

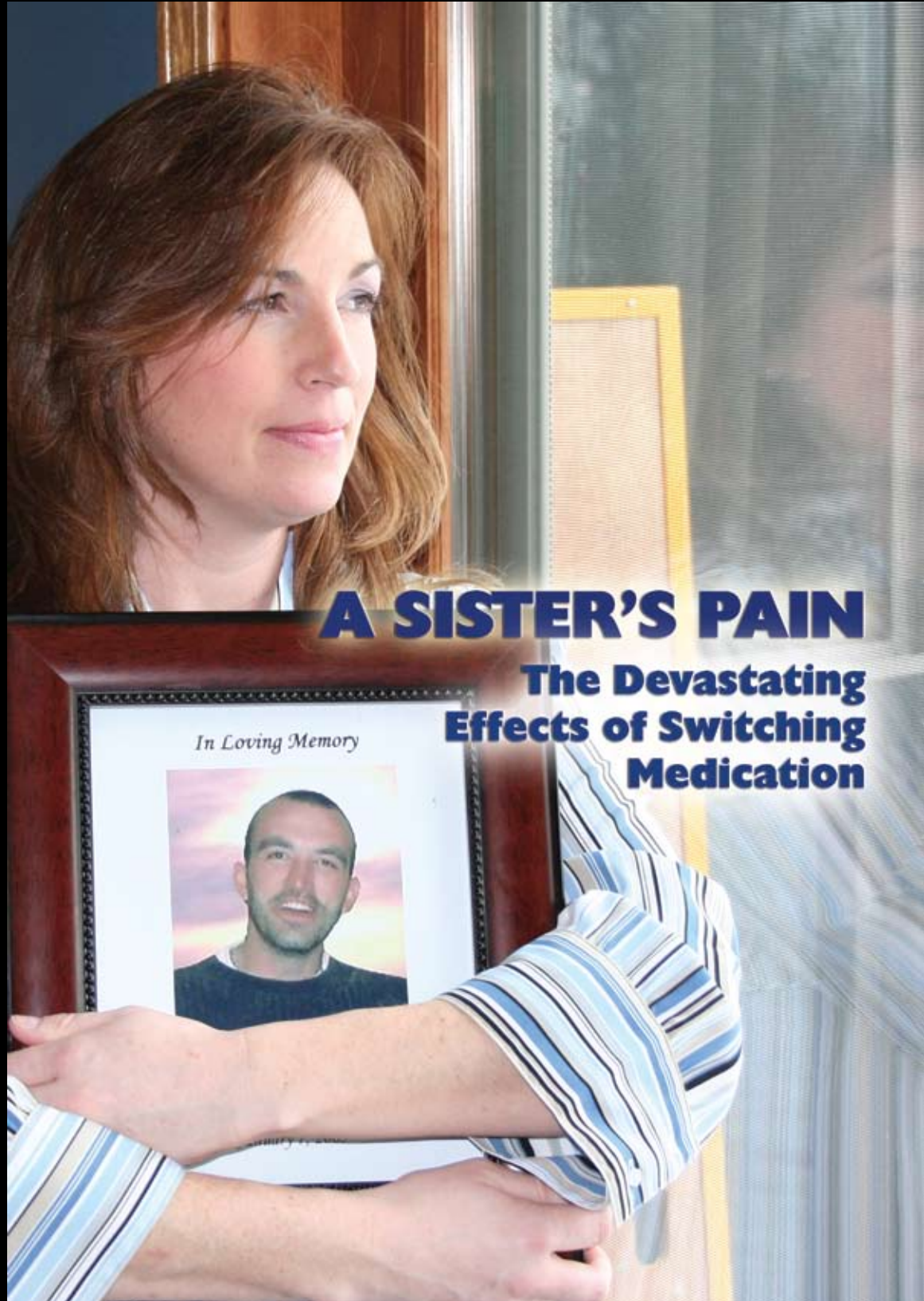
# HEADLINES

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## **A SISTER'S PAIN** **The Devastating Effects of Switching Medication**

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## From The President

We recently hosted a briefing in Lansing for key legislators along with Senator John Gleason and Representative John Espinoza to educate decision makers about two Bills we are calling Epilepsy Patient Protection Legislation. House Bill 5077 and Senate Bill 926 would prevent pharmacists from switching epilepsy medication—whether from brand to generic, generic to generic or generic to brand—without the consent of the patient and their physician.

We have heard stories from many of you about problems you or a loved one have had when your medication was switched. You have told us about the consequences of these changes that include everything from increased seizures, breakthrough seizures, side effects, and even death. The cover story of this edition of Headlines chronicles the devastating effects of switching medication. Kelly Van Singel, a passionate advocate for epilepsy and a true crusader for the Foundation, shares the

story of losing her brother to this practice.

We have also heard from neurologists who see many patients with epilepsy regarding this issue as well. When the American Epilepsy Society surveyed its members, it found a majority of physicians had concluded that the various formulations of the same anti-epileptic drug are not always therapeutically equivalent in every patient. They also reported that the high percentage of people whose medications were switched had adverse effects as a result. Dr. Brien Smith of Henry Ford Health System does a wonderful job explaining this phenomenon in his article on page 3.

Switching medication without notifying patients or their physicians is a serious issue, one that we will continue to fight against until there is a suitable solution. But we need your help in passing these Bills. This legislation is about preventing seizures and their consequences and doing what we believe is right. It's also about keeping people on the medication that works for them, whether it is brand or generic.

What can you do to help? You can complete the survey found on our Web site at [www.epilepsymichigan.org](http://www.epilepsymichigan.org). Not only will completing the survey provide much needed support to our cause, but by doing so you will automatically be entered into the drawing for a chance to win a \$500 Target gift card. There are two other ways in which you can help:

- Contact your legislator as these Bills move forward. Join our Epilepsy Action Network by signing up on our Web site so we can contact you when it is time to take action.
- Participate in our Legislative Recognition Event on May 6th in Lansing. This sponsored breakfast is free and will provide you with an opportunity to educate your legislator about epilepsy and about other important issues affecting you and your family relative to this condition. For more information on attending, feel free to contact our office manager, Pamela Bird, at (248) 351-7979 option 1, ext. 204, or at [pbird@epilepsymichigan.org](mailto:pbird@epilepsymichigan.org).

We look forward to your participation in this effort and trust that it will lead to the passage of the Epilepsy Patient Protection Legislation.

A handwritten signature in black ink that reads "Arlene S. Gorelick". The signature is written in a cursive, flowing style.

## RESEARCH IN PROGRESS:

# Is It Safe to Switch To A Generic Epilepsy Medication?



**Brien J. Smith, M.D.** is Medical Director of the Comprehensive Epilepsy Program at Henry Ford Hospital's Department of Neurology

By Brien J. Smith, M.D.

Generic medications have provided a significant savings of health care dollars and are strongly encouraged. The assumption is made by patients that generic medications have been thoroughly tested and do not place them at any type of risk when making a change from brand to generic. In the epilepsy world that means no risk for breakthrough seizures or toxic side effects when making a conversion from brand name to generic or from one generic to another. The Food and Drug Administration (FDA) further suggests there is no reason for concern with national media messages that "generics are safe" with no exceptions or cautions.

Despite this, there is a large caution flag being waved by many physicians treating patients with epilepsy. Although not considered "scientific" evidence, there have been surveys completed that report the majority of physicians involved in the care of epilepsy patients have identified patients who have developed toxic side effects or breakthrough seizures with the change from brand to generic or generic to generic. There has also been a study in Canada showing a high rate of physicians appealing to the government to allow their patients to return to the original brand name AED (13.4 - 20 percent) after problems with the switch to generic compared to only 1.5 - 2.9 percent with generic switches in other classes of medications. A more recent study looking at over 15,000 epilepsy patients in one health insurance computerized database, demonstrated an 81percent higher chance of requiring an ER visit or having an ambulance called when patients had recently undergone a generic switch.

Why is this happening? We don't know. Remember, generics have the same type and amount of the active chemical; they are just mixed or packaged a little differently. Is it because the FDA process is not accurately determining clinical equivalence in our special epilepsy population? Do the studies the FDA complete in a small number of healthy controls really represent our epilepsy population? For a generic drug to be approved, the FDA has a protocol where about 30 healthy adults are tested with a dose of the branded drug and then a dose of the generic medication. They do frequent blood draws to closely monitor blood levels and make a comparison between the two. The equation the FDA uses keeps a fairly narrow range to obtain generic acceptance, but is that narrow range enough for keeping epilepsy patients safe? Since the volunteers used by the FDA don't have epilepsy, we won't be able to answer that question of safety (seizure control or bad side effects) with their testing. It is assumed that there would not be a problem because the drug levels are expected to be fairly similar.

Our concern is the "pharmacokinetic" bioequivalence (similar blood level parameters) the FDA is claiming based on laboratory

testing with volunteers doesn't necessarily match up with the "clinical" bioequivalence (seizure control or side effects) we need to see in our epilepsy patients. Even relatively small changes in blood levels have resulted in seizures or bad side effects in some of our patients. How often do we hear, "I was late with my medication by 1-2 hours (resulting in small change in blood level) and had a seizure." The FDA says we do not yet have the data to prove their techniques wrong, but they also do not have the data to dismiss our concerns. Most of the major physician and patient advocacy organizations involved in epilepsy patient care have released position statements about the potential problems with generic substitution in epilepsy and the need for more studies.

Even though I believe at least 90 percent of the patients I see have no problems with the switch to generic epilepsy medications, it is the small number in which I can't predict there will be a problem that really raises my concerns. In the clinic, what patient type is my biggest concern? It is actually the well-controlled patients who have been seizure-free for a lengthy period. They are working and driving. You can imagine the possible consequences of an unexpected seizure after the generic conversion. They are not presently being forewarned of any possible risk.

We all agree a study needs to be done to try to answer this big question about the safety of generic switching with epilepsy medications. The problem is it may take at least 2-3 years and a lot of money to complete a well-designed trial. How that study will be designed and funded are still big questions. With four antiepileptic drugs becoming available in generic form over the next year or two, there is a sense of urgency here.

So what can or should we do in the meantime? I think the best thing is to educate physicians and patients that there may be a risk. Until we complete the study, attempt to avoid monthly changes by pharmacists unless the patient and physician have approved the change. Remember, we know there can be a change in blood level from brand to generic. There can be even a bigger change from one generic to another. In patients who want to change because of the savings, it surely can be done, as long as they understand the potential risk. Clinically, I will suggest checking a trough and/or peak blood level before the change and then shortly thereafter. They should talk to the pharmacist about maintaining their generic medication from one manufacturer to avoid monthly switches from one generic manufacturer to another (theoretically even a bigger risk). Finally, I will also raise the issue of possibly limiting their activities during the process.

You can help here by advocating for yourself, your family member or friend. There are Bills in Lansing which will not allow conversion to a generic epilepsy medication unless that change has been approved by the patient and treating physician. Encourage your legislator to support current Bills in the Michigan House (HB 5077) and Senate (SB 926). Until we have more information from a well-designed trial, we need to be aware of the potential consequences of a change. Even though the risk may be very small, the ramifications of an unexpected seizure in the wrong place or at the wrong time can be devastating. We all deserve the right to be informed of the risks we potentially face.



## 10TH ANNUAL LEGISLATIVE BREAKFAST AND "MICHIGAN KIDS SPEAK UP" DAY

**TUESDAY, MAY 6<sup>TH</sup>**

Mackinac Room, Anderson House Office Building  
124 North Capitol, 10-South, Lansing, MI

### LEGISLATIVE BREAKFAST (for adults and youth)

8:00 a.m. - 10:00 a.m.

Join us for a FREE breakfast in Lansing and have the opportunity to speak with your state representatives and senators regarding issues that concern you. By attending, you will also be able to help spread the word to other legislators who did not attend the session. You can prepare for the event by doing the following:

- RSVP by calling Pam Bird at (800) 377-6226 option 1, ext. 204, or by e-mailing at [pbird@epilepsymichigan.org](mailto:pbird@epilepsymichigan.org)
- Review a copy of the Epilepsy Foundation of Michigan's Public Policy Agenda
- Call, write or e-mail your state representative and senator and invite them to join you at the breakfast. To find your legislators, you can visit <http://house.michigan.gov> or <http://senate.michigan.gov/>. There are also links on our Web site that direct you to the appropriate locations as well.

### "MICHIGAN KIDS SPEAK UP" (for youth ages 8-16) 8:00 a.m. - 1:30 p.m.

The Epilepsy Foundation of Michigan invites youth with epilepsy from across the state to learn how to make an impact on legislation that affects them.

Activities include: legislative breakfast; legislative workshop; meet state legislators; Speak Up, Be Heard Luncheon; guided tour of the Capitol Building. This is a wonderful opportunity for kids and their family to witness first hand how democracy works in our state. This is a FREE event, but you must register first by calling Pam Bird at (800) 377-6226 option 1, ext. 204, or by e-mailing at [pbird@epilepsymichigan.org](mailto:pbird@epilepsymichigan.org).

## Summer Stroll for Epilepsy™

### SAVE THE DATES FOR 2008 SUMMER STROLL FOR EPILEPSY™

Mark these dates on your calendar:

**May 31<sup>st</sup>, Dow Diamond in Midland (NEW LOCATION!)**

**June 7<sup>th</sup>, Celery Flats in Kalamazoo County**

**June 14<sup>th</sup>, Detroit Zoo in Royal Oak**

**June 21<sup>st</sup>, Bayfront Park in Petoskey**

**June 28<sup>th</sup>, Riverwalk in Grand Rapids**

**Come out to the location of your choice  
and stroll with us as we spread epilepsy awareness,  
have fun and raise money for a great cause.**

It would be an honor to have your company as a sponsor or a corporate team for our 2008 Summer Stroll Season! For more information, contact Duc Abrahamson at 800-377-6226 opt. 1 ext. 236 or [dabrahamson@epilepsymichigan.org](mailto:dabrahamson@epilepsymichigan.org).

## **No Limits** TELEMENTORING

**No Limits Telementoring** is a great program for young people ages 18-25 with epilepsy who are entering the workforce. This program is designed to bring adults together with young people with epilepsy who are looking for a role model to help them make a transition into gainful employment.

You will correspond with a Telementor on a regular basis via e-mail and other means of electronic communication.

If you are between 18-25 and are looking to improve your job seeking and/or work-related skills, this program is for you. Contact the Epilepsy Foundation of Michigan today at (800) 377 6226 option 1, ext. 231, or visit [www.epilepsymichigan.org](http://www.epilepsymichigan.org) for more information.

# A Sister's Pain: The Devastating Effects of Switching Medication

It was a predictably cold winter day on Friday, January 7, 2005 when Debra Nelson decided to stop by her only son's apartment to say hello. Using her key to enter his unit, Debra quickly realized the place was eerily silent. As she made her way through the small dwelling, she called for her son—"Jay, are you ok?"—but received no response. She approached the bathroom and found Jay unconscious, lying facedown on the floor between the toilet and sink. Debra called 911 and rushed to his aid, but by the time paramedics arrived, Jay was already dead.

Lloyd James Nelson, known as Jay to family, died of a seizure at age 25. But his story goes deeper than merely dying as a result of epilepsy. Jay began experiencing grand mal seizures five years earlier, when as a vibrant 20-year-old with great enthusiasm for life, the electrical activity in his brain began to change. Early on, Jay seized constantly; he had even experienced a seizure while driving, which cost him his driving privileges. Unable to transport himself, he ultimately lost his job as an electrician.

"Initially, (the family) didn't quite understand seizures and how serious they can be," Jay's sister, Kelly Van Singel recalls. "We just said, 'hey, Jay has seizures; we'll deal with it and help him out.'"

Jay's doctor prescribed Dilantin to control his seizures. Although he experienced an occasional breakthrough seizure, taking Dilantin improved his quality of life. The prescription, however, proved costly. When Jay lost his job, his medical benefits were lost as well, and all prescriptions were paid for completely out-of-pocket. But with help from his family, Jay was able to maintain a regular medication regimen. He eventually applied and was approved for Medicaid, which assisted him with prescription costs. However, Medicaid mandated Jay use a particular pharmacy and informed him that they would not approve payment if he decided to go elsewhere.

On Wednesday, January 5, 2005, Debra drove Jay to the new pharmacy to have his prescription filled. By this point, the Dilantin was working wonderfully and Jay had been seizure-free for more than seven months. "He finally felt like he was going to get his license back," Kelly said.

"We all felt that he was getting back on track, and everything seemed to be going good." The pharmacist provided him with his new medication, but Jay quickly realized the pills looked different from the Dilantin he had been taking. He brought it to the pharmacist's attention, but was told that it was a generic version of an anti-seizure medication and that there was no cause for concern. Jay took the medication as directed and died 48 hours later.

The family later learned that the new pharmacy switched Jay's medication from Dilantin to Phenytek without calling, consulting or notifying neither Jay nor his physician. If the pharmacy had done so, it is likely that Jay's doctor would have prevented the switch and Jay would probably still be alive today. Kelly admits, however, that the family didn't take Jay's condition as seriously as they should have, and that being more proactive could have perhaps prolonged his life. "I didn't help him while he was alive, but I can help him now," Kelly said. And in her effort to help, Kelly has become a dedicated ambassador of the Epilepsy Foundation of Michigan and a devoted supporter of the Patient Protection Legislation, which, if passed, would mandate that pharmacists obtain consent from patients and their physicians before switching medications. "It's my way of saying 'I'm sorry' to Jay," Kelly said. Kelly hopes that by sharing her family's story, she will help spread the word on an important legislation that could literally save lives. "I want to prevent another family from going through what we've gone through."



Kelly Van Singel  
on her wedding  
day, with brother  
Lloyd "Jay" Nelson

## CALENDAR OF EVENTS

### APRIL

- April 2 Spring Open House (Southfield Office)
- April 8 L.E.G.S. - Living Well Special Workshop (Lansing)
- April 12 Teen EEG – Driving Range and Pizza Party (S.E. Michigan)
- April 24 Grand Rapids Group - Living Well Special Workshop (Grand Rapids)
- April 26 Charity Crop Party (S.E. Michigan)
- April 30 H.U.G.S. - Living Well Special Workshop (Kalamazoo)

### MAY

- May 6 10th Annual Legislative Recognition Breakfast (Lansing)
- May 6 2nd Annual Michigan Kids Speak Up (Lansing)
- May 13 L.E.G.S. Open Discussion Night (Lansing)
- May 21 EEG-Detroit Tigers game (SE Michigan)
- May 28 H.U.G.S. Open Discussion Night (Kalamazoo)
- May 29 Grand Rapids-Group Open Discussion Night
- May 31 Summer Stroll for Epilepsy™ (Midland)

### JUNE

- June 7 Summer Stroll for Epilepsy™ (Kalamazoo County)
- June 14 Summer Stroll for Epilepsy™ (Detroit)
- June 21 Summer Stroll for Epilepsy™ (Petoskey)
- June 25 H.U.G.S. – Living Well Special Workshop (Kalamazoo)
- June 25 L.E.G.S. – Living Well Special Workshop (Lansing)
- June 26 Grand Rapids Group – Living Well Special Workshop (Grand Rapids)
- June 28 Summer Stroll for Epilepsy™ (Grand Rapids)
- June 29 Camp Discovery
- June 30 3rd Annual Paul Neu Memorial Golf Classic

### JULY

- July 8 L.E.G.S. – Open Discussion Night (Lansing)
- July 18 EEG – Summer Hot Dog Bash (West Michigan)
- July 25 EEG – Summer Hot Dog Bash (West Michigan)
- July 30 H.U.G.S. – Open Discussion Night (Kalamazoo)
- July 31 Grand Rapids Group – Open Discussion Night

### AUGUST

- Aug. 12 L.E.G.S. – Living Well Special Workshop (Lansing)
- Aug. 16 Teen EEG – C.J. Barrymore's (S.E. Michigan)
- Aug. 21 EEG – Bowling at Holiday Lanes (West Michigan)
- Aug. 23 EEG – West Michigan Whitecaps (West Michigan)
- Aug. 27 – H.U.G.S. – Living Well Special Workshop (Kalamazoo)
- Aug. 28 – Grand Rapids Group – Living Well Special Workshop (Grand Rapids)

### SEPTEMBER

- Sep. 4 EEG – Bounce Party (West Michigan)
- Sep. 9 L.E.G.S. – Open Discussion Night m (Lansing)
- Sep. 18 Grand Rapids Group – Open Discussion Night
- Sep. 20 EEG – Glow-In-The-Dark Golf and Pizza Party (S.E. Michigan)
- Sep. 24 H.U.G.S. – Open Discussion Night (Kalamazoo)
- Sep. 25 Flame of Hope (West Michigan)



The Epilepsy Foundation of Michigan's Camp Discovery provides youth with epilepsy a safe, structured and encouraging home away from home for 5 days and 4 nights. All participants will have the opportunity to enjoy canoeing and kayaking, horseback riding, arts & crafts, swimming and much more. Camp staff includes Foundation personnel, pediatric neurologists and registered nurses. Financial assistance is available.

For a camper application or to sponsor a camper, please visit our Web site at [www.epilepsymichigan.org](http://www.epilepsymichigan.org). You can also call (800) 377-6226 option 1, ext. 231, or e-mail Sheryl Darroch at [sdarroch@epilepsymichigan.org](mailto:sdarroch@epilepsymichigan.org).

Space is limited and demand is ever-growing, so call today!

**Dates: June 29 – July 3, 2008 – Ages: 8 – 18**

**Location: Sherman Lake YMCA Outdoor Center in Augusta (northwest of Kalamazoo)**

# Mardi Gras Gala



More than 200 people attended our Third Annual Mardi Gras Gala in February at the Royal Park Hotel in Rochester. Held every year on "Fat Tuesday," the Mardi Gras Gala is a replica of the historic Mardi Gras Festival in New Orleans.

The highlight of the Gala was the crowning of the "**Mardi Gras King**," **Mr. Mark R. Bartlett** of Blue Cross Blue Shield of Michigan. Dinner Chairs **Jon E. Barfield** (Bartech Group), **William H. Black** (Teamsters), **Robert A. Patzer** (MITA) and **Colette Russell** (Pamar Enterprises) joined Mr. Bartlett in celebrating a memorable event that raised more than \$100,000 for the Foundation.

**Mark your calendars for next year's Gala:  
FEBRUARY 24, 2009!**



(l-r) **Arlene S. Gorelick**, President of the Epilepsy Foundation of Michigan, celebrates a successful Mardi Gras Gala along with **Jon E. Barfield** (Dinner Chair), **Robert A. Patzer** (Dinner Chair), **Mark R. Bartlett** (Mardi Gras King of 2008), **Colette Russell** (Dinner Chair) and **William H. Black** (Dinner Chair).

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Simone Vitale Band  
Photographer  
Wally Lubzik

**Volunteers**  
*Thank you for giving your time*

## Planned Giving

Does your estate plan provide for your favorite charitable organization?

With some preparation today, you can ensure the Epilepsy Foundation of Michigan continues to provide quality products and services to our consumers beyond your lifetime through bequests and estate planning.

Please consult with your attorney or tax consultant for more information, or contact the Epilepsy Foundation of Michigan at (800) 377-6226.

## Complete Our Online Survey For a Chance to Win a \$500 Target Gift Card

The Epilepsy Foundation of Michigan has developed a short survey regarding substituting prescription drugs. Switching medication is a serious issue, one that can put the well-being of those with epilepsy at risk.

We ask that you take a few moments to complete our online survey. Results from the survey will be shared with state legislators as they continue their quest to enact laws that prohibit switching medication without physician or patient consent.

And as an added bonus, you will be entered into the drawing for a \$500 Target gift card just for completing the survey. Please, one entry per household.

Visit our Web site at [www.epilepsymichigan.org](http://www.epilepsymichigan.org) today for your chance at a \$500 Target gift card.

60  
YEARS

## SHARE OUR MOMENT

The Epilepsy Foundation of Michigan is celebrating its 60th Anniversary this year, and we'd like you to commemorate this accomplishment with us. We're looking for individuals to share with us their stories of battling and overcoming epilepsy.

Those with epilepsy and family members affected by epilepsy are free to participate. Our 60th Anniversary is as much about you as it is about us. You share in this moment with us, and we'd like to hear from you.

Share your story today at [www.epilepsymichigan.org](http://www.epilepsymichigan.org)



Harleigh & Darcy Lukaart



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