-uny.org](http://www.epilepsy-uny.org) and don't forget to change our web address in your favorites!



## EF Outreach Luncheons

The Epilepsy Foundation of Rochester-Syracuse-Binghamton hosted three outreach luncheons over this spring and summer. These luncheons were made possible by a grant from the National Epilepsy Foundation and the Centers for Disease Control and Prevention.

The luncheons were held in Ithaca, Albion, and Corning and were all well attended. Over 150 people attended the series.

We thank everyone who made these luncheons a success - from our funders, to the staff who worked hard, to the doctors who volunteered their time, and of course the participants!

Stay tuned to our website for our next set of educational offerings. We are currently planning a series for November in celebration of epilepsy awareness month

For more information about our educational offerings, please visit our website at [www.epilepsy-uny.org](http://www.epilepsy-uny.org) or call us at (800) 724-7930.



1650 South Avenue, Suite 300  
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**Mission:** To ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through services, education, advocacy, and research.

**Vision:** Remove stigma, be first-in-mind for innovative programs, provide fast response and high-quality services for people with epilepsy and related disabilities so they may reach their potential.

The Epilepsy Foundation is a not-for-profit human service agency addressing the needs of area residents affected by epilepsy/seizure disorders and related disabilities. The agency serves all individuals and families without regard to race, color, sex, age, or national origin. Our target population is people with epilepsy and traumatic brain injury; we also serve people with developmental disabilities of all kinds. Programs include information and referral, educational programs, community services, family support services, residential services and Camp EAGR: a residential summer camp for children with epilepsy. Funding is provided by Medicaid contracts with New York State, the Counties of Monroe and Wayne, the Finger Lakes Developmental Disabilities Services Office (DDSO), Central DDSO, Broome DDSO, NYS Office of Mental Retardation and Developmental Disabilities (OMRDD), Department of Health (DOH), Vocational and Educational Services for Individuals with Disabilities (VESID), National Epilepsy Foundation, Epilepsy Coalition of New York State, Inc., United Way, grants, foundations, planned gifts, general donations, and special event fund-raising.

**Newsletter Editorial Team:** Debbie Baker, Debra Lewis, Sarah McLellan, David Milliman and Michael Radell.

## From David Milliman, President & CEO



Winston Churchill once said that "The pessimist sees difficulty in every opportunity. The optimist sees the opportunity in every difficulty."

So far, 2009 has certainly been full of difficulties, but at the Epilepsy Foundation we have resolved to be optimists and we are seeing opportunities everywhere. Despite the economy, I am very happy to report a very positive trend at the Epilepsy Foundation. We have seen a significant increase in community support from across our twenty-two counties. More individuals and companies are investing their time in raising money for the Epilepsy Foundation. And we are extremely grateful.

BCC Software, Inc.; Preferred Mutual Insurance Company; and The PMA Insurance Group are three companies who believe in the value of supporting the communities in which employees live and work. These companies encourage their employees to donate to various charities. This year, we were the lucky beneficiary of the fundraising activities of these three companies.

In Onieda County, Mrs. Carol Mandour and her husband wrote and produced a musical review in March. The Epilepsy Foundation was one of three charities that were chosen to be the beneficiaries of the money this play raised. We received \$1,200 from their hard work.

And as you read about on the front page, Carrie Gibbs along with a committee of dedicated volunteers, organized a walk in Phoenix, NY. Over 100 people attended and they raised over \$1,400.

Not only are we seeing more community support, but we are also seeing increased opportunities for new collaborations. Webster Theatre Guild reached out to us in late 2008 regarding their 2009 production of Evita. We helped to publicize their event on our website and in our newsletter and in turn we had a performance dedicated to us, where we were able to provide information about epilepsy and our Foundation to the Webster Theatre Guild patrons. We even received a portion of the proceeds from this performance!

The Epilepsy Foundation has been an active member of the Al Sigl Community of Agencies for many years. Just recently, the Al Sigl Agencies have formed a collaborative fundraising committee to explore ways in which we can effectively fundraise together. Our first venture is a special Independent's Day mailing to Monroe County celebrating the independence of our many clients.

Smiles are said to be infectious - and we are hoping that optimism is too. Join in our optimism and start seeing opportunities - opportunities that will ensure that all people with seizures are able to participate in all life experiences.

The Epilepsy Foundation and the children, adults and families it serves thank you for your support.

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My donation is \$ \_\_\_\_\_

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Please make your check payable to the Epilepsy Foundation *Donations to the Epilepsy Foundation are tax deductible. Thank you.*

|  |             |
|--|-------------|
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 Please send me more information about the Epilepsy Foundation including how I can include it in my will.

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*We care about our donors and friends!*  
*We have made every effort to list names correctly. If there is an omission or error, please accept our apology and let us know by calling (585) 442-4430 x2731 or e-mail s\_mclellan@epilepsy-ny.org.*



October 2008 - March 2009

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Grand Finales  
Hedonist Artisan Chocolates  
Jonathan Leach of JonJohn's  
Laico Café  
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## Epilepsy Medications: The Generic vs. Brand Debate

These days everyone is interested in saving money, especially when it comes to healthcare costs. One of the more popular ways of saving money for both patients and insurance companies is to switch to generic versions of drugs.

Generic drugs are currently estimated to save consumers up to \$10 billion a year at retail pharmacies because they cost less than the brand name versions. The Epilepsy Foundation actively supports the increased use of generic medications as a way to save money in healthcare. Because medications are a major cost of epilepsy care, the availability of less expensive versions of brand name medicines can be very good news for people with epilepsy.

While many patients can safely switch their medications among different formulations of the same antiepileptic medication, the Epilepsy Foundation recommends that individuals with epilepsy talk to their physician before any such substitutions are made. A growing number of studies show that when an antiepileptic drug is concerned, switching to a generic may not be a safe alternative.

From November 2006 to March 2009, the National Epilepsy Foundation conducted a survey via their website regarding switching. Over 1,000 individuals responded. In their recently released report of the survey's findings, the National Epilepsy Foundation notes an increase in reported breakthrough seizures and unexpected side effects when a patient switches to a different version of the drug they were prescribed.

The Foundation's just-released survey report supports other newly published studies documenting that switching can cause breakthrough seizures and unexpected side effects. The switch can be between different manufacturers' versions of the same generic drug, from a generic to the brand-name drug, or from the brand-name drug to a generic. It can also be caused by a switch from one manufacturer's formulation of its antiepileptic drug to a new formulation of the same drug. A link to the full report from this survey along with links to additional studies on this topic can be found on our website at [www.epilepsy-uny.org](http://www.epilepsy-uny.org).



## What You Can Do

Visit <http://www.epilepsyfoundation.org/medication-switching> for more information and to access all of the links mentioned in this article.

1. Tell the FDA Commissioner that you need the FDA to act on this problem, as part of their responsibility to ensure that medications for epilepsy are safe.

Visit <http://www.epilepsyfoundation.org/medication-switching/whatyoucando.html> to send a message directly to the FDA.

2. Inform your pharmacist about the issue. Ask him or her to put a note in your electronic record explaining that you take antiepileptic medications for seizures and not to switch you to a generic without your and your doctor's consent. Download a letter for your pharmacist from [www.nomoreseizures.org](http://www.nomoreseizures.org).

3. If you have had unusual side effects or unexpected seizures within 4 to 6 weeks of a switch, immediately call your doctor to let him or her know **AND** inform the FDA by contacting the Commissioner's office and MedWatch to file a report of a problem with switching. For information, call 1-800-FDA-1088 or visit the web site at <http://www.fda.gov/medwatch>.

4. Join the Epilepsy Foundation's eCommunities at [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) and let people know what you think or how you've been affected by medication switching. It's a great place to connect with people facing similar issues.

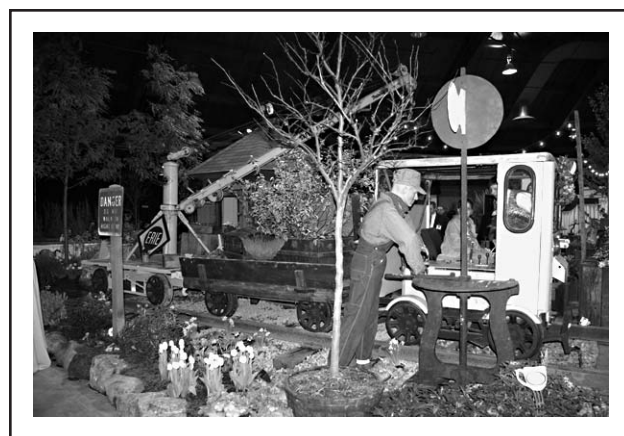
Medication switching is a major concern because seizures are serious events that can have considerable cost to one's health, well-being, and pocketbook. To find out what you can do, see the box above, or give us a call at (800) 724-7930.



### A Taste of Spring at GardenScape 2009

The Epilepsy Foundation extends a big thank you to the GardenScape Professional Association for choosing us as their charity of choice for the 9th year in a row. Pictured right is the garden *Eden Station* by RJ Schickler and the 2009 People's Choice Award Winner. Congratulations to RJ Schickler for winning People's Choice for the 4th year in a row!

It was such a pleasure to be a part of this year's event. The theme was *Gardens of Eden: An Oasis for the Soul*. This theme perfectly captures the feeling one gets when stepping out of the dreary March weather in Rochester, NY into the completely transformed Dome Center. Join us next year for the 2010 show!



### Scenes from Under the Mandarin Moon

The 23rd Annual Chocolate Ball was a resounding success! The decorations were beautiful, the chocolate desserts were fabulous, and the dancing was lively. Over 425 people attended, helping us to raise over \$100,000!

#### 2009 Chocolate Ball Sponsors

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2009 People's Choice Award Winner  
Sweet Jin Ju by Grand Finales



Chocolate Ball Planning Committee Members  
Rose Swiskey, Courtney Deckman, Pamela Rhoda,  
and Lisa Noonan



Honorary Board Member  
Don Soule

### Walk for Epilepsy continued

for more awareness regarding seizures and epilepsy in this area. Perhaps Carrie's seizures would have been detected sooner if more people were aware that brief lapses in awareness or uncontrolled muscle contractions could be seizures.

In the spring of 2009, Carrie decided that she needed to do something to bring awareness about epilepsy to her hometown and so she decided to organize the first Walk for Epilepsy in Phoenix, NY in Oswego County.

"There needs to be more awareness about epilepsy and seizures locally, and so my idea was to organize an event that would bring people together," states Carrie.

Carrie and a team of committed friends organized the Walk for Epilepsy, which took place on June 13, 2009. It was a huge success with over 100 people attending. They were also able to raise over \$1,400 for the Epilepsy Foundation of Rochester-Syracuse-Binghamton. "I think the event was extremely successful. There are definitely things that I would do differently as I have never organized an event on this scale before. It was a great learning experience and we are already thinking about what our next event will be," stated Carrie.

Congratulations to Carrie and her committee for hosting such a successful event. We are eagerly looking forward to helping them with their next event in Oswego County.

### Seizure Types (from page 1)

**Absence seizures** (also called petit mal seizures) are lapses of awareness, sometimes with staring, that begin and end abruptly, lasting only a few seconds. There is no warning and no after-effect. More common in children than in adults, absence seizures are frequently so brief that they can escape detection, as was the case for Carrie. Seizure education for parents, teachers and school nurses can help with early detection.

**Myoclonic seizures** are rapid, brief contractions of bodily muscles, which usually occur at the same time on both sides of the body. Occasionally, they involve one arm or a foot. People usually think of them as sudden jerks or clumsiness.

**Generalized tonic clonic seizures** (also called grand mal seizures) are the most common and best known type of seizure. They begin with stiffening of the limbs (the tonic phase), followed by jerking of the limbs and face (the clonic phase).

For more information regarding seizures, visit us on the web at [www.epilepsy-uny.org](http://www.epilepsy-uny.org).

### Fall Golf Outing

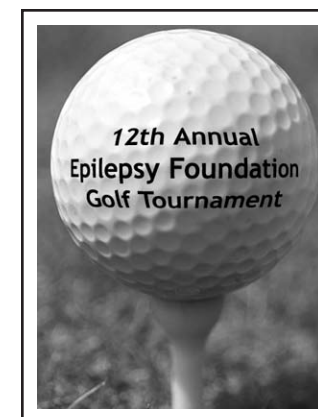
Join us for a beautiful fall day of golf on September 28 at Brook-Lea Country Club for our annual golf tournament.

Registration and lunch start at 11:00, shotgun start is at 12:30.

Can't make it during the day? Join us for dinner at 6 pm.

Proceeds from this tournament benefit the Epilepsy Foundation's programs and services.

Call Debbie Baker at (800) 724-7930 x2707 for more details and to register.



### Fun Week for Kids with Epilepsy

On August 16th, the 18th season of Camp EAGR will begin and 70 kids will arrive at camp ready to have an exciting and fun-filled week!

Registration is on a first-come, first-served basis, so if you have a child with epilepsy, aged 8 to 17 or know someone who does, get their camp registration form in soon.

Camp EAGR also needs your help! We are always accepting donations for camp. Donations can be as simple as arts and craft supplies up to money for scholarships.

For more information about camp or to see how you can help, call Mike Radell, our camp director, at (800) 724-7930 x2702.