From the President

Happy New Year! The Epilepsy Foundation of Michigan is very excited about 2006. We are confident many great things are ahead.

The treatment of epilepsy has recently undergone a great deal of change as result of the Decade of the Brain of the 1990s. To put this in perspective, epilepsy is a condition mentioned in the Bible, but its first major breakthrough did not come until the introduction of Dilantin (phenytoin) in 1958 by Parke-Davis Company in Detroit, which is now part of Pfizer. Today we have a larger array of treatments, including medications, devices and surgery.

However, some things haven’t changed that much. There is still a stigma to epilepsy. We have more treatments than we have ever had, but as many as 40 percent of the people who have this condition are not able to completely control their seizures. Some of these people could be helped if they had access to new treatments.

The effect of epilepsy on quality of life can be devastating. The Epilepsy Foundation is dedicated to eradicating the stigma and misunderstanding surrounding this disorder and improving the quality of life for those struggling with this condition.

In 2006,

- We are dedicated to reducing the treatment gap between what can be done for people with epilepsy and what gets done.
- We need to reach people with epilepsy to make them aware of new treatment options.
- We must ensure that people have access to specialty care and all treatment options including medications regardless of their income or insurance status.
- We will work to eliminate the stigma and discrimination that prevents people with epilepsy from gaining access to life experiences including education, employment, and transportation.
- We will spread the word about epilepsy, so that seizures are understood, and no one will think that shoving something in someone’s mouth is proper first aid for a seizure.
- Above all, we will teach people to be self advocates, whether for appropriate care or for public policy that affects their lives on a daily basis.

The Foundation will do this by providing a variety of services, including:

- Information through the Foundation’s Education and Consultation Program, our toll free education line that offers individualized education on any issue related to epilepsy such as medication, surgery, and so on as well as referrals to physician services, employment programs, and help with issues related to school.
- Conferences and workshops on a variety of topics about epilepsy that would help individuals take control of their treatment decisions, and provide tools to improve the quality of their lives.
- Camp Discovery, where children with epilepsy test their wings, and develop independence and self-confidence. We also want to expand our program to reach more children, and to include adult retreats, week-end family camps, and teen camps so more people will benefit from this experience.
- Seizure Smart program, which educates school personnel, health care workers, police, fire and businesses about epilepsy and epilepsy first aid. We are particularly concerned that we train the teachers of any child with epilepsy.

We can’t do this without support. We need an army of volunteers who can help spread the word about epilepsy. Please help us as we work to achieve these goals. Together, we can make a difference.

Not another moment should be lost to seizures

Sincerely,

Arlene S. Gorelick, M.P.H.
President
The Blue Ribbon Physician Workforce Committee has launched a campaign to educate state and federal policymakers on the projected physician shortage. The committee commissioned New York State University’s Albany Center for Health Workforce Studies to perform a state-specific study of physician supply and demand. Denise Holmes, assistant dean for government relations for the Michigan State University College of Human Medicine, recently presented preliminary results of the Michigan study.

Preliminary Results of the Michigan Physician Workforce Analysis

- Michigan currently has 30,000 active patient-care physicians and will need 58,000 physicians by 2020.
- Michigan will be 900 physicians short by 2010; 2,400 short by 2015; and 4,500 doctors short by 2020.
- Michigan is going to experience a more severe shortage of doctors than the nation as a whole. The United States will be 7.9 percent short, and Michigan will be 11.9 percent short.
- On the basis of population alone, Michigan should experience a shortfall of 2,814 physicians by 2020; this study projects a Michigan shortfall at 4,500 physicians by 2020.
- Michigan is losing physicians after graduation at much the same rate as are many of the northern states. New York has a very similar problem, despite being the largest producer and trainer of physicians in the United States.
- While Michigan’s primary care physician projections indicate physician supply will be adequate for demand until 2018, the specialist projections indicate that a shortage will begin in 2006.

The Blue Ribbon Committee convened about a year ago to create a comprehensive strategy that is supported by the four Michigan medical schools (University of Michigan School of Medicine, Wayne State University School of Medicine, Michigan State University College of Osteopathic Medicine, and Michigan State University College of Human Medicine); the State of Michigan, as represented by the Michigan Department of Community Health; the Council on Graduate Medical Education; and statewide associations and organizations impacted by physician supply concerns. Michigan’s four medical school deans attended the briefing and each presented one component of the Committee’s plan to meet the challenges related to increasing the number of physicians trained in Michigan.

- **Robert Frank, M.D.** – University of Michigan School of Medicine. Allow Michigan’s teaching hospitals to train more physicians in Michigan by raising the cap on the number of residents and fellows eligible for Medicare reimbursement by 10 percent.
- **Allen Lichter, M.D.** – University of Michigan Medical School. Maintain commitment to Medicare indirect medical education financial assistance to support the nation’s teaching hospitals.
- **William Strampel, D.O.** – Michigan State University College of Osteopathic Medicine. Maintain federal commitment to the Medicaid program to prevent further cost shifting to already overburdened states.
- **Marsha Rappley, M.D.** – Michigan State University College of Human Medicine. Adopt the Senate version of Title VII funding allocations to support programs that encourage distribution and diversity of our nation’s health care workforce.

*Information issued by Wayne State University School of Medicine.*
New Medical Option Available For Patients With Epilepsy
Jonathan Edwards, M.D.

The FDA has approved pregabalin as the newest medicine on the market for the treatment of seizures. Pregabalin is manufactured by Pfizer, and is sold under the brand name “Lyrica”.

Pregabalin is approved for the treatment of three different conditions: (1) nerve pain caused by shingles, (2) nerve pain caused by diabetes, and (3) adjunctive treatment of partial onset seizures in adults. In terms of its use in epilepsy, the term “adjunctive treatment on partial onset seizures” means that it can be added on to another medicine (or medicines) for seizures that start in a focal part of the brain. Pregabalin has not been thoroughly tested yet in use by itself, or in “generalized seizures” (seizures that start on both sides of the brain at once).

Pregabalin is somewhat similar in structure to the older medicine “gabapentin” (Neurontin), although it has significant differences from the older medicine. Pregabalin acts as a stabilizing agent for the membranes in brain cells, decreasing excessive electrical discharges associated with epilepsy. In clinical trials, pregabalin reduced seizures by 50% or more in just over half of the patients who used it. Common side effects include those that are common to many seizure medicines: sleepiness, dizziness, trouble concentrating or blurry vision. Weight gain is seen in approximately 10% of patients, and swelling in the hands or feet (edema) may occasionally be noted. However, few patients in clinical trials chose to stop taking the medicine due to side effects.

Pregabalin does have several positive features that make it an appealing choice for many patients and clinicians. It has no significant drug-drug interactions, so it does not increase or decrease the concentration of other medicines that a person may be taking for epilepsy or for other conditions. Pregabalin has not been significantly associated with any dangerous reactions (there is no “black box warning” listed). Additionally, the incidence of allergic reactions to pregabalin is quite low, compared to many other seizure medicines, and pregabalin does not appear to have an injurious effect on the liver or on the production of blood cells. Unlike the older drug, gabapentin (Neurontin), which is typically taken three or four times per day, pregabalin only needs to be taken twice (or occasionally three times) per day. Finally, pregabalin is available in a wide array of strengths, ranging from 25 mg to 300 mg pills, making dose adjustment much more convenient.

One-third of all people who take medicine for seizures are not currently seizure-free. However, many new treatment options are currently being developed. Pregabalin is the first new seizure medicine to be approved by the FDA in over five years.

Wear Your Support
JEWELRY SHOWCASING THE FOUNDATION’S LOGO IS NOW AVAILABLE

These stunning pieces provide epilepsy awareness by showcasing the Foundation’s logo. Fifty percent of the proceeds will help fund our programs and services allowing us to further our mission of “empowering people with epilepsy to live productive lives.”

All the silver, including the silver on the leather cord is sterling and rhodium plated, for a non-tarnish finish. The leather cord is adjustable between 16” and 18”.

$28 for the flame piece and $35 for the enamel piece, including sales tax.

ART CONTEST
A Girl In A Grid

Art Submitted by: Jennifer Sebela

Jennifer Sebela submitted this piece in our 2005 Art Contest. She’s 13 years old and has had epilepsy since she was in first grade. When Jennifer describes how epilepsy makes her feel she says she feels like “a girl in a grid.”

The Epilepsy Foundation of Michigan is now accepting submissions for the 2006 Art Contest.

Submissions can be in any two-dimensional medium. Examples include paintings and drawings in watercolor, pastels, oil, pencil, etc. Size should not exceed 20” x 30”.

For more information or to make an art submission, please call 1-800-377-6226 ext. 1-218.
The 2nd Annual Mardi Gras Gala was a huge success! Nearly 400 guests enjoyed the festive Mardi Gras atmosphere at the Royal Park Hotel on February 28th. The entertainment captured their attention while spectacular Mardi Gras themed food impressed the guests’ taste buds. With talents ranging from an authentic style Dixieland band, fire eating, stilt walking, baton twirling, and much, much more. The program included a King’s Court parade and the crowning of this year’s Mardi Gras King, Mr. Bob A. Patzer, Executive Vice President of Michigan Infrastructure & Transportation Association (MITA). Mr. Patzer was honored for his commitment to the community. The evening ended with guests dancing to the sounds of the Simone Vitale Band.

Not only was this event a successful fundraiser, but it also provided an opportunity to educate a captivated audience about epilepsy and the Foundation’s mission.

8th Annual Legislative Recognition Breakfast

MAY 2
ANDERSON HOUSE OFFICE BUILDING (MACKINAC ROOM), LANSING, MICHIGAN

A free breakfast to bring patients together with their State Representative and Senator.

After the event, attendees will have an opportunity to visit the offices of the Legislators who did not attend.

Preparation for the Event

1. RSVP your attendance to this free event. Contact Pam Bird at (800) 377-6226 ext. 204 or email pbird@epilepsymichigan.org.

2. Review the EFM Public Policy Agenda.

3. Call, write, or email your Michigan State Representative and Senator and invite them to join you at the breakfast. To find your legislators visit http://house.michigan.gov/ (Michigan House) and ttp://senate.michigan.gov (Michigan Senate).

Event Follow-up

1. Send a thank you to your representative or senator who attended this event. Let him/her know how important this was to you.

2005 EPILEPSY FOUNDATION CONFERENCES

The Midwest Regional Conference was extremely well-received by 124 attendees, including attendees from Ohio, Illinois and Wisconsin. The Epilepsy Foundation of Michigan was proud to host this regional event in the Detroit area. There were an additional 89 attendees at the Port Huron Conference, and 65 attendees at the Grand Rapids Conference. Each conference location offered an unprecedented number of breakout sessions, expert speakers, and new topics. See this year’s conference dates on page 8 under Calendar of Events.
Getting My Son Back

My name is Laura Holling and I am the parent of an amazing, loving, athletic and kind 11 year-old boy, who happens to have epilepsy. My son, Trevor, has generalized epilepsy and his seizures consist of tonic-clonic (grand-mal) and absence (petit-mal) seizures.

When Trevor was an infant he had febrile seizures. At the age of five, he fell to the floor in the kitchen having a grand mal seizure, turned blue and was rushed to the hospital. This was when he was officially diagnosed with epilepsy.

I was so scared and nervous and felt completely helpless. I just knew that this was something I could not fix. I didn’t know what to do or where to turn. I put all my faith and trust into the staff neurologist at the hospital where they rushed my son to.

We went through a handful of neurologists and my son was put on too many of the wrong medications – some of which had horrible side effects. Some medications were for completely different types of seizures - ones he never had. His seizures, at times, became much more frequent and lasted much longer.

My son now has a slowing in his brain – as a result, he has many learning disabilities. For many years he has never felt like a “normal” child. His weight fluctuated, his hands shook so badly he could barely write, some medications even made him angry and some made him depressed. I now know that we had to experiment with some medications to see what would work best for Trevor.

I finally found a pediatric neurologist that I love. My son’s current neurologist and his colleague have both treated me and my son with respect, have listened to my concerns and have helped us tremendously. My son went through numerous tests to determine the exact type of epilepsy he has and is now on medications that work great with his seizure types – and with minimal side effects.

This is about the same time I became familiar with the Epilepsy Foundation of Michigan.

I learned so much by just going to their website. They have a wonderful library online that explains so much about epilepsy. The information that I have obtained off of the website is unbelievable! They explain about the research that is going on and the clinical trials. There is an advocacy section where you can learn what lawmakers are helping our cause and who isn’t – who we need to reach. There is a section that explains my son’s legal rights.

There is even a section called e-communities that is a wonderful resource for me. It is a chance for me to interact with other parents of children with epilepsy and people who have epilepsy and get some advice. Being a single parent has made this an even more difficult journey and this has been a wonderful resource for me.

Last summer, Trevor went to Camp Discovery, a camp for children with epilepsy. It is a wonderful five day adventure where the children are able to build their self-esteem, challenge themselves, make lifelong friendships and just have a lot of fun! Keep in mind that he has never been to camp before because of his epilepsy. Trevor had so much fun and felt like a “normal” kid for the first time in a VERY long time. When I arrived to pick him up at the end of camp, he didn’t even get all the way out of his cabin when he turned to me and told me that he was coming back next year!

Wow! This was amazing! I can honestly tell you that for the first time in many, many years, I feel like I have my son back.
Scientists Develop Microchip Used to Detect Seizures to Cool Brain Cells Involved

By Adam Modzelesky, EpilepsyUSA staff

Researchers at Washington University in St. Louis recently developed a microchip that can detect an oncoming seizure and prevent it from happening by cooling the brain cells involved.

Led by Steven Rothman, M.D., Ph.D., the group of scientists aimed to develop a system that would chill the cells without the subject with epilepsy knowing what has occurred. The study cooled brain cells from body temperature (about 37 degrees Celsius) to around 22 degrees Celsius. They found that this stopped the pending seizures from spreading with no apparent harm to the cells. The study’s results were recently published in the medical journal New Scientist.

The microchip, which is implanted in the subject with epilepsy's skull, has only been tested in rats and is a long way from being tested in humans. Researchers hope this will one day be a new solution for those with epilepsy for whom medication and surgery has not worked. The scientists are currently working to confirm their findings and to seek technical solutions to building an implantable cooling device.

UPCOMING WORKSHOPS AND PRESENTATIONS

LOCATION: UNIVERSITY OF MICHIGAN
DEPT. OF NEUROLOGY,
1500 E. MEDICAL CENTER DRIVE ROOM 1912,
1ST FLOOR, TAUBMAN CENTER, ANN ARBOR, MI

MARCH 28, 2006
TIME: 7:00 - 8:30 PM
Topic: “Epilepsy 101”
Speaker: RUSSELL DERRY, MPH,
Epilepsy Foundation of Michigan

APRIL 25, 2006
TIME: 7:00 - 8:30 PM
Topic: “Epilepsy and the Senior Years”
Speaker: CINDY HANDFORD, RN,
Epilepsy Foundation of Michigan

MAY 23, 2006
TIME: 7:00 - 8:30 PM
Topic: “Epilepsy and Depression”
Speaker: RUSSELL DERRY, MPH,
Epilepsy Foundation of Michigan

NOVEMBER 28, 2006
TIME: 7:00 - 8:30 PM
Topic: “Family Issues for Caretakers”
Speaker: SUSAN LITTLE, LMSW, ACSW,
University of Michigan,
Dept. of Social Work,
Clinical Social Worker Medical,
Adult Neurology

For more information, contact:
Sheryll Marshall, 734-936-4549
CALENDAR OF EVENTS

8TH ANNUAL LEGISLATIVE RECOGNITION BREAKFAST
May 2nd
To attend, call 1-800-377-6226 ext. 1-204

2006 SUMMER STROLL FOR EPILEPSY™
June 3, 2006
Millennium Park, Grand Rapids

June 10, 2006
Detroit Zoo, Royal Oak

June 17, 2006
Spring Valley Park, Kalamazoo

June 24, 2006
Bayfront Park, Petoskey

WEST MICHIGAN FLAME OF HOPE AWARDS RECEPTION
September 26th

SOUTHEASTERN MICHIGAN FLAME OF HOPE AWARDS RECEPTION
October 3rd

EPILEPSY TODAY CONSUMER CONFERENCES
October 20th - Grand Rapids
November 3rd - Detroit
November 16th - Port Huron

PICTURES OF HOPE
The Pictures of Hope is an opportunity for the Foundation to introduce our mission to business and community leaders. Those who attend learn about epilepsy, the Foundation’s history and our goals for bringing epilepsy awareness to the public.

April 11, 2006
May 18, 2006
(Time: 8:00 a.m. – 9:00 a.m.)
20300 Civic Center Dr., Ste. 250
Southfield, MI 48076
To attend, call 1-800-377-6226 ext. 1-217

CAMP DISCOVERY
(for grades 3 – 10)
August 20th – 24th
For more information, please call 1-800-377-6226 ext. 1-211

The Epilepsy Foundation of Michigan Welcomes New Staff Member in Grand Rapids

Mia Cooke has been hired as a Health Educator serving West Michigan. She is an MSW candidate with a family connection to epilepsy. We feel fortunate that Mia’s skills and passion will greatly enhance our Mission.

EPILEPSY FOUNDATION MICHIGAN
20300 Civic Center Dr., Suite 250
Southfield, MI 48076