

Visit to Capitol Hill lays foundation for help that could be vital to future

By Sandy Leap

For my husband's birthday July 16, Rich and I brought our daughter, Brittany Leap, to Capitol Hill to raise awareness about NBIA as part of an event called Genetics Day on the Hill. We had never been inside the halls of Congress and it was a bit intimidating. Just wheeling Brittany from one maze-like building to the next was a challenge. Thankfully, the Genetic Alliance (GA), which sponsored the event, made sure each group had at least one person who knew their way around.

Here's how the day was set up: The GA prepared a folder with instructions and a summary about the people we were going to meet. We met Carrie Haas, legislative correspondent for Sen. Jim Bunning of Kentucky; James Walkinshaw, chief of staff for Rep. Gerald Connolly of Virginia; and Aryana Khalid, legislative assistant for Sen. Mark Warner, also of Virginia.



Many different lay advocacy groups were represented at the Genetics Day on the Hill in Washington on July 16. Sandy and Brittany Leap are on the far right in the front row and Rich Leap is in the back row, representing NBIA Disorders Association.

(see *Capitol Hill* on pg. 3)

Good news: Efforts paying off in NBIA Hayflick Lab Campaign

By Patricia Wood

I am pleased to report that the outpouring of support for our Hayflick Lab Campaign has been wonderful and we have been making steady progress. Many of our NBIA families have risen to the challenge to raise money to help Dr. Susan Hayflick keep her lab open at the Oregon Health & Science University and have been very busy holding events in their communities this summer and fall.

You may recall in the previous newsletter we brought you the news that Hayflick said she feared she would have to close her lab because of a loss in federal grants that she had routinely received. She said she needed \$250,000 over the next two years to stay open.

I am inspired by the response we received to our call for action and so grateful that many families who have never done fundraisers stepped up and made a big impact. Several of these fundraisers are featured in this newsletter. (see *update* on pg. 4)

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What is NBIA?

Neurodegeneration with Brain Iron Accumulation (NBIA) is a rare, inherited, neurological disorder.

The common feature among all individuals with NBIA is iron accumulation in the brain, along with the progressive movement disorder. Patients can plateau for long periods of time and then rapidly deteriorate. The most common symptom is involuntary muscle cramping, called dystonia.

Symptoms vary greatly from one person to the next, partly because the gene affecting them can differ. Different mutations within a gene also can cause a more or less severe form of the disease.

The movement disorders can result in clumsiness, difficulty controlling the body and speech problems. Also common is a degeneration of the retina, which causes night blindness and a loss of peripheral vision.

Some individuals eventually lose the ability to walk, talk or chew food and become totally dependent on others for all their needs.

Our sister non-profits in Germany and Italy who work with us in the promotion of research and treatment of NBIA, can be contacted at the following addresses:

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Capitol Hill

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The GA advised us to choose three topics from a list to focus on during our meetings: health care reform, genetic testing, public access, date of service rule, electronic health records, comparative effectiveness research and funding. The GA also encouraged us to share personal examples that applied to the topics we choose. We went in there ready to follow the rules and not make it all about Brittany and NBIA.

But as we spoke with the staffers, they became very interested in our story. It was not because of Rich or me, it was because of Brittany. We can talk about NBIA all day, but having someone see a person affected with the disorder tells a better story. Walkinshaw was so moved by Brittany that he took our message directly to Congressman Connolly. The congressman was equally inspired. On July 30, he spoke on the House floor about Brittany's challenges and the need to raise funds to keep research alive.

The day did not end with those meetings. Lynne Boyle, director of federal relations for Oregon Health & Science University was so helpful and set up meetings with aides to Sens. Ron Wyden and Jeff Merkley, both of Oregon. They understood the urgency and the impact that closing Dr. Susan Hayflick's lab at OHSU would have on their community.



Sandy, Rich & Brittany Leap with Dr. Susan Hayflick visiting Congressional offices and NIH representatives in September.

On July 20, both senators wrote a letter to the ranking members of the Appropriations Committee in support of increasing funding from the National Institutes of Health for rare disorders including NBIA.

On July 27, a letter was sent to all senators who had NBIA families in their districts, laying out our concerns regarding rare disease research funding. The association received a response from Senator Barbara Boxer addressing our concerns, and several of the families heard directly from their representatives.

On Sept. 7, Dr. Hayflick was interviewed on WUSA, the local CBS station in Haymarket, Virginia about the funding challenges she and other researchers are facing. A great big thank you to Asha Bruot of ASHA Public Relations, LLC in Haymarket for setting up the interview.

We also met with legislative aides to four members of Congress and staff from the NIH's Office of Rare Diseases, including director Steve Groft, David Eckstein, senior health administrator; and others.

I believe the meetings were very productive. The NIH staff understood the financial strain and provided several suggestions about what we can do as an association and how Hayflick can partner with them to raise awareness about the funding challenges for investigators of rare disorders. Suggestions included:

- * Planning a scientific conference to raise awareness about the funding issue placing emphasis on NBIA. NIH provided contact names for Hayflick to use.
- * Seek more specific language for next year's budget process to help increase NBIA research funding.
- * Get NORD and Genetic Alliance to encourage the NIH to ensure the current peer review "significance" criteria better recognizes rare disease research.
- * Researchers should consider meeting with the NIH department heads when applying for grants from their divisions.

We were able to get the following "report language" accompanying the Senate appropriation bill that funds the NIH: Neurodegeneration With Brain Iron Accumulation [NBIA] - The Committee urges the ORD to put a higher priority on research involving NBIA, a disease for which there is no treatment or cure.

In general, report language provides important Congressional guidance to federal agencies. While non-binding, such language is an important communication and executive branch agencies take them seriously because they must justify their budget requests annually to the Appropriations Committees. The NIH funding bill still has to be passed by the Senate and be resolved with the House before being signed into law.

So what does all this mean? I wish I could say that NIH is going to write us a check, but it is not that easy. But the groundwork is being laid in raising awareness at the government level. I would like to thank Lynne Boyle of OHSU on behalf of NBIA Disorders Association for her time, consideration, compassion and kindness. Because of her this whole process has been less intimidating than we initially thought it would be.

We still have a long way to go and still need to continue helping the Hayflick lab. Next year we all will have to write letters to Congress and visit staff to build on what has been started. We cannot stop now.

Hope's Hope and NBIA Disorders Association announce partnership to better serve others

Hope's Hope and the NBIA Disorders Association announced at the 2009 Family Conference that they are teaming up as partners to better serve the medical and research communities, as well as NBIA families.

Hope's Hope is a non-profit organization based in Raleigh, N.C., whose mission is to ease the financial and emotional burdens of families affected by NBIA. Initially founded for families with Infantile Neuroaxonal Dystrophy (INAD), Hope's Hope recently revised its mission to include all NBIA Disorders.

"We are thrilled to come alongside NBIA Disorders Association in an effort to streamline and optimize our efficiency and outreach," says Hope's Hope president Cheri McDonald. "It is an exciting new chapter for both organizations."

Families are also looking forward to the endeavor. "I am very thankful for the family connections I have received through Hope's Hope," says Rachele Chrismer of Apple Valley, Minn.

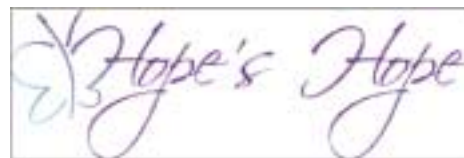
Her son, Zach, 9, has INAD. "Knowing that you are not alone and you have other families that 'get it' helps make the nastiness of this disease a tad bit better," Chrismer said. "I am excited to be able to meet other families through this partnership!"

Kristi Ose of Louisville, Ky., agrees. "I came upon the Hope's Hope Web site on a day I was feeling distraught, confused and all alone regarding Jared's disease." Her son Jared is 8 and also has INAD. "Through Hope's Hope, I was able to find a family who could relate to what I was feeling, and I have continued to make some incredible, lasting friendships. The partnership with NBIA will benefit families greatly."

Hope's Hope and NBIA Disorders Association plan to work together to assist families by advocating a strong network of support, including the creation of an extensive online resource library, development of a welcome packet for new families and connecting new families with veteran families who can share experiences, guidance and encouragement.

Hope's Hope plans to contribute regularly to the NBIA newsletter, with a focus on highlighting NBIA family connections. The two organizations also will collaborate in planning the 2011 family conference.

Both organizations will continue to provide financial support in



accordance with each of their missions. While NBIA Disorders Association will continue to focus

its financial efforts on funding research, Hope's Hope will provide financial support to qualifying NBIA families through its grant program. While the details of this have not yet been finalized, the Hope's Hope board recently met to discuss an NBIA-wide grant program and hope to have it ready in January.

For more information, visit the Hope's Hope Web site at www.hopes-hope.org, or contact Cheri McDonald at cheri.mcdonald@hopes-hope.org. She is available by phone at (919) 819-2736.

Update

(continued from page 1)

As we go to print, the fundraising thermometer on our Web site home page stands at \$76,480, but that doesn't tell the whole story. We have also raised another \$22,000 at various events in October, but that money is not yet in hand or deposited. We have a few more fundraisers scheduled in November, and we are continually looking for new ways to bring in more. We expect to hit at least \$100,000 before the end of the year and hope to go way over.

In addition, Oregon Health & Science University has awarded the Hayflick lab \$50,000 in bridge funding as a show of faith it will continue its research. Hayflick has committed to keeping her lab open as long as funds are available, so we have at least one year funded at this time.

Not only have our families been busy raising funds, but they have made their voices heard on Capitol Hill. A letter writing campaign to senators in states where NBIA families reside, and visits by Hayflick and the Leap family with staff in Washington have made a difference. Our work has paid off with several congressional offices championing our cause, and we are hopeful that the final Appropriations bill will have language regarding NBIA research funding. (see Sandy Leap's article on pg. 1 for more information.)

We still believe a miracle is possible and that we will find a way to raise the rest of the money. Best of all, this campaign has taught all of us what we can do if we work together. It has showed us that even small efforts can come together to create a big effect.

If you would like to be part of our miracle, please consider sending in a donation in the envelope provided with your newsletter before the end of the year. Mark it for the "Hayflick Lab Campaign" to be sure it gets credited accordingly. We truly appreciate your support.

Mom in France raising money for Hayflick Lab Campaign

Valerie Bensch of Alsace, France, is an energetic mother of three boys. Six months ago her 10-year-old son, Romain, was diagnosed with PKAN, a form of NBIA.

Bensch didn't know anyone else in France who had NBIA so she searched the Internet in earnest. When she found the NBIA Disorders site, she learned about the Hayflick Lab Campaign, an urgent effort to raise \$250,000 by the end of the year to keep open the laboratory of Dr. Susan Hayflick after it lost essential federal support.

Bensch decided there was something she could do from France to help Hayflick at the Oregon Health & Science University. The next week she began an information campaign at her work where she is a buyer for a factory that employs 1,500 people and manufactures kitchens.



Valerie Bensch and her son, Romain Lerognon, from Alsace, France raise funds for the Hayflick Lab Campaign.

Bensch met with the factory owner and won her full support. She translated into French the original "Hayflick" letter the NBIA Disorders Association board sent out, and wrote a more personal appeal telling her co-workers about Romain and her family.

Four coworkers have been very helpful in distributing information and collecting funds. They are Sylvie, Colette, Gaby and Peggy. Their efforts appear

to be paying off. NBIA has had several large PayPal donations from France and received a wire transfer of \$7,022 at the end of October for the factory campaign.

As for the family, Romain returned to school after a two-month summer holiday in September. He still attends a "classical" school and has an aide, Virginie, whom he loves very much.

In October Valerie and Romain are going to Paris to see a new doctor. Romain says he is much more excited about seeing the Eiffel tower for the first time. Can anyone blame him?

'Miracles' video ready to e-mail or show at NBIA fundraisers

Some of you may know the NBIA Disorders Association stars in a music video. You may have seen it on the home page of our Web site - it is titled "We Believe in Miracles."



Bill Hartwell & Luann Rein singing Miracles video.



Alexander Rennie teams up with Luann Rein to produce visual portion of Miracles video.

The idea was inspired by the Fifth International NBIA Family Conference in Indianapolis in May, which had as its theme, "We Believe in Miracles." It came about when the association's Executive Director, Luann Rein and musical friend Bill Hartwell got together and changed up the old tune, "I Believe in Miracles." Together they wrote NBIA appropriate words and harmonized, creating the new miracles song. That became the musical portion of the video. Rein then teamed up with Alexander Rennie and produced the visual portion of the video using photos from the conference.

It is with tremendous gratitude that NBIA acknowledges Hartwell and Rennie for donating their time and talent so generously to this project. It could not have been done without them.

(see video on pg. 13)

Bowl-a-thon in son's memory strikes perfect note for Mom

By Cheryl Lamos

This was my first fundraiser, and I was nervous, but I shouldn't have been. Honoring my son's memory by holding a bowl-a-thon — Bruce Belcher loved to bowl — was perfect. And we raised \$3,000.

The band "Hour of Need" (I can't think of a more appropriate name) came through for us on Oct. 11 at Spare Time in Latham, N.Y. Many others contributed time and energy to make the day memorable.



Cheryl Lamos and her daughter Barbara Belcher of Rensselaer, N.Y., at fundraiser in memory of Bruce Belcher who had NBIA.

To get us started, I sent out letters to businesses and doctors I know from working as a nurse at St. Peter's Hospital in Albany. I tacked up fliers in the hospital, in local stores and even in the local library, inviting people to the Bruce Belcher Memorial Bowl-a-thon.

I also visited businesses in the East Greenbush and Rensselaer areas to explain what I was doing and that I wanted their help with gift baskets for a raffle.

My good friend Ora Frenchak did the same where she works in Schenectady as a nurse anesthetist. She made four marvelous baskets to raffle off filled with homemade chocolate candy and items donated by businesses. She also promoted the bowl-a-thon to her friends and neighbors as well as businesses in the Clifton Park area.

We received gift cards from businesses that could not make cash donations and raffled those as well.

For publicity, I managed to get an article in our local newspaper and tried desperately to land some TV coverage. While that didn't work out, I know I raised a lot of awareness.

I also realized you just don't know what people will do until you ask. My aunt Yvonne, who is retired, did secretarial work for me typing letters I sent to the businesses. I was not afraid to ask for help or to share my story. I brought along pictures of Bruce, which I think inspired others.

On the day of the event, we had a great turnout of family and friends as well as people who used to work with or bowl with Bruce. As a special treat, former NBIA board member Gerry Barbiero and his wife, Bela, came out. They brought their newly adopted baby daughter Kassiana.

Everyone was more supportive than I expected. The event was a wonderful experience. You should try it. Your friends and family want to support you and probably feel powerless to help. This is something they can do. Fundraisers for research give us hope of finding a treatment for our kids. That kind of help is huge.

Bowl-a-thon Sponsors

Accent On Skin
Albany ENT & Allergy Services
Blue Fiddle Gifts
Carol Judge & Spare Time
Bowling
Colonie Motors Inc.
Country True Value Hardware
Crystal Spa
Devoe's Rainbow Orchard
Exit 9 Wine & Liquor

Farmer Boy Diner
Gardenworks
Govel Welding
Green Grocer
Greenbush Reformed Church
Hannaford Plaza Discount Wime & Liquor
IHOP, East Greenbush
Kennedy Ophthalmology Associates
Lindsey's Country Store

Mail Center USA, Clifton Park
Martin Harding & Mazzotti
McGovern Electric & Shine Time
Carwash
Mosaics by Christine
Our Savior's Lutheran Church
Parable/ Living Word Christian
Book Store
Rensselaer Appliance & Exchange TV
Saratoga Apple
Schenectady Anesthesia Assoc.

Sheron's Uniforms
Sonia C. Houck @ www.purse-n-pals.com
Sponsors & Prize Donors
Styling Corner, Hannaford Plaza
The Band Hour of Need
The Bonks
The Melting Pot
Therapeutic Massage & Body Wellness
Upper Crust Pizza
Upstate Neurology Consultants

Fundraiser brings in over \$19,000 for Hayflick Lab Campaign

By Susan Bennett

More than 150 friends and relatives of the Meade family of Dimondale, Mich., enjoyed a lunch, silent auction and other activities to support the Hayflick Lab Campaign and some who could not attend sent donations, netting more than \$19,000 for the family's fundraiser.

The Oct. 10 event, held at the R Club restaurant in Lansing, Mich., was held in honor of Cameron Meade, 10, who was diagnosed with NBIA in early 2007. His parents had consulted with Dr. Susan Hayflick and her team in Portland, Ore., in 2008, and he and his family saw the team again at the NBIA Family Conference in Indianapolis in May. The Hayflick lab continues to be involved in Cameron's care.

When Cameron's parents, Lynda and Sally Meade, heard about the possible closing of the Hayflick lab because of its loss of federal grants, they called on their many friends to organize a fundraiser, with a goal of raising \$10,000.

The owners of the R Club, who also are Meade family friends, solicited a donation from a food supplier so they were able to offer lunch at no charge. The family set a suggested donation to attend the R Club event at \$25 a person.

A friend donated time and talent to produce a flier and posters titled "Cameron's Courageous Climb," which were widely distributed. Posters were placed in local businesses, many of which donated gift certificates and prizes.

A Silent Auction featured beauty baskets, car care items, sports memorabilia, beautiful handmade quilts and home décor items, many handmade by friends. The Balloon Pop in which people buy a balloon and pop it to get a number was very successful and was a great way to keep people involved between the three silent auction end times. A 50/50 raffle and door prize drawings also filled the event with lots of activity and all of these events together produced nearly \$5,000. Cameron's sister Kylie, 7, held a "Dollar Dance" at the event and raised \$50. Friends and family paid a minimum of a dollar to dance with Kylie with accompaniment by Kathy Ford, a well-known local singer.

The generosity of caring people was overwhelming. Friends and family contributed another \$10,000 in cash and checks, and donations are still coming in. Many people volunteered time and organizational skills to create a perfect event. The Meade family is most grateful for the outpouring of support, and very proud to help Cameron and NBIA Disorders Association.



Meade Family fundraiser in Dimondale, Mich. at the R Club.
 First Row: Cameron & Kylie Meade
 Second Row: Lynda Meade, Sally Meade, Susan Bennett, Tricia Meade & Steve Meade
 Third Row: Doris Meade

Cameron's Courageous Climb Auction/Prize Donors

- | | |
|----------------------------------|---|
| A-1 Mechanical | Kylie's Crafts |
| Angela's Hair and Tanning | Meijer |
| Arriva Cosmetic Center | Michigan State University |
| Baskets by Barb | Women's Basketball |
| Buddies Grill | Michigan State University Tennis Facility |
| C. Weaver Physical Therapy | Mysdy Prints Farm |
| Capital Fitness | Panera Bread |
| Carl's of Dimondale, Inc. | Patrick's Hair Salon |
| Carrabba's | Port Huron Museum |
| Celebration Cinema | Quota International of Port Huron |
| Centennial Wireless | R-Club |
| Cheddars | R-Club Staff |
| Class Act Car Care | Red Cedar Grill |
| Coffee Jam | Red Robin Restaurant |
| Cones and Bones | Riverview Church |
| Dusty's Cellar | Royal Scot |
| Eagle Eye Golf Course | Shaheen Chevrolet |
| Edru Skate-A-Rama | Sparrow Weight Management Center |
| Essex Hair Design | Talk of the Town |
| Fat Boy's Pizza | The Peanut Shop |
| Finley's | Tote Along |
| Great Harvest | Wheat Jewelers |
| Green Barn Llama Farm | Wheatfield Valley Golf Course |
| Hawk Hollow Golf Course | Wilcox Pharmacy |
| Hershey's Steak House | Wild Strawberry Florist |
| Holt Eye Care | YMCA of Lansing |
| Holt Schools Athletic Department | Zoe Life Spa and Salon |
| Honey Baked Ham | |
| Houlihans | |
| Iron Dragon Inc | |

Golf marathon for NBIA nets \$14,000 despite challenges

By Rick Tifone

It wasn't the kind of weather golfers like — rain the entire time — but the day was a perfect one for the NBIA Golf Marathon nonetheless.

With help from NBIA board member and fundraiser extraordinaire Richard Leap, my wife and I decided to try and put together a golf marathon in Pennsylvania. Leap provided guidance, samples of marketing materials and inspiration.

Our connection to NBIA came through our son, Adam. Adam, was diagnosed with NBIA (PKAN) in 2007. He is 18 years old and will graduate from high school in the spring. His interests include his collection of snakes, video games, SCUBA diving, and camping.

Initially, the biggest hurdle we faced was finding a golf course owner who would rent the entire course for the day at a reasonable price. Leap had a lead on a course in Butler, Pa., who knew his family. Lake Arthur Country Club agreed to rent the course.

The next part was finding businesses and other donors who would be willing to help us with prizes, food and other contributions. I sent e-mails to friends, clients and family promoting the event and soliciting support. My wife, Diane, also sent out more than 100 letters to friends, clients and family promoting the event and soliciting donations. We also set up a Web site, www.nbiagolfmarathon.com to provide information about the event.



Golfers at the Adam Tifone Golf Marathon in Butler, Pa. First row: Gary Hengelsberg, Greg Woodhall, Mike Leap, Don Finke, Rick Tifone, John Druga, Rich Logan Second Row: John Nobbs, Jeff Martin, Steve Goodman, Brian Elledge, Scott Kime, Ryan Fisher, Dave Cominski Not Pictured: Ted Benko

We recruited five platinum (\$500) sponsors and four gold (\$250) sponsors and many donations from friends, family and clients. We also focused on getting prize donations so that our golfers would be rewarded for their efforts. We rounded up some wonderful awards, including a three-month athletic club membership, golf clubs, and a recliner.

The next challenge was to find golfers. The marathon format is relatively unknown but it involves playing as many holes as possible (up to 100) in one day. The concept is similar to a walkathon; players get sponsors to pledge a certain amount of money for each hole played or make a flat overall pledge. The lesson learned is that it's important to stress to participants that they don't have to play 100 holes to participate. Play as many as you want.

We ended up with 15 golfers. The golf course turned out to be perfect for the event, although the weather was not. Even though it rained the entire day, we still played. Some of the true diehards played as many as 87 holes; the average was 55 holes.

The net result is we raised more than \$14,000 for NBIA research and all had a good time.

Golf Marathon for Adam Tifone Prize Donors

Alexanders
Alpine Pools
Atrias
Eat N Park
Fast Signs

Giant Eagle
Great Clips
Halo/Lee Wayne
Martin E. Lazzaro & Assoc.
NexTier Bank

Panera Bread
Skyline The Exhibit Place
Steve Cerque Custom Golf Clubs

Minnesota bands rock for Hayflick Lab Campaign

By Mike Cohn

In late July, www.bandsforacause.org went live.

Bands for a Cause is a project in which musicians donate concerts in support of NBIA. It is one of many ways the music community focuses some of its energy and desire to help others into raising awareness and funds for NBIA. It's been a great marriage and a lot of fun. Together, we've raised more than \$4,000 for NBIA.

All of the current donations are going to the lab of Dr. Susan Hayflick, which faces closure because of the loss of federal grants.

Right now, all of the bands that have helped us are from Minnesota. Some have done NBIA benefit concerts while others have passed around the jar asking for donations for NBIA.

On Aug. 15th at MainStreet Bar and Grill in Hopkins, Minn., Ashley Gold, Kerve and Concentral helped us raise about \$1,000. That was our first event, and we were so encouraged by what we could do with a little help from our friends. Many thanks to Tom and Linda Supri who helped set up and organize the event.

On Oct. 10, we had our most successful outing to date. At a concert featuring The Mason Dixons and Concentral, we raised \$2,200 at Bogart's in Apple Valley Minn. with Bogart's donating \$950.00 from the cover charges.

We still have a couple of other concerts to go before the year is out. "Sick of Sarah" and "Dr. Salty" will be playing at a holiday concert here in Minnesota with the date and location to be determined. We will be raffling off a donated guitar from Tim Mahoney at The Mason Dixon concert on New Year's Eve. There will be a number of artists signing the guitar between now and New Year's Eve. If you are interested in a raffle ticket, you can contact me at mikecohn@yahoo.com.

All of the bands who are on bandsforacause.org are musicians I have become good friends with. I have been nicknamed "The Rock Star" for getting the concerts going and helping people to open their hearts to NBIA. Many more people are aware and are giving their money and time to help us save the research lab.

Besides the music, I've been involved in several other fundraising events:

On Oct. 3rd we held a walk-a-thon that raised \$210.

On Oct. 24th, we raised \$268.00 raffling off a guitar signed by Brian

Leighton and band at G.B. Leighton's Pickle Park in Fridley Minn. The staff was very helpful in selling raffle tickets.

We also held raffles and auctions at several of the concerts and would not have been so successful without the help of the following businesses: Pizza Luce, Old Chicago, Davanni's, Applebee's, Brueggers Bagels, Caribou Coffee, NBA City, GrandStay Hotel, The Scooter Store, Hitching Post, Chipotle and G.B. Leighton's Pickle Park.

We are grateful to those businesses and also to Nicole Lynn Langer for donating \$250 plus a \$30 gift card that was raffled off Oct. 10. We raised more than \$400 in raffle ticket sales at our events thus far.



Bands For A Cause Fundraiser at MainStreet Bar and Grill in Hopkins, Minn.

We also thank Lorenzo Michelutti from Concentral who donated a three-hour acoustic concert that we auctioned off at the Oct. 10 concert. The winning bid went to Zach West, who has INAD, one of the NBIA disorders. Zach's mom, Rachele Chrismer, and her friends joined to bid on the concert for a block party for Zach and friends.

Michelutti and his family have a special interest in NBIA because his niece died of a neurological condition and they want to help others with similar disorders.

Two Saturdays a month I have been working at a store called Community First, which is donating 35 percent of its sales to NBIA on the days I work. Community First is a store that gives back to the community by partnering with non-profits. The owner has chosen NBIA Disorders Association as a partner, and as such, hopes to put on a fundraiser for us before the end of the year.

Family's fundraisers knit them to community while raising money for Hayflick campaign

Michael and Wanda Fox, parents of Kevin, an 11-year-old boy with the PKAN form of NBIA, took personally the call for help raised by Dr. Susan Hayflick whose Oregon lab is endangered by federal research funding cuts. They began reaching out to friends, colleagues and neighbors to raise awareness and support for the Hayflick Lab Campaign.

"Taking care of Kevin and the rest of our family, and dealing with the impact of his illness on our lives has at times felt so overwhelming that we never really made the attempt to reach beyond ourselves for NBIA funding," Wanda Fox said. "But when we learned that Dr. Hayflick's lab was in danger of closing we knew we had to make those efforts."

And not only has fundraising proved easier and more fun than they imagined it would be, but the Fox family has discovered a hidden benefit to sharing their story: a closer connection to community and the encouragement that comes with it. "People have been so generous and caring," the Foxes said. "We wish we had done this sooner!"

The couple began by brainstorming about how they could reach a lot of people in a short amount of time. They decided Facebook was the answer and they created a fundraising page for Kevin and started sending out "friend requests."

"Many people who know us didn't understand a lot about Kevin's challenges," Michael Fox said. "This was a great way to give them a window into our world and let them know how they could help." Kevin's page was formatted with links to the NBIA Cause page and NBIA Web site, a personalized version of the NBIA letter sent to senators, and a PayPal link for donations. Michael and Wanda Fox also posted pictures of Kevin and a video taken during his Make-A-Wish trip to Sesame Street.

Once the page was up, news about Kevin and the Hayflick Lab Campaign spread. A reporter from WTVD, Raleigh/Durham's ABC news affiliate, called the Fox home and asked to come the following day to meet Kevin and learn more about the fundraising cause. Several days later Kevin and his family were featured on the popular "Person of the Week" news segment at 6 p.m. The report spotlighted the efforts being made by the Foxes and other NBIA families to raise money for the Hayflick Lab, and a link on the station's Web site gave viewers information about where to donate. Since then, NBIA Disorders Association has received many viewer donations in honor of Kevin. (see interview on our Web site)

After that, Wanda Fox contacted the owner of Swagger, a popular



Swagger employee Heather Lilly, Kevin Fox and Wanda Fox at raffle for Trollbeads bracelet.

her, she wanted to do something really special," Wanda Fox said. "She contacted the sales rep for Trollbeads, one of Swagger's best selling lines, and they decided to dedicate their fall trunk show to Kevin and the Hayflick Lab Campaign."

Trollbeads, an international jewelry and bead company, donated a bracelet valued at \$350 to be raffled off during the event with all proceeds going to the Hayflick fund. In addition, Swagger donated 10 percent of proceeds from the event and 10 percent of online sales from that day to the campaign. The Foxes said the "Shop for the Cause" raffle came together easily, was a lot of fun and brought in more than \$1,000 for the Hayflick Lab Campaign.



Global Knowledge in Cary, North Carolina donated \$10,000 to the Hayflick Lab Campaign.

Throughout the fundraising efforts, Michael Fox's colleagues at the international corporate training company Global Knowledge embraced the opportunity to support his family's cause. Many made generous donations in Kevin's honor and helped widen the circle of awareness. Global Knowledge CEO Brian Branson presented Michael Fox with a check for \$10,000, made out to NBIA Disorders Association and the Hayflick Lab Campaign! The Foxes were overwhelmed with excitement and gratitude.

The couple say they're not finished yet. "During all of this, different people have approached us with new ideas and lots of energy. We'd like to do something else before the holidays, but at the very least we're going to keep reminding everyone that we have a very important goal to reach before the end of this year."

You can visit Kevin's Facebook page at: <http://www.facebook.com/kevinfox.fox>.

local gift shop, to see if she could help with the fundraising efforts.

"Mandy knew me as a loyal patron and knew my daughters, but she had never met Kevin. When I told her more about him and shared his pictures and videos with

Dedicated friends, old and new, help us raise money year round for NBIA

By Sandy Leap

Whether they had a birthday, a wedding or a great idea this year, our friends never forgot our favorite charity, the NBIA Disorders Association.

Since our daughter Brittany's diagnosis 3 ½ years ago, we have been blessed with old and new friends, who are always ready to help raise awareness and support for NBIA research. If the dollars raised in Brittany's honor help lead to a cure and prevent one family from going through years of uncertainty, our family's journey with NBIA will be well worth it. We thank the following people for their kindness and generosity in helping us keep the hope for a cure alive.



Volunteers at Haymarket Day in Virginia help raise awareness about NBIA.

Florinda Russell, your 50th birthday bash in February was great fun. Brittany had a wonderful time dancing and we appreciate your requesting donations for NBIA in lieu of gifts.

Congratulations, Rich Rahfield and Pat O'Brien, on your wedding in April, and thanks for sharing your special day with Brittany and requesting donations to NBIA instead of gifts. We wish you a lifetime of happiness.

Thanks to the Haymarket Masonic Lodge for dedicating their annual Ride to the Wall breakfast for the second year in honor of Brittany. The support means a great deal to us, and Brittany enjoys taking her picture on a motorcycle. You made her day.

Also, we are grateful for the second year to Mike Leap, Brittany's uncle and the Pittsburgh Police Department for their "Hill District Open" in which golfers competed in a putting contest and annual golf tournament to raise funds for NBIA. We appreciate the continued support.



Golfers at the Queen Bee Golf Marathon on October 12.

Rich Leap, Robin Firestone, Peggy Gough, Michelle Ayala, Heather Porter, Jim Penn, Sandy Surabian, Chris Kase, Bryan Firestone, Jim Carney, Charlie Deliee, Rich Lieb, Jayelene Betoti, Jane Deliee, Frank Wood, Mike Leap, David Rodenas. Not pictured: Jeff Schurmann, Mike Rauh, Brian Frye

Thanks to Colleen Wood, Brittany's physical therapist for holding a yard sale to raise money for NBIA. Colleen is the reason we kept searching for a diagnosis. Each time we received one, Colleen would say, no, that is not it. We thank her for not only helping to raise awareness and for being a great therapist, but most of all, for being such a good friend.

Colleen Corrado, you and the many friends who helped raise awareness of NBIA at Haymarket Day were outstanding. Whether you took part in a parade, baked goods or helped at the information table, we are very grateful.

Colleen Corrado also is running three marathons to raise awareness for NBIA, two in October, and the last one in Richmond on Nov. 14. If you want to guess how long it will take her to complete the last one, log on to www.queenbeeworld.com for information.

(see Bees on pg. 12)

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Thomas Huard

Bees

(continued from page 11)

Finally, thanks to all of the friends who helped with the 4th Queen Bee Golf Marathon Oct. 12. It was a bit chilly, but that did not deter the small but very dedicated group of golfers. They played from 7:30 a.m. to about 6 p.m. During dinner, Brittany helped to pass out prizes. No one left empty handed. At the end of the evening everyone went home with NBIA and Queen Bee logo bags as well as a bottle of wine with the Queen Bee label.

Thanks to Sarah Jackowski for helping with the wine. Thanks to Quest Diagnostics for sponsoring the marathon, assuring that 100 percent of what was raised went to NBIA. We are so grateful to all of our hole sponsors, prize and goodie bag donors as well as the volunteers.

Haylick Lab Campaign Donors

Thanks to all those who donated to the Haylick Lab Campaign. Due to the overwhelming response and our desire to acknowledge all of our donors, we have listed many of those who donated for a specific family fundraiser on the insert that came with your newsletter. Also, if you donated for the campaign and noted that it was in honor or memory of someone, your donation may be listed on page 14 under the appropriate heading.

Nancy Alinovi	Nancy Dieterich	Kelly Klein	Tatiana Quiros
Joy Allen	Jane Dunworth	Jaonne Knchmiak	Richard Rawson
AppleCon	Ann & Lawrence Edson, Sr.	William Konefay	Dawn Ray
Daphne Armati	Linda Erickson	Sharon Kovela	Todd & Chris Richards
Kathryn & Francis Austin	Shahriar & Nanaz Fathpour	Conrad Kress	Mary Ann Roser & Ted Thomas
Edwin & Michelle Ayala	Carlos & Jacqueline Feder	Joseph & Sachiko Kuspa	Darlene Saraceno
Yamshi Babbula	Daniel Flores	Anita Laffen	John Schenck & Susan Kalia
Elaine Barnard	Patti Freeman	Cheryl Lamos	Mapi Schlissel
Timothy Barnhart	Elaine & James Fulton, III	Patricia Lamos	Ginette Schmitt
Natacha Baumann	Daniel Ganley	Bonnie Lanham	Alfred Seba
Tony Beckrow	Dennis Gansen	Sue & Simati Laupola	Nedda Shishegar
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Letuy & Duy Dao	Sue Kimball	Tara & Scott Quenneville	C.P.Yochem
William & Christina DeBlock			Hana Zima

Video

(continued from page 5)

NBIA families and friends can use this new video to touch the hearts of supporters by e-mailing it directly to them. There are two easy ways to do this. You can e-mail the link from the NBIA home page at www.NBIAdisorders.org and tell the recipient the video is the second picture down on the home page. A second option is to e-mail the YouTube site short cut, which is www.youtube.com/watch?v=6JghpvqrDew.

If the person viewing the video is so inspired, he or she can easily click a link to donate to the organization on NBIA's home page.

You can also e-mail Rein at Irein@NBIAdisorders.org at least 15 days before your fundraiser and she will get you a copy of the DVD to play at your event.

If you would like more information about this video, or if you want ideas on how to use it for fundraising, e-mail Rein. If you have a great success story or wonderful idea on how to use this video to help our cause, please let us know.

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.

In Honor Of

Belcher & Lamos Family

Margaret Carknard
Arthur & Myrna Cartner
Kathleen Gallichio
Deborah Marra
Raymond & Michelle Martin
Sharon Morrissey
Kenneth & Gloria Near
Donald & Sharon Oppedisano
Dr. Teddy Pan
Mary Grace Pietrocicola
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Allison Mochizuki
Bridgitte Rodgers

April & Tracie Flinn

John & Del Bodwell
Bud & Althea Brown
Joyce Judd
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Andrew Kourakourtis

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Michael Komenda

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Barbara Mattaliano

Brittany Leap

Michael Cooper
Christina Melton Crain
Marilyn Darvish
Barry Dominick
Barbara Dupree
Melissa Gutch
Dr. & Mrs. Darshan Khalsa
Sherri Leach
Gloria Lim
Kathleen McBride
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Romain Lerogon

Jacques Haas

Ashley Middendorf

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Cameron Meade

Kim Eastman
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Elaine Lyon

Brandon Richards

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Carol Ann & Robert Letterman

Keri Patton

Paul & Janet Buhay
Charles & Florence Waniak

Mark & Martha Nell Richards

Richard & Georgette Peckham

Jared Ose

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Jane Burns
William Clodfelter
Kyle Fair
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Lois Klein
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Patricia Wood

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Keith Josephson
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Jack Thornley
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In Memory Of

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NYS-DEC QA Lab
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Carmen & Mary Del Grossa

Angela Steinker

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Pete Tague

Diana Mackall

Scott Tommey

Mark & Martha Nell Richards



Wendy van Schijndel
November 26, 1981 - August 17, 2009

*You can rest now,
 You've fought your fight,
 You've done it bravely.
 Who can understand how you've suffered,
 Who can feel what you've endured?
 You can rest now.*

With these words we want to indicate how difficult the last years of Wendy's life have been. She was a happy, sweet child, and although she became ill at a young age, she still could enjoy even the smallest things in life.

Wendy was a little girl with great courage. She was never frightened. She had to adapt to an ever-changing situation. But none of that took away her sense of humor.

Now she has left all of that behind. Her sister Cristel wrote:

*Never more walking together outside,
 To hear how the birds whistle.
 Also no longer going together to the city,
 where I've had so much fun with you.*

Wendy loved to tease others and also didn't mind being teased. Mostly, she loved being pampered. She enjoyed having attention showered upon her. To tease and get pampered, perhaps that's the reason elephants became her most darling animals.

We gladly would have given you even more attention. Now we will do that in our memories. Thanks for all the joy you gave us. Mum and Dad

You were a lovely sister with incredible willpower; know that you will always be in my heart. Cristel

Wendy, you were a great sister to us. You showed us what fighting and enjoying is. We would have gladly gone on pampering you and giving you our love. The only thing we have now are the beautiful memories, which we will forever carry in our hearts. Jurgen and Maayke

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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Aylesworth Family Fundraising Donors

Thanks to those who donated in response to a letter writing campaign by the Aylesworth family that brought in over \$3,000 for the Hayflick Lab Campaign and they are still receiving donations.

- | | | |
|------------------|-----------------|-----------------|
| Chris Anderson | Mary Felton | Sandra Mosher |
| Sandra Basista | Nathan Gesler | Ellie O'Brien |
| Karen Benesh | Maureen Jung | Bernard Snaizys |
| Jacob Erickson | Michelle Mallie | Thomas West |
| Matthew Erickson | | |

MESSAGE FROM THE PRESIDENT



Patty Wood

The good news is we had so many recent fundraisers to share with our readers that it filled our newsletter to the brim and even made an insert necessary.

Unfortunately, I had to make the type a bit smaller when listing all of our many wonderful donors, so forgive me if you need to get out your magnifying glass this time around!

I am grateful we have so many to thank and so many new donors made aware of the need for NBIA research. I hope we can continue our momentum next year and make our voices heard by an ever-increasing population. Please read my article on page 1 for more information on the Hayflick Lab Campaign and our progress.

There are many great ideas for fundraising in this newsletter, and we are always willing to help new families with their planning. Please think about adding your voice and efforts to the cause if you have not yet done so.

Thanks again to all of you for the support, hard work and amazing difference you have made in the lives of those affected by NBIA.



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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

2082 Monaco Ct.

El Cajon, CA 92019-4235

E-Mail: info@NBIAdisorders.org

phone: (619) 588-2315 fax: (619) 588-4093

Visit our Web site at

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