

## Magic benefit in Claremore brings in 4,000 for research

An evening of magic in Claremore, Okla. had a magical ending for the NBIA Disorders Association in April. A fundraiser sponsored by Scott and Rhonda Mayfield raised more than \$4,000 for NBIA's research fund.

Magician Michael Platten entertained young and old with his tricks while many children eagerly took part in the magic show as they were called on stage. A silent auction also was held, featuring 18 baskets of donated items from businesses, individuals and others in the community. Competition was keen for baskets donated by football rivals Oklahoma State University and the University of Oklahoma. A University of Oklahoma fan ended up ensuring that his school won by making the highest bid for a basket.

Two newspapers did feature stories. The Mayfields' church youth group helped in setting up the hall for the benefit, and the Sunday school class helped with the clean up. Family and friends helped to decorate with balloons and pictures. The United Methodist Women's groups helped cook and serve the food. So many others helped and had fun that the Mayfields said one thing is certain: they'll do it again.

*Please see pg. 5 for a listing of the sponsors and donors for this event.*



*Magician Michael Platten performs magic trick with the help of audience participant at fundraising dinner in Claremore, Okla.*

## Family turns to new drug, oil, organic foods in quest to help their ill daughter

*By Rhonda Mayfield*

In the four years that our daughter, Kelsey, first started showing symptoms of NBIA, our family's struggle to understand the disease and help Kelsey has been like trying to put a giant puzzle together with many of the pieces missing. We've struggled to figure out why Kelsey is affected by certain foods, why her weight plummets and why she has so many painful muscle spasms.



*Mayfield family  
Rhonda, Kelsey, 8, Kenneth 11, Scott  
and Kaylinn, 14.*

Trying to fit these pieces of the puzzle together has led us to some novel therapies, including working with a metabolic doctor, Dr. John Coldwell, giving Kelsey a special oil, and putting her on an experimental drug that I am convinced has saved her life. We turned to these treatments after trying all of the usual methods that many of you have also tried: warm water physical therapy and an assortment of drugs, including Artane, Carbitrol, and Baclofen.

What led us to these new treatments were several ongoing problems: Kelsey's recurring pneumonia, her muscle spasms and weight loss. On July 3, 2001, Kelsey had a feeding tube inserted. It

*(see Kelsey on pg. 3)*

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### Disclaimer

The views expressed in the NBIA Disorders Association newsletter do not necessarily represent the views of the Board of Trustees or the Medical Advisory Board. Check with your doctor before trying anything new.

## OHSU investigators to examine PKAN in families this summer

By Allison Gregory



Allison Gregory

Our quest to learn more about Pantothenate Kinase-Associated Neurodegeneration, or PKAN, got a boost in June when we enrolled the first participant in a clinical study at the Oregon Health & Science University. PKAN is a disorder that is related to NBIA, and we will be studying more families with PKAN throughout the summer.

Each person who takes part in the study will undergo two procedures: a flash electroretinogram, which we hope will teach us more about the retinal problems observed in some individuals with PKAN, and magnetic resonance spectroscopy, which we expect to enhance our understanding of the chemical changes that occur in the brains of affected people.

Here are more details about both tests:

### Electroretinogram (ERG)

The electroretinogram, or ERG, was first developed in 1865 by a researcher working with frogs. The test records the eye's electrical responses following visual stimulation. For our patients, the stimulation involves brief flashes of light of various colors and speeds.

When the light enters the eye, it triggers an electrical response from the photoreceptor cells of the retina and the other cells that process the signal. The signal is sent along the optic nerve to the portion of the brain that puts the picture together for the person, all within thousandths of a second.

The cells of the retina include two types of photoreceptors called rods and cones. Cones provide central reading vision and color vision and are more densely packed in the middle area of the retina. Rods provide night vision and detect motion. They are also more responsible for peripheral vision. By varying the flashes of light used to stimulate the retinal cells, it is possible through this ERG test to selectively stimulate some cells more than others, such as rods more than cones. In this way, the function of a certain type of cell can be analyzed.

Because some individuals with PKAN have progressive loss of peripheral vision and retinopathy, or disease of the retina, it is helpful to assess different cells of the retina with ERG. In classical PKAN, ERG has shown characteristic changes that reflect rod photoreceptor degeneration specifically. These types of changes

(see OHSU on pg.4)

## Kelsey

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seemed that when she ate foods high in vitamin C, her muscle spasms and rigidity would worsen. A pharmacist explained that vitamin C aids our bodies in using iron and that perhaps it was causing Kelsey to store iron at a faster rate in her brain, aggravating her symptoms.

To make her more comfortable, we were giving her Valium rectally several times per day. It was an awful experience, and Kelsey's weight was continuing to drop. In August 2001 a lady called me from Oklahoma City. She had seen a picture of me and my husband, Scott, on the NBIA Web site after the first family conference. She told me she had two children with the disease. Her daughter was in heaven and her son was 33 with the classic form of NBIA.

This woman had taken her son to Baylor University Movement Disorders and Parkinson Center in Houston to see the leading expert on movement disorders — Dr. Joseph Jancovic. She considered the trip her last hope; her son was dying. Dr. Jancovic prescribed an experimental European anti-psychotic drug, and her son began getting relief from his severe rigidity and spasms. He also began gaining weight for the first time in years.

After we hung up, I immediately called Scott. My next call was to Dr. Jancovic's office: 713-798-5998. By the end of the day we had an appointment, flight arrangements and a hotel room. We took Kelsey to Houston in August 2001. Dr. Jancovic told us that he had numerous patients with NBIA who have benefited from using the drug Tetrabenazine. Within two weeks, Kelsey was doing much better on the TBZ.

We were able to greatly reduce the Valium. Kelsey can now go days without any Valium and can sometimes go longer than a week without Valium. Scott and I have no doubt that Tetrabenazine saved Kelsey's life. Today, Kelsey takes 1/2 tablet every 4 hours around the clock (10-2-6-10-2-6). When a dose is late she begins to have rigidity and spasms, which let us know we have gotten off schedule.

Tetrabenazine is now the only medication Kelsey takes regularly. We buy the TBZ from Dr. Jancovic for \$170 per bottle of 112 tablets of 25mg each. The bottle lasts Kelsey five weeks. Our insurance will not cover this drug because it is classified as experimental.

Sadly, Kelsey's weight has continued to decline, despite the TBZ. It fell from 34 pounds to 22 pounds. In March 2002 Kelsey was in the hospital again for pneumonia. We just about lost her. We found that when we gave her any kind of formula she would require Valium. I began to give her only organic food that was put in a blender and

liquefied. We saw improvements and some setbacks. Again, I was puzzled with the foods that were causing the increase in spasms and rigidity.

I took a class on nutrition at the university to try and understand why different foods were affecting her so strongly. During this time we sought out the guidance of a natural doctor, Dr. Jack Wise, who entered Kelsey's blood test results into his computer. She had six items out of the normal range. We received a printout that showed us what supplements were needed to get her blood back in balance. After starting those supplements, Kelsey began gaining strength and being able to eat by her mouth.

Today, Kelsey eats by her mouth to satisfy her taste sensation. She also gets fed five times a day by tummy tube. Dr. Wise sent us to an internal medicine doctor, Dr. James Block in Kansas, in November of 2002. Dr. Block gave us the solution to Kelsey's weight loss problem. Dr. Block said that the NBIA appears to be a mitochondria disease. He sent me information from [www.umdf.org](http://www.umdf.org) (United Mitochondria Disease Foundation) which explained that people with mitochondria diseases can not break down even the smallest oil (triglyceride) in nature. Mead-Johnson offers an oil called MCT oil that is broken down smaller than nature. UMDF also suggested supplements that may help. Kelsey began gaining weight after starting on the MCT oil. She did not get pneumonia this past March 2003.

Our favorite piece of equipment is the pulse/oxygen monitor that we attach to Kelsey's toe at night. An alarm sounds with fluctuations in Kelsey's pulse rate or her oxygen level. We sleep much better knowing that if Kelsey needs our help we are alerted.

For the last two months, Kelsey has been getting a full body massage at least two times a week. I was shocked when the massage therapist was able to totally relax Kelsey with her lying on her stomach. Kelsey has not been able to lie on her stomach since November 1999 because of the muscle spasms.

Kelsey is now 8 and weighs just under 27 pounds. She is looking better than she has in years. She has regained some movement in her hands, legs, and neck. I feel that she has gotten better as a result of TBZ, MCT oil, massage therapy, an organic diet and supplements.

An article on page 138 of *Pediatric Neurology* magazine, (August, 2001, from the First Scientific Workshop on HSS) discusses which supplements makes NBIA symptoms worse and which supplements (mostly antioxidants) control symptoms by reducing oxidation. A biochemist is helping me to decipher the article.

We are still putting the NBIA puzzle together, but at least, we feel we are finding some of the missing pieces.

*Kelsey is now 8 and weighs just under 27 pounds. She is looking better than she has in years. She has regained some movement in her hands, legs, and neck.*

## OHSU

(continued from pg. 2)

may be found by ERG before any vision loss is detected in affected individuals. It's important to establish typical ERG results, or "norms," so that when doctors have new therapies to try, they will be able to determine the effects of these interventions.

The test is done by wearing contact lenses with small wires that conduct the signals to a computer. The responses are recorded and compared with those from control subjects. Before starting, the pupils are dilated and topical anesthetic drops are given to make wearing the contacts more comfortable. The test does not hurt, but it does require that individuals hold still and look straight ahead. This has been one of our challenges for the study, since dystonia can make it so difficult for individuals to hold still for long periods of time.

### Magnetic Resonance Spectroscopy (MRS)

Magnetic resonance spectroscopy, or MRS, combines the more familiar MRI evaluation with spectroscopy, which plots the chemical components of cells in particular areas of the brain. It essentially allows physicians to obtain a "virtual biopsy," meaning they can look at chemical levels in the brain without doing an invasive procedure.

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*Charting what is happening with these various chemicals in NBIA individuals will help us in the future to know whether interventions have affected them in significant ways.*

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Certain chemicals have been identified as markers for various brain changes. N-acetylaspartate (NAA) levels decrease when the axons of nerves have been damaged. Choline levels rise when there has been breakdown of the brain's support structures. Choline is released from cell membranes, fats, and myelin, the lining around the nerves that serves as insulation. Changes in creatine and lactate can reflect alterations in brain energy metabolism, and lactate also increases when brain cells have been deprived of blood flow. Charting what is happening with these various chemicals in NBIA individuals will help us in the future to know whether interventions have affected them in significant ways.

The applications of this technology are growing rapidly. For example, recent research conducted at Loma Linda Medical Center in California suggests that MRS may be a very accurate tool for predicting outcome after traumatic brain injury. In the Loma Linda study, an MRS performed only seven days after a brain injury could help predict how a patient would be functioning six months later. Measurement of NAA levels in persons diagnosed with multiple sclerosis has also been found to help predict

prognosis, and some patients with Alzheimer's disease and Parkinson's disease are now having their treatments determined, in part, based on MRS results.

Since MRS has not been used in the small population of persons diagnosed with PKAN, we hope it will shed some light on the biochemical changes occurring in the brains of affected individuals. Although we know there is atypical iron accumulation in the brain, it is not clear why this happens or how it is related to the neurodegeneration observed in people with PKAN. Looking at additional markers to assess damage of brain structures and brain energy metabolism may help us to better understand the disease and, we hope, give us some leads regarding potential treatments.

## Physician Referral Network data collection underway

If you have not yet done so, please send in your information on the physicians who are caring for NBIA individuals. We would like to begin putting this information on the Web site so doctors can network with each other, and perhaps be a referral for newly diagnosed patients.

If you no longer have the form, but wish to participate, please e-mail [info@NBIAdisorders.org](mailto:info@NBIAdisorders.org) and it will be sent to you.

## Family helps raise money for research selling candy

The Stromsta family of Shorewood, Ill., has raised \$560 for the NBIA research fund by selling Fanny Mae candy bars.

Pam Stromsta said the sales were quick and easy because the candy bars are popular. The big favorite? The chocolate bar with caramel. They sell for \$1 each and half of the profits go toward the research fund.

The Stromsta children took the bars to school where they sold well and they had them available at their home when friends came over. A family friend also sold them at her restaurant, with a flyer about NBIA placed next to them.

The Fannie Mae Candy Co. requires a minimum order of four cases with 144 bars to a case, with free shipping. The Stromstas paid by credit card and after selling the candy and repaying the cost of the candy, sent a check to our organization for the profits. Other families wishing to help with this quick and easy fundraiser can reach Fannie Mae at (312) 243-2700 to place orders.

## Family Fun Day fundraiser to be held in New York

A Family Fun Day, modeled after the successful ones held the past two years by the McGourthy family in Massachusetts, will be held in upstate New York on Oct. 4 to raise money for the NBIA Disorders Association Research Fund.

The event is being organized by Anabela Ferreira-Barbiero, the mother of two daughters with NBIA, Sabrina, 8 and Alyssa, 7, and Cheryl Lamos, who has four adult children, three with NBIA. They are Rebekah, 26, Bruce, 24, and Barbara, 23. It will be held at River Road Park in Niskayuna, near Albany, and will feature a 5k trail run/walk along with a fun 1 mile run/walk for children, parents with strollers and the physically challenged. Other activities include face painting, raffles, games, clowning, barbecue, cotton candy, popcorn and more.

An army of friends is helping Anabela and Cheryl with the fundraiser, including Marisa Barnes, Linda Cross, Chris Feeney, Liz Kasper, Holly Lape, Jacquelyn Lape, Megan McKeighan, Patrice Mcmorrow, Renee Michalisin, Colleen Rubeor, Barbara Sauter and Carol Venezia.

All are welcome to attend. For more information, contact Anabela at (518) 381-4774 or by e-mail at fbela@hotmail.com.

*Please contact [info@NBIADisorders](mailto:info@NBIADisorders) if you are interested in having a fundraiser. We have handouts and information on fundraising and will be happy to assist you with your planning.*

**NBIA Disorders Association** would like to thank the Glen Wright Donor Advised Fund of the Greater Cincinnati Foundation which awarded a \$1,500 grant to our organization in May.

Your support is greatly appreciated.



*Guests at the Magic Benefit in Claremore enjoyed dinner, a silent auction and magic show.*

## Magic Benefit

NBIA Disorders Association is extremely grateful to the individuals and businesses who helped make this fundraiser a success.

## Sponsors & Supporters

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## Kids' Day America fundraiser to benefit NBIA research fund

**A**nother fundraiser for the NBIA Disorders Association Research Fund will be held in Tulsa with help from a local chiropractic business, Brooks Spinal Care.

Kids' Day America will be held Sept. 13 at the Holiday Inn Select at I-44 and Yale Ave. and will feature health screenings, disease prevention, nutrition awareness, sports safety, fire prevention and environmental awareness. Health screenings will include examinations for such conditions as spinal misalignment, scoliosis and dental problems.

It won't all be serious, however. The day will include clowns, face painting, balloons, cartoon characters, entertainment by local childrens' choirs, karate and dance groups. Door prizes also will be awarded.

All proceeds will benefit the NBIA Disorders Association Research Fund. Brooks Spinal Care is the host and is asking local businesses to contribute so that the event is free to all comers.

One of our NBIA families, the Mayfields, are clients of Dr. Robert Brooks, the host and a member of the National Upper Cervical Chiropractic Association. This is a little known chiropractic technique that relieves distress from the central nervous system by correcting the entire spine at the level of the first vertebra, the atlas. For more information about Dr. Brooks and the fundraiser, see the Web site at [www.brooksspinalcare.com](http://www.brooksspinalcare.com).



*Brooks Spinal Care Group*

*left to right: Lesley Louvar, Sandra Lowry, Alvin L. Rozier, D.C., Sharon Brown, Robert Brooks, D.C., Christine Saferight, Scott Hanson, D.C.*

*You can honor the memory of a loved one or a friend through a gift to NBIA Disorders Association. The thoughtful people listed below have made a donation on behalf of their friends and loved ones during the last few months.*

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Archie & Bettie Smith  
Bernadette Easton

Tara Leigh White  
The Beach Hut

## MESSAGE FROM THE PRESIDENT

# Don't be afraid to question prognoses by physicians



*Patty Wood*

I have found that there are times when this disease called NBIA confounds the most experienced doctors. And I know I'm not the only parent who has been shaken by a mistaken medical judgment.

I have received numerous e-mails and phone calls over the past six years after parents have been told by medical professionals that their child is near death and that they should prepare for the worst.

My family was told that Kimberly had less than six months to live when she was 3.5 years old. We went into hospice and stayed for two years before it sank in that, while she had some very rough times, she was very resilient. She weathered that storm, went on to stabilize and has enjoyed some very good years. We just celebrated her 17th birthday in June! The disease moves on. We struggle, off and on, with a variety of issues, but I have a very different outlook than the one doctors prepared me for years ago.

I tell this story to encourage other parents who are going through the storm right now to hang on. Don't lose hope. And most of all, make sure doctors don't make rash decisions that could have dire consequences.

Just recently, the Wylie family in Tennessee was told their son, Jacob, who is 9, would not make it through the night. Jacob was in the hospital, and one doctor took it upon himself to turn off Jacob's baclofen pump -- an act that caused him and his parents a night of intense suffering. It could have ended Jacob's life. Fortunately, another doctor turned the pump back on in the morning. Jacob is now recovering at home.

I am not arguing that we should seek to prolong the life of someone who is truly dying. But I am imploring parents to ask questions and make sure they are fully and accurately informed before major decisions are made. I also want parents to know that many NBIA children have gone through very difficult times -- and survived.

It seems to me that after about two to four years of intense, touch-and-go episodes, many children stabilize for five to ten years and do not have life-threatening problems during this time. My own daughter was able to participate in family activities again, go back to school and be mainstreamed. We've had some very happy memories to cherish.

I pray for all NBIA families, that they will experience cherished memories to counter all those difficult times that go with this disease. God bless each of you.

*NBIA Disorders Association is grateful to its supporters for their generosity. We extend our deepest thanks to the contributors listed below who have donated in the past few months.*

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## Listserv coming soon

As a benefit to those interested in NBIA disorders, we are setting up a listserv that will connect those with Internet access to a large group who shares many of the same issues concerning NBIA. Listservs consist of multiple addresses so a person has to send only one e-mail to communicate with all of the people in the group at once.

The listserv is open to all. Once you join, every e-mail sent to the listserv will automatically go out to everyone on the list. It comes right into your e-mail so you don't have to go somewhere else and check for postings. You may respond to messages or learn by reading them.

We believe this will be very helpful to families who want to share information, ask questions or exchange news about therapies they've heard about or tried. It's also a way for families or affected individuals to give and receive emotional support. Because we are so spread out geographically, this is an opportunity for families to network in a very important way.

Please be sure to send in your current e-mail address to [info@NBIAdisorders.org](mailto:info@NBIAdisorders.org) if we do not have it. We will be in touch with startup dates and other news about the listserv. We will also post information on the Web site once it is in operation.



2082 Monaco Ct.  
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Syndrome  
Association



Our Mission:

**NBIA** Disorders Association is a non-profit organization dedicated to providing emotional support to families affected by NBIA, educating the public about this disease, and monitoring and supporting research and informing others of its progress.

NBIA Disorders Association

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Visit our Web site at

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