

Family's first-time fundraiser nets \$23,000 Plus, a grant for research equipment of \$50,000

By Anabela Ferreira-Barbiero

The seeds for our successful NBIA Fun Day were planted last December when my oldest daughter was going through a rough time. Everyone — our family, friends and neighbors — wanted to do something to help. Cheryl Lamos, another NBIA parent, and I formed a committee and met once a month to plan a fundraiser in Niskayuna, New York. It was the first time we had ever tackled anything of this magnitude.

We decided to hold a variety of activities that people of all ages could enjoy. To help us get started, classmates of my daughter, Sabrina, held a bake sale on their street for two Fridays to raise money for NBIA. Carly Kirchner, Kira Nathan, Carly Seminer and Taylor Tear, all third graders at Rosendale Elementary School, came up with the idea on their own, their parents said. They put up posters around the school and the neighborhood. One little boy said, "Now finally I can do something to help my friend Sabrina."



Sabrina's friends hold a bake sale to raise funds for NBIA research.

Others pitched in, too. Girl Scout Troop #38 members Kara Williams, Kerri Valero and Leah Lubert did hair wraps for \$1, where you take a piece of hair and wrap it up with colored

(see **Fun Day** on pg. 8)

Dr. Susan Hayflick receives Art of Listening award

By Patricia Wood

Support and praise for Dr. Susan Hayflick and her tireless efforts to assist families with NBIA came, literally, from around the world. That's why we were not surprised when she received the Art of Listening Award at the 2003 Genetic Alliance Conference in Washington, D.C.



Dr. Susan Hayflick with her "Art of Listening" award and a memory book given to her by NBIA Disorders Association to commemorate the event.

The award was created to celebrate those caring, receptive professionals who assist individuals and families living with genetic conditions. It also is designed to increase awareness of listening as an invaluable key to understanding and helping.

Eleven NBIA families nominated Hayflick for the award and many echoed her willingness to always take time with them, answer their questions and give them a ray of hope at a difficult time.

"As the young sister of a patient, I have known the disease since very early in my childhood," wrote a nominator from Brazil. "Fortunately, not too many people know the feeling of not having anywhere to turn, of having so many questions and nearly no answers. I do, though. ... Not only does Dr. Hayflick seek a cure for NBIA, but she also reaches out and touches people who have been

(see **Award** on pg. 10)

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Two more \$30,000 grants awarded in September to advance research into NBIA

The NBIA Disorders Association Research Fund has awarded two more grants worth \$30,000 each to help scientists advance their understanding of neurodegeneration with Brain Iron Accumulation. Money for these grants comes from fundraisers and donations earmarked specifically for scientific research.

This is the second consecutive year that the National Organization for Rare Disorders has administered competitive research grants on behalf of NBIA Disorders Association. Last year, NORD awarded three \$30,000 grants on our behalf. One of the winners, Dr. Susan Hayflick, whose lab was involved in the discovery of a gene responsible for a form of NBIA, received a second \$30,000 from NORD in September.

Hayflick's latest project will study rationale therapies for pantothenate kinase-associated neurodegeneration (PKAN). PKAN is a genetic neurodegenerative disorder of children and adults with dystonia, retinopathy and high brain iron. It is caused by the *PANK2* gene, the gene Hayflick helped discover.

Potential therapies will be investigated by using fruitfly and mouse models of this disease. These studies will serve as a foundation for future research into treating humans with PKAN, a form of NBIA.

The second grant NORD awarded in September went to Dr. Natalie Canham of Birmingham University's section of Medical and Molecular Genetics. She will look for the gene responsible for another form of NBIA. Her goal is to find mutations in the gene. That will lead to genetic testing for members of families affected by this condition. In the long term, such information will provide an understanding into the causes of NBIA.

With last year's grant, Hayflick teamed up with researcher Dr. Penny Hogarth to bring NBIA patients and their families to the Oregon Health & Science University in Portland for a study. There, families were able to tour the research lab and meet those involved in NBIA research. Each participant in the study also underwent two procedures; a flash electroretinogram and magnetic resonance spectroscopy, which were discussed in detail in our August newsletter. The team is continuing to recruit families. If interested, contact Allison Gregory at (503) 494-4344 or gregorya@ohsu.edu.

Mother of son with Baclofen Pump warns others: proceed with caution

By Loma Cohn

My son, Michael, who has NBIA, was encouraged by his neurologist to be tested for a Baclofen Pump implant to help alleviate some of his symptoms.

We were given quite a bit of information about the pump and Mike was told very clearly that it would involve a major commitment on his part. But he's an adult, and it was his decision. I still had doubts from the first time we explored this avenue, but supported his right to choose.

We were encouraged by the fact that the pump program had grown and matured considerably. Mike chose the implant. So, on Sept. 11, 2001, while Mike was in surgery, I sat with several family members in the waiting room. The television was on and we watched with horror as the tragedy unfolded in New York.

Mike's recovery was very easy. The results were initially astounding! His speech improved dramatically. His walking steadied to the point that he was able to give up his walker and use a cane. However, these improvements began to diminish after about two months. We have recently learned that this frequently happens when the primary problem is spasticity. The pump apparently is more effective when treating the problem of rigidity.

So often we are told what to anticipate, but it's phrased in such bland, non-specific terms that we think, "Okay, we can do this." For example, when the doctor says, "You will have to monitor your child," we think, "Well, we do that every day, right?" Wrong.

Monitoring in this case means when you notice more rigidity, you must head back to the clinic for an adjustment. When the person is getting too little Baclofen, it's back to the clinic for an adjustment. There's no more just cutting back or increasing the number of pills. Yet, no one told us that Mike might have to go in for adjustments as many as two or three times a week.

A few months after the pump was implanted, the catheter separated from the pump. He had gone to the clinic several times because of swelling in that area and was told repeatedly that it was just a fluid buildup. It wasn't. It was the baclofen leaking. Mike had to have surgery to have it fixed.

The monitoring warning we didn't get was the most important one of all: When the pump is refilled or adjusted, you receive a computer printout of the dose, frequency, refill date, etc. Mike always brought them home and filed them. It never occurred to me to read them and because of Mike's vision, he wasn't able to read them.

On July 24, 2003, Mike had his pump refilled. Fortunately, he came home immediately after that. Within thirty minutes of his arrival, he was unconscious. Within three minutes of dialing 911, the police arrived, and the paramedics a few minutes later. Mike went into cardiac and pulmonary arrest.

The ambulance rushed him to a trauma center, which fortunately has a pump program. The doctors turned off the pump, as it appeared Mike was overdosing on Baclofen. We learned there is an antidote for an overdose. We faced two choices of treatment: 1) let the Baclofen work its way out of his system, or 2) administer the antidote knowing there was a significant risk of a heart attack. We chose the first option.

The physician who had set the pump that morning had made a huge error. It was supposed to be set to deliver a dose every six hours and was actually set to deliver a dose every six minutes. Mike remained unconscious for about 24 hours and was on a respirator. He seems to have made a good recovery and the only long-term damage we are aware of is some short-term memory loss.

Now when he goes for an adjustment, he insists the physician or nurse review the computer printout with him before he leaves.

Still, Mike has decided to have the pump removed. We have learned that it will take about a year before that can be done.

I understand that the pump has been effective for some people. However, I would encourage anyone considering the implant to explore alternatives before making the decision.

On July 24, 2003, Mike had his pump refilled. Fortunately, he came home immediately after that. Within thirty minutes of his arrival, he was unconscious. Mike went into cardiac and pulmonary arrest.



Michael Cohn, 35, lives in Minnetonka, Minn.

NBIA parents might want to consider wish programs for their kids

One family lives in the United States; the other lives in Germany. But they experienced a similar joy when the Make-A-Wish Foundation here, and Wunschtzettel e.V. in Germany, gave them a lasting memory.



Mike McGourthy, Sr., and son Michael share time with the cruise ship captain (left) while on board for Michael's wish.

The McGourthy family of Middleboro, Mass., was ecstatic about the vacation Make-A-Wish made possible. About two years ago, the McGourthys contacted the foundation about enrolling Michael and Bobby. After sending in the required paperwork, including a doctor to contact, both boys were approved for "wishes."

The family decided to honor Michael's wish first. He's the oldest. He wanted a Disney cruise, and they got that — and more. Michael's best friend, Drew, was included, and the foundation paid for everything. It flew the entire family and Drew to Florida where they boarded the cruise ship and sailed for seven days. Spending money also was provided.

Michael and Drew had their own teen room, and the other kids were entertained by special programs onboard the ship. Michael received many presents, hand-delivered to his room, including a stuffed Mickey mouse, a gift certificate to the game room and invitations to meet the captain and the other Make-A-Wish kids onboard.

The group visited beautiful islands and had an amazing time. Bobby is next and is working on his wish.

In Velbert, Germany, the Klucken family enrolled Dietmar. His wish: to meet Campino, the leader of the rock band, Die Toten Hosen. The wish was approved, and the band performed Dietmar's favorite songs, at his request. His father, Stephan, taped the encounter.



Dietmar Klucken's (center) wish comes true when he meets his favorite musicians, the rock group Die Toten Hosen.

Dietmar was so full of joy, and still is. His condition also suddenly improved. After losing the ability to sit normally, he can now do so. "We don't know what caused this improvement, but we're very happy and we presume that a very special event has contributed to the unexpected improvement... his appointment with a very famous rock band," his mother, Angelika said.

The McGourthys and the Kluckens encourage other families to contact a wish foundation and make a wish they won't forget.

For more information on how to receive a wish, visit www.makeawish.org.

Regional Training Workshop held in San Francisco

The Office of Rare Diseases and the US Dept. of Health and Human Services sponsored a workshop on "Gaining Access to Research Resources" in San Francisco Nov. 7-9. NBIA Disorders Association was represented by President, Patricia Wood. This workshop provided valuable information on how research is done at the National Institutes of Health.

We are grateful the institutes are attentive to our needs. Through opportunities such as this, the agency has shown it is willing to listen, partner, and financially support research into NBIA through scientific workshops and grants to individual researchers.

Let's join forces to meet the challenges ahead

By Angelika Klucken

Imagine someone wants to enter a room but the door is closed. He doesn't know what to do and goes away. Another man comes along, finds the door closed, and tries the door handle. The door, however, is locked. He also gives up. A third man finds a key, but it doesn't fit. He loses hope and leaves. Finally, a fourth man looks for tools to make a key and considers getting others involved to help him.

This story opened the Genetic Alliance 2003 Conference held in August in Arlington, Va. It reflects the situation that NBIA patients and caregivers find themselves in as they grapple with a disease that is rare and incurable. But it also demonstrates that each of us can become a 'keymaker.' We can contribute something to help find the key for a cure: a blood sample, the sharing of experiences with other affected individuals, a fundraising activity, taking care of someone affected with the disease or conducting professional research.



Mary Davidson, Executive Director of the Genetic Alliance and Patricia Wood, President of NBIA Disorders Association, at the Genetic Alliance conference in August.

We can also join patient support groups, such as the NBIA Disorders Association and Hoffnungsbaum e.V., a patient support group for NBIA families in Germany. And we can also get help from organizations such as the Genetic Alliance, which does advocacy on behalf of individuals with genetic conditions and works with more than 600 affiliated lay groups, as well as research and health care organizations. The alliance is a broad and inclusive coalition, working to serve the growing numbers of people identified with genetic diseases. One of the ways it does this is by providing mentoring and resources to lay group leaders, which, in turn, benefits their organizations and members.

This conference was an excellent example of how that mentoring and resource sharing can be done, with much important information provided during presentations and workshops on a variety of topics.



Angelika Klucken, accepting Dr. Hayflick's award at Genetic Alliance dinner Saturday night.

Keynote addresses by two international leaders in genomic science — Eric Lander, of MIT's Center for Genomic Research, and Francis Collins, director of the National Human Genome Research Institute at National Institutes of Health — were impressive and moving. Lander said the completion of the Human Genome Project has influenced research and advances in treatments. He used two genotypes of leukemia to make his point.

Collins said that the main task of genetic research is finding cures to alleviate suffering in human beings. He emphasized that collaboration is the magic word — the way to promote scientific progress. This collaboration between families, advocacy groups, physicians, researchers and the public health system needs to move forward with undiminished effort, while always keeping uppermost the well-being of patients.

A workshop on Research Interventions and Treatments discussed strategies to accelerate research such as diagnostic testing and therapeutics. A vice president of a drug company was one of the speakers and he shared the need for high-quality data collection from lay advocacy groups. We should ask ourselves, he said, "How could helping them (the industry) help you?" Some answers are blood and tissue sample repositories; novel methods for encouraging cross-lab and cross-disease collaborations; and promoting rare diseases as gateways to understanding common diseases. We need to work together to create win/win situations so that a cure for our disease becomes a viable option industry can provide.

One of the most beneficial aspects of this conference was the chance to network with many different groups, researchers, industry and government representatives. Opportunities abound to exchange information, ask questions and share experiences with other caring individuals who understand your circumstances.

At the end of the conference many of us returned to our homes to take care of our loved ones again and to work for our patient organizations, but with renewed vigor. We are excited about the new possibilities and opportunities for growth. We realize we now have many more tools to make that key.

Night of bowling nets 10,000 for NBIA research efforts

The 1st Annual Scotch Doubles Crazy Bowl turned out to be a perfect game for the NBIA Disorders Association. An evening of bowling and laughter drew wide community participation and ended with \$10,000 in NBIA's research fund.



Ashley Middendorf, 17, and her cousin, Nicole Yocks, from Mascoutah, Illinois enjoy themselves at the fundraiser.

The fundraiser in honor of Ashley Middendorf was organized by Ashley's mom, Donna Helton, and her family, and Ashley's dad, Steve Middendorf, and his family. The Panarama bowling alley in Belleville, Ill. was packed with 115 bowling couples, and many others who came to support Ashley and have a good time.

But there was more to the evening than bowling. Local businesses and individuals donated more than 100 items for a silent auction, and a wheelbarrow of alcohol was also raffled off.

A highlight of the evening was Ashley's chance to hurl a bowling ball while everyone watched. Then, she thanked the crowd, using her communication device, and told everyone that the money



raised that night would be used to help find a cure for her disease. The previously boisterous bowling alley was silent as many listened with tears in their eyes.

Ashley's parents believe a tradition has been born: The 2nd annual Scotch Doubles Crazy Bowl fundraiser will be held in 2004.

Crazy Bowl November 8, 2003

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Family Fun Day Fundraiser



NBIA individuals (left to right) Rebekah Belcher, Alyssa Barbiero, Bruce Belcher, Sabrina Barbiero, Barbara Belcher



SLP runners support NBIA; Maureen Woerner, Ginny Gritmon, Michelle Ryan-Rivers, Kitty Kelly, Grace Kramer, Beth Turner, and Debbie Abba with Anabella Ferreria-Barbiero



Sabrina Barbiero enjoys the antics of Pur Cee the clown.



Supporters Enjoy the Day



Fun Day

(continued from pg. 1)

thread, and donated the proceeds to NBIA.

On the day of the fundraiser, Oct. 4, cold, rainy weather threatened to dampen the event, but family and friends from other states and even from Montreal came to cheer us on. Everyone huddled under a pavilion and tents that we had set up, hoping for a break in the clouds.

Meanwhile, Pur-Cee and Cupcake the clowns kept the kids entertained with balloons and face painting. Jacqui Lape kept everyone happy with a continuous supply of fried dough. There was a huge table of baked goods to enjoy. Adrienne Bowman, Sabrina's summer Instructional aide, sang for the crowd. John Tobin from local radio station WPYX 106.5 kept us going with his humor, trivia and games.

A huge attraction was the raffle, which included two free roundtrip tickets anywhere Southwest Airlines flies. The tickets sold faster than we expected.

*The Wright Family Foundation
generously donated \$50,000, which
NBIA Disorders Association is
authorized to spend on research equipment.*

We raised more than \$23,000. In addition, the Wright Family Foundation, a philanthropic non-profit started by the family of the founder of Schenectady International, Inc., where my husband Gerry works, generously donated \$50,000, which NBIA Disorders Association is authorized to spend on research equipment.

We are extremely grateful to the foundation, Southwest Airlines and our other sponsors.

There are so many others to also thank. This day would not have happened without the dedication and support of all the volunteers, especially Marisa Barnes, Linda Cross, Chris Feeney, Liz Kasper, Holly Lape, Jacquelyn Lape, Megan McKeighan, Patrice McMorrow, Renee Michalisin, Barbara Sauter and Carol Venezia who gave up a lot of their Saturday mornings to attend our monthly meetings. We are forever grateful. Thanks to Sandy Paniccia, Donna Flynn and Kathy Fitzgerald who stayed the whole day setting up and cleaning up. I cannot forget all the Key Clubs from Niskayuna High School who helped with the parking and race.

And a special thanks to John Tobin who exceeded the festivities and made us forget about the weather. Before the day ended, the clouds disappeared and a big beautiful rainbow appeared over us. What a great ending to a successful day!

Family Fun Day

October 4, 2003

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

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Gerry Barbiero (center) receives \$50,000 check from Ashley Palm (left) and Heather Ward, great granddaughters of the founder of Schenectady International Inc. and board members of the Wright Family Foundation.

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 Brain A. McHugh
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 Patrice McMorrow-Klemballa
 Kathryn A. Mensinger
 Michael Mercier
 Embarek & Aliza Mesbahi
 Arleen Meyer
 Renee Michalisin
 Jeffrey & Kathy Millistein
 Dean & Lori Mitchell
 Joseph & Cheryl Moon
 Mabel Moreno
 Jon & Jill Morrill
 Lynn A. Morse
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 Deborah A. Myers
 Marilyn Jo Nauman
 Catherine M. Oak
 Barbara Ochampaugh
 Nancy O'Donnell
 Sharon Oleson
 Vincent & Tevis O'Mahony
 Karen & Charles O'Neil
 Donald & Sharon Oppedisano
 Franca Passarelli
 Patricia Paulding
 Richard & Melissa Pedone
 Stacy Pena
 Edmond A. Pereira
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 Jayne Prendergast
 Tara Quenneville
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 Dennis & Marcy Quinn
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 Marjorie Rosenthal
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 Jo Ann M. Sabourin
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 Barbara Sauter
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 June Schechter
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 Helene A. Wilson
 Steven & Kathleen Winckler
 Allen & Maureen Woerner
 Patricia Wood
 Richard Wyles
 Tim & Kathleen Zakriski

Please contact 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.

Award

(continued from pg. 1)

struggling with it, like I have. She gave us answers to our questions and solutions to our problems when no one seemed to be able to help. But she did more: she gave us hope."

"Dr. Hayflick has gone all over the world listening to parents, gathering information, getting to know our children at conferences, talking to each of us individually and answering hundreds of questions, never seeming to tire even if it's the same old questions," wrote a nominator from Illinois. "I remember needing to talk to Dr. Hayflick during a rather difficult period just to reassure me about a question I had. I was amazed at her promptness and genuine concern in answering our call...We parents of special needs children live in a world most people would rather not enter, except people like Dr. Hayflick."

And a nomination letter from Europe wrote: "We live in Poland, far away from the U.S., but we always feel Susan Hayflick is very close to us. We are absolutely sure she deserves this award."

I was asked to present the award, and Angelika Klucken of Germany accepted it in Hayflick's absence and delivered her acceptance speech:

"The recognition that comes with my receiving this award is deeply gratifying. Often the work itself is what keeps us toiling in medical research. For me, the connection to families whose lives are affected by our work is the driving force for my own motivation.

Some days we feel as if we are making little progress, and often we are faced with immense frustrations that threaten to sap our energies. There are days when we need to stop to remember why we persist. But the answer is always easy to find. It's there in a photograph of Kim, in a painting by Dietmar, in a picture of an Amish horse and buggy.

The painting by Dietmar, which hangs on my office wall, is of a snail traversing the top of a rainbow. The message to me is that the work is slow and often a great challenge, but with perseverance and determination we can achieve anything. The partnership between our OHSU/UCSF research team and the NBIA Disorders Association and all of its members is that snail. Together we will traverse the rainbow from discovery to cure."

As a keepsake of this award, we made a scrapbook for Hayflick that included all the nomination letters and copies of the presenting and acceptance speeches. It is our hope that she will always look back at this event and remember how grateful we are for everything she does for our NBIA families.

Newlyweds help NBIA Disorders Association Research Fund on wedding day in August

A newly married couple presented the following letter, along with a check for \$1,225, to the NBIA Disorders Association's research fund shortly after their Aug. 2 wedding in Montreal, Quebec, Canada. Here is a slightly edited copy of their letter:

Dear Patricia,

It was a pleasure to be able to help out a little and donate to a cause that is very dear to our hearts. We chose to donate to the NBIA Research Fund to help find a cure for a disease that has affected Claudia's two small cousins, Sabrina and Alyssa Barbiero.



Claudia & Alessandro on their wedding day.

We thought that instead of giving our guests small wedding favors, they would instead appreciate a donation to an organization that helps others. We had considered just donating on our own but decided that letting our guests know more about the disease was a good way of spreading the word and creating awareness. So we ended up printing a little card indicating that the donation was made in honor of the friends and family sharing our wedding day.

We included the NBIA Internet address for information and attached the card to a little flower made with sugar covered almonds. Although the gesture was a small one and we wish that we could have done more, we hope that this can inspire other couples to do the same.

Regards,
Claudia Barbiero and Alessandro Di Taranto
Foggia, Italy

MESSAGE FROM THE PRESIDENT

Scientific Workshop planned; check out the new NBIA listserv



Patty Wood

I have exciting news about our research endeavors. A second Scientific Workshop is being planned to further research into NBIA disorders. We hope to schedule it for Spring 2005, in conjunction with our next International Family Conference.

Some of you may recall that our first Scientific Workshop and first International Family Conference were held in Bethesda, Md., just outside of Washington, D.C., in May 2000. Both events were successful, and the scientific meeting was the first-ever gathering of researchers and physicians presenting papers and discussing the latest scholarship on NBIA.

We had always dreamed of doing this again, and now with the discovery of one of the genes responsible for NBIA and our research fund having seeded five projects so far, we feel like the timing is good for another scientific workshop.

I know some families were hoping for a family conference in 2004, but the board decided it would be best to hold off a year and have the scientific meeting at the same time. This way researchers and families could interact and help each other better understand this disease. We don't want to strain our resources either, and this gives us time to plan and organize a worthwhile event for everyone.

In other good news, our listserv is up and running. It is providing information and support to families, physicians and other interested parties on an almost-daily basis. We have 32 subscribers at present, and invite those families not yet participating to join us. You will find instructions on how to join on the home page at our Web site. It is very gratifying to know that several recently diagnosed families joined immediately, seeing this free service as an opportunity to learn from those who have been dealing with this disease for much longer. I believe our archives will be a repository of information for families in the future looking for answers and support.

I am so proud of all the NBIA families who have held fundraisers. Your success has bowled me over (see the story in this issue about the bowling night in Ashley Middendorf's honor). Many thanks to those of you who are now in the planning stages for future fundraisers. I know it is a lot of hard work, but your participation is truly making a difference. Without you, the five research grants awarded so far, and the one we plan to offer in 2004, would not be possible. Research is our hope for a cure.

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.

Heather Byford-Brown	Angelika Klucken
Slava Buchkovich	Ella Laird
Mr. & Mrs. Paul Buhay	Sue & Simati Laupola
David & Marianne Clark	June McClure
Wayne Gateman	David & Mary Miller
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Jim Hayes	Kevin & Diane Schmitz
Mr. & Mrs. George Jones	Jack Smyth
Joyce Judd	Mr. & Mrs. Gary Steinker
Bill Kelso	Mr. & Mrs. Charles Waniak

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

Sabrina & Alyssa Barbiero
Claudia Barbiero & Allesandro Di Taranto

Brent Bonfiglio	Forstall Family
Nancy Fathpour	Mr. & Mrs. Lowell Judd
Kuldeep Kalonia	Sue Spradley
Mr. & Mrs. Michael Morgan	Rev. James Wilson
Wayne Wu	Pete Cassidy

Mayfield Family	McGourthy Family
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Greg & Julie Wood	Mr. & Mrs. Bruce Egerton
	Kathleen Sweeney

Kimberly Wood
Mr. & Mrs. Charles Murdock
Regina Neal

In Memory Of

Susie Miller	Tony & Jean Venuto
Walter & Clara Troyer	Mr. & Mrs. Charles Murdock



2082 Monaco Ct.

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Return Service Requested

Formerly
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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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E-Mail: info@NBIAdisorders.org

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

Visit our Web site at

www.NBIAdisorders.org

from discovery to cure

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