

Get ready to celebrate, send in recipes for NBIA association's 10th anniversary cookbook

It's time to party, everyone.

I know it's hard to believe, but the NBIA Disorders Association is going to celebrate its 10th birthday this year. That's right. On September 23, 1996, the secretary of state of California granted the association corporation status, officially creating this organization and the Internal Revenue Service granted us non-profit status effective this same date.

We encourage families to send us a letter or e-mail on how having the NBIA Disorders Association in your life has made a difference to you. We will be publishing some of these letters in our August newsletter, along with a picture of each family. Send to info@NBIAdisorders.org.

We also hope you will take an opportunity to give back to an organization that for a decade has helped to connect families, educate the public and support research. Our board is asking all NBIA families and friends to hold a fundraiser sometime before the end of 2006. It can be as simple as you like or as elaborate.

Our board can help with details and suggestions. We will have 10-year anniversary merchandise available and can help with wording for letters, fliers, etc. Just contact Patty Wood at pwood@NBIAdisorders.org or Kris McGourthy at Rural9@aol.com for assistance.

We need all recipes by May 1, 2006, so please do not delay. We need your help to make this project a success.

Also, here's a fundraising idea that's hard to resist: yummy family recipes from each of you! We are going to print a cookbook with recipes from NBIA families and friends from around the world. Please send in your favorite recipes to nbiacookbook@hotmail.com and include your name, city, state and your e-mail address so we can contact you if any questions. If you live outside of the United States, please include your country.

(see Anniversary on pg. 3)

Look after your own needs when taking care of another

By Dianne Gray

We are reminded, with the way-too-early passing of 44 year-old Dana Reeve, wife of the late Christopher Reeve, of our own mortality. While most of us certainly would never trade a minute of being with a loved one who has NBIA, how often have we heard that we need to take care of our own health so that we can care for our loved one?

My own son, Austin, was diagnosed with NBIA in 1995 and passed away in February 2005 from complications of the disease. As



Dianne Gray from Naples, Florida, with daughter Christine and son Austin.

(see Caregiver on pg. 6)

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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.

New board member joins team



Lisa Shook from Maineville, Ohio joins board of trustees.

Lisa Shook joined the NBIA Disorder Association's board of trustees in March. Lisa is a grants specialist at Cincinnati Children's Hospital and will be bringing much-needed grant-writing expertise to the organization.

Lisa has a bachelor's degree from Indiana University and is working on a master's degree in health communication from IU. She also received grantwriting certification from Northern Virginia Community College in 2005. She brings the board's membership to 9.

Disclaimer

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

Anniversary

(continued from pg. 1)

We have a form that makes it easy to participate, so if you have not already received it, please e-mail me and I will be happy to send it to you, or you can find it on our Web site.

If your language is not English, you can submit your recipe in your native language. But if you can translate it into English, that would be great.

Feel free to submit as many recipes as you like in a variety of categories. We plan on publishing a minimum of 150 of them and are looking for a recipe from every NBIA family, as well as their friends.



We are using the company, Morris Cookbooks. For more information about Morris, see www.morriscookbook.com.

We need all recipes by May 1, 2006, so please do not delay. We need your help to make this project a success.

We hope to have the cookbooks available by the end of July. You can order them to sell at your fundraiser, or just to co-workers, friends and family members. We will also have the option for you to get pre-sales, so you will have already sold the cookbooks and gathered the money before they are shipped to you. If you are interested in this option, please contact Patty Wood for the proper paperwork.

We will also have advertisement space at the back of the book. Costs will be \$200 for a full page ad, \$100 for a half page, \$75 for 1/3 page, \$50 for 1/4 page (business card size), \$35 for 1/6 page and \$15 for patron ads. Please ask businesses in your community if they would like to show their support and advertise their company. Forms for this are also available by contacting Patty.

The books present a nice way for NBIA families who wish to pay tribute to lost loved ones, to honor someone or simply show their support to the organization. Families may also purchase space for these purposes at the above rates.

If you have other suggestions on how we can celebrate our 10th, please let us know. Once you decide on your fundraiser, please let our office know of your plans. Any fundraisers held before July will be featured in our August newsletter, while those after will be in a later issue.

Let's make our 10th anniversary an exciting, memorable celebration.

Research grant to be offered; deadline looms for application

By Patricia Wood

Because families held several last year — and we hope more of them will step up with fundraisers this year, the NBIA Disorders Association will be able to offer at least one research grant worth \$30,000 in 2006.

Our organization has used the National Organization for Rare Disorders to administer seven research grants that we awarded in the past four years. But we have evolved. Thanks to our new Scientific & Medical Advisory Board, we now have the in-house expertise to do the work ourselves, saving \$5,000 in administrative costs per grant. The advisory board will review proposals and make recommendations to the Board of Trustees, which will have final say in grant selection.

Any advisory board members wishing to apply for grants will recuse themselves from the selection process to avoid conflicts of interest.

We are accepting applications for one-year grants for clinical research studies related to the early detection, diagnosis or treatment of patients with NBIA. The application and instructions can be found at our Web site at www.NBIAdisorders.org under the RFP link on our home page. The deadline for letters of intent is June 15, 2006. The grant will be awarded in November.

The purpose of these grants is to encourage meritorious clinical studies designed to improve the diagnosis or therapy of Neurodegeneration with Brain Iron Accumulation. The research will be conducted in the United States, Europe, Canada, Australia, New Zealand, Brazil, Argentina, Chile, South Africa, Japan, or Israel, and where supervision of grant administration is possible.

Grants will be awarded to academic researchers to initiate small clinical trials, the results of which could be used to obtain funding from NIH, FDA or other funding agencies, or to attract a corporate sponsor. Procedures or proposed therapeutic trials may be new, based on recent biochemical or pharmacological evidence, or be in preliminary states of clinical investigation.

Evaluation of proposals will include careful consideration of protocol design, objectiveness of parameters measured, and statistical evaluation proposed. Protocols that will focus on early detection, diagnosis, or treatment (Pharmacological, devices, surgery or dietary) will be given priority.

For more information, contact Patricia Wood at pwood@NBIAdisorders.org.

Milestones - the first decade

Following are key dates in our 10 year history:

May 1996 – Patricia Wood visits Dr. Susan Hayflick at the Oregon Health & Science University. Hayflick is studying Hallervorden-Spatz Syndrome (name of disease at that time). They decide to collaborate on starting a non-profit for the disease to unite families and raise money for research to help find a cure.

Sept. 23, 1996 – Non-profit status granted to organization in February 1997 and made retroactive to September. Name of organization is Hallervorden-Spatz Syndrome Association (HSSA). It has two board members: Wood, president and treasurer; Susan Laupola, secretary.

January 1998 – Pamphlet created and logo, a rainbow with tag line: From hope to discovery.



First logo and tag line for the organization.

May 1998 – First newsletter published with a mailing list of 75. Networking Program starts with five families.

August 1998 – Three new board members join: Gayle McMahon, treasurer; and trustees Mary Ann Roser and Dianne Gray.

February 1999 – Web site created.

July 1999 – Debbie Forstall joins board.

January 2000 – Research Fund created.

May 2000 – First Scientific Workshop on HSS held in Bethesda, Md., with 30 international researchers.

May 2000 – First International HSSA Family Conference overlaps in Bethesda, Md., with 23 families (18 affected individuals) from



First International Family Conference held May, 2000 in Bethesda, Maryland

four countries. Families and researchers meet together at the end of the Scientific Workshop to exchange information and ideas. It was the first time many of the researchers had ever met an individual with the disease, and the first time most families affected by the disease had met another family like them.

August 2001 – Discovery of *PANK2* gene announced. It affects about half of NBIA individuals and causes a form of the disorder called Pantothenate Kinase-Associated Neurodegeneration (PKAN).

October 2001 – Kris McGourthy and Mary Tapke join board of trustees.

December 2001 - \$85,000 in Research Fund, raised by families during the year.

May 2002 – Second HSSA International Family Conference held in Indianapolis, Ind., with 23 families from five countries. An international family is inspired to return to Germany and starts a sister non-profit.

August 2002 – Family fundraisers net \$60,000 for Research Fund.

September 2002 – Three \$30,000 research grants awarded by the National Organization for Rare Disorders for NBIA research with funds from HSSA.

January 2003 – Name for disease changed to Neurodegeneration with Brain Iron Accumulation and name of organization changed to NBIA Disorders Association. Change is to disassociate from Hallervorden and Spatz, two German doctors notorious for their activities during World War II. New tag line also created for organization: From discovery to cure. Newsletter mailing list now at 2,000.

July 2003 – Dr. Susan Hayflick chosen for Genetic Alliance "Art of Listening" Award after being nominated by NBIA families.

(see Milestones on pg. 5)

Milestones

(continued from pg. 4)



Dr. Hayflick wins "Art of Listening" Award from the Genetic Alliance after being nominated by NBIA families.

September 2003 – NORD awards two more \$30,000 research grants with funds from NBIA Disorders Association.

October 2003 – Family fundraiser nets \$23,000 for the Research Fund plus association lands a \$50,000 grant to fund BioBank membership.

November 2003 – Family fundraiser nets \$10,000 for Research Fund.

December 2003 – Listserv started.

February 2004 – NBIA Disorders Association joins

Genetic Alliance BioBank as one of seven founding members.

May 2004 – Board members Dianne Gray, Debbie Forstall and Gayle McMahon end terms. Gerry Barbiero, Jeff Doerner and Phil West sign on.

September 2004 – One \$30,000 research grant awarded by NORD for NBIA research with funds from NBIA Disorders Association.



Leaders of the seven founding groups of the Genetic Alliance BioBank meet in Washington D.C. to discuss this new venture.

October 2004 – German NBIA non-profit donates \$10,000 to Research Fund.

March 2005 – PKAN knock-out mice created and studied at University of California at San Francisco with funds from research grant awarded by NBIA Disorders Association.

May 2005 – New Scientific & Medical Advisory Board created with seven members, making it possible for the association to award research grants without using NORD, thus saving administrative costs of \$5,000 per grant.



The Scientific & Medical Advisory Board with the Board of Trustees of NBIA Disorders Association. Advisory Board member Steven Richieri and trustee Lisa Shook not pictured.

May 2005 – Third International NBIA Disorders Association Family Conference held in Gaithersburg, Md., with 23 families from seven countries.

May 2005 – Second Scientific Workshop on NBIA held in Gaithersburg, Md., simultaneously with 40 researchers from around the world.

August to October 2005 – Family fundraisers contribute \$20,000 to the Research Fund.

September 2005 – One \$30,000 research grant awarded by NORD for NBIA research with funds from NBIA Disorders Association. Future awards will be made with assistance from new advisory board.

March 2006 – Lisa Shook joins Board of Trustees.

April 2006 – 24th issue of the organization's newsletter published. Mailing list at 3,000.

Caregiver

(continued from pg. 1)

caregivers, we face exhaustion and unparalleled stress, not only from caring for our family member with NBIA, but also as we strive to function in our various roles with other family members and friends. Life doesn't stop because we are caregivers.

We also realize the clock is ticking to the time when we will no longer have our loved one to care for. The "just a little longer" theory comes into play as we convince ourselves that if we can simply get by another day or week, it will be over and then we can care for ourselves.

Yet the days turn into weeks, the weeks into months, and the months into years. In the back of our minds, we contemplate the questions: "Just how important is it to take care of myself anyway? Aren't I being selfish? What do I have to complain or feel tired about?"

A recent nine-year groundbreaking study of 518,240 couples backed by the National Institutes of Health highlighted the importance of caring for the caregiver and the potential health effects for our nation's 44.4 million family caregivers. While the study focused on heterosexual married couples older than 65, the "finding could apply to almost anyone in a close relationship," stated Nicholas Christakis of Harvard Medical School, co-author of the study in the *New England Journal of Medicine*.

In the article, Christakis says, "the realization that the health of the people is interconnected could change how we view the proper delivery of health care."

So, how do we care for ourselves while agonizing over the pain and impending passing of our family member or friend with NBIA? Do we try therapy, exercise, alcohol, reiki, prayer, vitamins or medication? After talking with many other caregivers, I believe that most of us have tried some combination of these approaches at different times, as well as some we didn't mention.

In my own 10-year-plus stint as a primary caregiver, I can tell you that watching my child in pain and caring for him was the most excruciating, exhausting, yet rewarding experience of my life. During that time, I did try to care for myself as best I could, but my friends and family will tell you that I was a walking, talking, sleep-deprived klutz just trying to get through the day so that I could get to the next day which, I hoped, would be better. What did that process do to my own health? Time will tell.

That said, I realized that some things did help and you, too, can find ways to maintain balance and a sense of sanity during this extraordinary journey of love and suffering. Evidence supports that if you are to make clear, sound decisions for your loved one, it is important to care for yourself as well.

However, it is equally important to be selective with your choice of self-prescribed help. One day I realized I needed a break from the intensity of the situation, and wanted to clear my head. With a nurse in the house, I set out on my bicycle thinking I would return refreshed after a brief ride. While heading out of the garage, I heard the cell phone ring, tried to reach for it and ran into a car in my driveway! The message there may have been that I needed more sleep, not a bike ride! Maybe humor was also the message of the day. I am sure the sight of me riding into a parked car (without injury) was plenty funny.

As caregivers, we face exhaustion and unparalleled stress, not only from caring for our family member with NBIA, but also as we strive to function in our various roles with other family members and friends. Life doesn't stop because we are caregivers.

What worked for me at first was spending as much time with Austin as possible, exercise, prayer, being outdoors, and discussions with friends, family and clergy. Yet eventually, I found that none of those provided me with the real peace I needed at that time. I then tried meditation, brief travel with my daughter (which itself provided its own stress due to being away from Austin!) and watching Timon and Pumbaa with Austin, which made things better for me, even momentarily. Have you ever seen how funny those two can be? Even he laughed or smiled at their antics up until his last week of life, which helped to lower my stress, making me feel enormously better.

Unplugging the phone helped at times, as did the scent of lavender and an occasional dose of "chocolate therapy." I also tried a few minutes in the sun which in itself probably added a few more wrinkles and the potential for skin cancer, but who cared at that point? I just needed to get through the day without falling apart. Truthfully, sometimes there was simply nothing that would provide much peace. A realization washed over me — that this horrible disease, NBIA, was in charge, not me. Giving up perceived control did as much to alleviate stress as anything else I tried.

So, while we will never know whether or not cancer or an untimely passing is the result of an incredible stress filled journey as a caregiver here on Earth, we do know that caregiving is a job of love and sacrifice and one most of us do with commitment and passion, regardless of the effect on ourselves. Yet with that said, statistics show we indeed, need to balance our lives with some sort of respect and care for our own mind body connection so that we can take care of not only our loved ones, but also try to put our lives back together with some modicum of health, following their passing or even better, so that we live long healthy lives with them, in the event of a cure.

West Australian airline club donates \$1,000 to research

The Interline Club of Western Australia, an organization made up of staff members of various airlines, chose the NBIA Disorders Association as its charity for 2005, and presented a \$1,000 check to support the Research Fund at a function in February.

"The Interline club is always thrilled to choose and support a charity close to Interline's heart each year with the money raised from their raffles," said Nicole Passarelli. She is a cousin of NBIA association board member Gerry Barbiero, who, along with his wife, Bela, lost their two daughters to the disease in 2004.

Passarelli works at Consolidated Travel and helped organize a quiz night that raised \$12,000 for the association's Research Fund last year. She approached her manager, Kerry Coupar, a member of the Interline club, about donating to our organization, and Coupar proposed the club adopt the NBIA Disorders Association for its charity in 2005. The club agreed, and made the donation at an event hosted by Royal Brunei Airlines at which more than 100 club members attended.

Passarelli was invited to the function as a special guest to accept the donation.



Nicole Passarelli of Western Australia accepts a \$1000 check from the Interline Club on behalf of NBIA Disorders Association. She is pictured here with Kerry Coupar, Air Canada Interline Club Member.

Please contact info@NBIAdisorders.org 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.

Please don't ignore recent letters about BioBank, even if you donated previously

By Patricia Wood

Did you get your letter yet?

The NBIA Disorders Association mailed letters the first week of March telling families about our BioBank and why we need their help with this important endeavor — even families who have already donated blood. For previous donors, a few signed forms are all we need.

Specifically, we are requesting that families who have previously donated blood samples for the NBIA Research Registry housed at Oregon Health & Science University send in the release forms to our office that were included in the packet.

This release asks OHSU to send a sample of the DNA and the medical records of NBIA individuals to our BioBank. We need a separate release form for each individual who donated blood.

OHSU will still have DNA available for its research, but these samples will now also be available to other researchers who wish to study NBIA.

Instructions for those who haven't donated blood also are in the packet, and we are urging families to take part in the BioBank.

Our membership in the BioBank greatly increases the odds of encouraging new researchers to study NBIA. All researchers desiring samples and data must have their projects approved by the association's Scientific & Medical Advisory Board to make sure their research is an appropriate use of our valuable resources. Researchers will also have to report back to us on their findings and we will then inform everyone on their progress through our Web site and newsletters.

The BioBank eliminates families having to donate blood multiple times for different research projects. It also protects the privacy of those donating. Names and identifying information will be removed and researchers will not have access, but will have anonymous data. Our organization will also be able to gather information from families over a period of years, giving a clearer picture of how the disease progresses.

As many of you know, this is crucial information in working toward a cure for NBIA.

(see BioBank on pg. 9)



Julie Smyth
May 29, 1969 - February 17, 2006

My sister Julie's struggle with NBIA has ended. Only a few weeks have passed, and the loose ends surrounding her death still need to be taken care of. And even though the loss is still constantly on my mind, this may be the best time to reflect on her struggle, the impact of her death and the influence Julie had on my family.

Shortly after Julie was born in Flint, Mich., my parents as well as my brothers and I knew our youngest sibling and only sister would not be like other girls. She was developmentally challenged and would require much more care. Our family and friends rose to the challenge. We were drawn closer together and became very protective of Julie. The struggles we faced were nothing like what was to come.

Despite her impairment, Julie was very active and had many interests. She attended school at the Elmer Knopf Learning Center. She was active in the Special Olympics, bowling and just about everything else the school offered. My parents, Roy (who preceded Julie in death Feb. 7, 2001) and Maxine Smyth saw to that.

Julie loved music and dancing. She loved going to concerts and listening to country music. She was one of Elvis's biggest fans. She vacationed from Michigan to Florida to California and places in between. My family had a summer cottage on Elk Lake in an area people from Michigan call "up north." Julie cherished her visits there and named it the "rock pile," after a pile of rocks used to construct the fireplace. Her life was relatively good and she was a very happy person.

When Julie got older she moved to a group home with other special adults. Not long after that, we noticed a slight change in her condition. Tests were inconclusive. Finally, doctors at Henry Ford Hospital made the diagnosis of NBIA. As you can imagine, the prognosis hit us like a ton of bricks.

Later Julie left the group home and lived at an area nursing home that offered physical therapy to assist in Julie's declining condition. Although her abilities worsened she still had a smile for everyone. Not much information was available eight years ago and what information we could find was not good.

As her abilities declined and reached a plateau, we searched for answers. Eventually we heard of NBIA Disorders Association and turned to this terrific association for information. We read each newsletter and knew we were not alone in our search for answers. We read stories about other young people deprived of a long, healthy life and somehow hoped our sister could cheat the inevitable. We appreciate the association being there as a source of support and information.

On Feb. 17, the inevitable could wait no longer. Julie was taken from us. Though her life was cut short, the impact she had on those who loved her will last forever. She made us better people.

Thanks for everything,

Jack Smyth

Donations In Memory of Julie Smyth

- | | |
|---------------------------|-------------------------|
| Roger & Vivian Bahr | Patricia Kline |
| Mary Banks | Eugene & Lucille Krepp |
| Darryl & Sherry Barnhart | Dave Krupa |
| Dora & Al Beamish | Lucy Loje |
| Priscilla Beard | Kathy MacAinsh |
| Alan & Jill Bell | Janet McArthur |
| Robert & Julie Bell | James & Susan Mesrobian |
| Betty Jane Blondin | Joan Thana Most |
| Jack & Bernadette Blondin | Stephanie Resky |
| Janet Branham & Dee Odom | Jack & Sandra Smyth |
| Eldon Carlson | Linda Smyth |
| Elk Tip Drive Association | Maxine Smyth |
| Roy & Marilyn Ferguson | Roy & Karla Smyth |
| Mary & Joe Foust | Stuart & Paula Soper |
| Mark & Bonnie Guith | Joseph & Ann Stolz |
| Betty Hanzek | Tammy Thomas |
| Douglas & Linda Henry | Tony & Colleen Tinnin |
| ICMCF Dietary Dept. | Tom & Deb Trigger |



Stijn R obbercht
November 16, 1993 - January 29, 2006

Hi Stijn,

'Mama' is here and I'll stay for the whole day with you.
Saying these words to you
I entered your room for eight weeks.

I have to let you go now, but as I told you,
"Go now Stijn, you'll be forever in my heart."

Stin, you have taught me what profound pleasure means,
You have taught me so much.
But what I will miss most are
your arms around my shoulders
And those words only you could say with such sincerity,
Those words deep from your heart,
"Mama' you are so sweet."

Thanks Stijn.
Have a nice trip,
And remember, Stijn, in my heart,
I am traveling with you.

Love,
Mama

Can someone tell me what happiness is?
Can someone tell me what pain is?
Can someone tell me what loving is?
Can someone tell me what suffering is?

Yes, Stijn can.

Stijn can tell what happiness is,
His smile, his life, simply his charisma.

Stijn can tell what pain is,
Real pain, not a scratch, but enduring pain.

Stijn can tell what loving is,
Showing every day again I love you.

Stijn can tell you what suffering is,
His last three months, those were suffering.

All this, and so much more, made him an exceptional kid,
one of a kind.

His smile every day, a real kid.

Stijn, I'll never forget you.
Thanks to you, I started believing.
Now I know there is something up there.

One day, I'll come join you
And we'll be one again.

Love,
Your brother Michiel

BioBank

(continued from pg. 7)

So, if you have donated blood previously to OHSU, please send in your release forms as soon as possible. If you are a newly diagnosed family or have not yet donated blood to OHSU for other reasons, you can fill out the request for consent forms and we will send you the necessary paperwork to participate. Please contact me, Patricia Wood, at pwood@NBIAdisorders.org or call 619 588-2315 if you have any questions.

Any NBIA families not receiving the packet should also contact me to make sure we have your correct address and that you are listed in our NBIA families database.

(see BioBank on pg. 11)

Association joins program that donates sales proceeds

If you shop online, you can help the NBIA Disorders Association raise money.

The association is now taking part in an online program in which common merchants, such as Target and Best Buy, donate a percentage of a shopper's spending to various charities. All you have to do is go to www.iGive.com, find what you want to buy and credit NBIA Disorders Association during check out.

Prices for iGive members are identical to those offered at each individual Web site, and a percentage of your purchase goes directly to our organization. It's that simple.

The amount donated to our organization, which can be up to 26 percent of your total purchase (most companies are in the 2 percent to 5 percent range) qualifies for a tax deduction.

All you have to do is go to www.iGive.com, find what you want to buy and credit NBIA Disorders Association during check out.

An even easier way to donate is to use the site's "Shopping Window." Downloading the iGive Shopping Window is fast, doesn't affect the speed of your surfing and respects your online privacy. It is compatible with almost all Web browsers. When you type the name of any iGive store (like "Target.com") into your browser, your purchase will automatically count for a donation. That way, you can go directly to a company's Web site and our organization still gets credit if you have the Shopping Window and have previously registered at the iGive.com site for our organization to benefit.

iGive merchants include Hallmark, Adidas, Bath and Body Works, Discovery Store, Ann Taylor, Apple Store, Barnes and Noble, Best Buy, Circuit City, Coldwater Creek, Gap, Gateway, Expedia, Lands End, LL Bean, Office Depot, Red Envelope, Sephora, Sports Authority, Staples, Target, and many more. Right now, 654 stores participate in iGive.com.

iGive.com is the pioneer of the online-giving concept. It has been around since 1997 and lists more than 31,000 charities and non-profit organizations.

Each new member who registers at iGive.com (for free) and makes a single purchase within 45 days receives a bonus \$5 donation to NBIA Disorders Association.

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

Brent Bonfiglio
Joy & Avery Allen
Mr. & Mrs. Gaetano Bonfiglio
Gene Mochizuki

April & Tracie Flinn
Bud & Althea Brown
Mr. & Mrs. Lowell Judd
June McClure
John Menkes

Kevin Fox
Michael & Wanda Fox

Madison Frederick
Randolph & Doris Frederick

Tammie Holland
Debra Holland

Jenna Huffman
Evelyn Lee

Mayfield Family
Bill & Helen Burks

McGourthy Family
Mr. & Mrs. Paul Blinstrub
Tombo Burbridge
Sherry Cowan
Diana Deene
Sarah Phillips

Ashley Middendorf
Sandra Bettis

Mandy & Amy Miller
David & Mary Miller

Kerry Patton
Mr. & Mrs. Paul Buhay
Mr. & Mrs. Charles Waniak

Ken Stromsta
Vera Williams

Kimberly Wood
Frank & Debbie Cogliano
Gail & Rich Kelly
Simati & Susan Laupola

In Memory Of

Alyssa &/or Sabrina Barbiero
Norman & Marisa Barnes
Chris DeLuke
Mr. & Mrs. Donald Norman
Brian & Donna Novotry

Bruce Belcher
Mr. & Mrs. Paul Baglow
Jim & Elaine Finke

Austin Gray
Bradley Boaz

Kelsey Mayfield
Mr. & Mrs. Oscar Reeder

Wade Patton
Mr. & Mrs. Paul Buhay

Tony &/or Jean Venuto
Mr. & Mrs. Charles Murdock
Anella Roser

MESSAGE FROM THE PRESIDENT

IN 10 YEARS, MANY GOALS MET; WORK REMAINS



Patty Wood

I can hardly believe it has been 10 years since my first meeting with Dr. Susan Hayflick in Oregon and my impulsive decision to start a non-profit for NBIA while sitting in her office.

In some ways the time has flown by and in other ways, it seems like a lifetime ago. What did I do with all my spare time before that?

So much has happened, not just for our group, but lay advocacy groups as a whole. The Internet changed life for practically everyone, but for those with rare diseases and the people who advocate for them, it has made a profound difference. Isolation is no longer the norm.

When Kimberly was diagnosed in 1989, little information was available about NBIA, which then was called Hallervorden-Spatz Syndrome. It took me two years to find another family affected by the disease. Today, the Internet unites individuals and families who once were far apart from others like them, physically and emotionally.

Ten years ago, small lay advocacy groups were usually not much more than emotional support groups for affected families contacting each other by snail mail and usually restricted to the country where they lived. Today, many of us can truly say we have friends all over the globe.

Today, even small lay advocacy organizations are becoming partners with researchers and playing a big part in furthering research into their disease of interest. Our organization's efforts made scientific workshops possible in 2000 and 2005.

Our ability to raise funds has resulted in seven research grants being awarded since 2002, with more to come, including at least one this year.

In 2001, Dr. Hayflick's lab in cooperation with Dr. Jane Gitschier's lab in California discovered one of the genes that causes half of the cases of NBIA, a breakthrough in our understanding of the disease.

Our participation in the BioBank is another step up the ladder.

We are setting bigger goals each year. Ten years ago, I hoped for much of this; many of you dared to dream along with me. Together, we are steadily making progress. Will we be able to look back in another 10 years and say we have a cure for this disease? We can hope, can't we?

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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Dan & Cindy Venuto
Rose & Rod Walker

BioBank

(continued from pg. 9)

We are very excited to be moving forward with our BioBank. As one of seven founding members of the Genetic Alliance BioBank, we envisioned this repository moving research forward at a faster pace. Our participation was possible with a \$50,000 grant from the Wright Family Foundation.

One of our other founding groups, CFC International that is also a small, rare disease group, recently made news with the discovery of three genes related to their disease. This research was possible only because the organization had DNA and medical records available to a researcher that otherwise would have had no access to this material. It took only a few months for her lab to discover these genes, but it would never have happened without CFC International's participation in the Genetic Alliance BioBank. CFC International was named a co-author of the gene discovery, only the third time that a lay advocacy group had accomplished that feat.

The discovery may help with the study of cancer, as these three genes are part of a complex pathway called Ras/MAPK that has a central role in cell growth, where disruptions can lead to cancerous tumors. As cancer is not part of CFC, this sheds new light on the complex process of this pathway.

Please do your part to help NBIA Disorders Association further critical research. Many families report feeling helpless in their fight against NBIA, but this is a way to fight back and make a difference.



2082 Monaco Ct.
El Cajon, CA 92019-4235

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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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from discovery to cure

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