

## Make plans now to attend NBIA's family conference

It's time for NBIA families from around the world to meet again.

After months of planning, the Fourth International NBIA Disorders Association Family Conference has been set for May 4 to 6, 2007, at the Embassy Suites Hotel Cincinnati NE, 4554 Lake Forest Drive, Cincinnati, Ohio.



*Embassy Suites Hotel in Cincinnati has an atrium with the hotel rooms surrounding this beautiful spot for lunch and socializing after family meetings.*

Registrations for the conference will be available in early January at our Web site. We are busy planning an informative and fun weekend for all NBIA families, friends, members of the medical community and people interested in NBIA.

*Individual family appointments with some members of our SMA B will also be available, primarily on Thursday, May 3.*

We have a variety of stimulating topics on tap — including time for families and NBIA individuals to mingle. Those who have attended past conferences said the support and information they gain from other participants has been the most meaningful part of the weekend to them.

Topics that families have requested and that will definitely be  
(see *Conference* on pg. 3)

## NBIA board awards new research grant to study patients with two NBIA genes

*By Patricia Wood*

Fundraisers by NBIA families have paid off, enabling the NBIA Disorders Association board to award another \$30,000 research grant. It will go to Dr. Susan Hayflick's lab at the Oregon Health & Science University and is the fifth such grant her lab has received among eight the board has awarded in five years.

Hayflick's latest project will look at molecular changes in cells of patients with two genetic forms of NBIA. The genes involved are *PANK2* and *PLA2G6*. By identifying cellular changes that are common to both forms of NBIA, her lab expects to generate new understanding of the disease process and also identify promising new targets for therapies.

Research support from the NBIA Disorders Association continues to be a critical resource to enable investigators to generate preliminary results so they can compete for funding from the National Institutes of Health to carry the research further. In the past, \$30,000 of seed funding has blossomed into \$1million in federal grant support. The NBIA board considers that a good return on its investment.

This is the first time the organization has used its Scientific & Medical Advisory Board to review grants and advise the Board of Trustees, which has the final say on grant awards. Before, the National Organization for Rare Disorders evaluated the grant proposals and recommended awards, for a fee of \$5,000 per grant.

Dr. Hayflick serves on NBIA's SMAB and recused herself from the review process to avoid a conflict of interest.

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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-profit in Germany who works with us in the promotion of research and treatment of NBIA, can be contacted at the following address:

#### **Hoffnungsbaum e.V.**

Hardenberger Str. 73

42549 Velbert

Tel.: 02051/68075

Web.: [www.hoffnungsbaum.de](http://www.hoffnungsbaum.de)

E-Mail: [hoffnungsbaum@aol.com](mailto:hoffnungsbaum@aol.com)



## 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.

## Conference

*(continued from page 1)*

covered are the latest research findings, deep brain stimulation treatment and various other treatment options.

Individual family appointments with some members of our Scientific & Medical Advisory Board will also be available, primarily on Thursday, May 3. Any families or individuals interested in appointments need to fill out a questionnaire so we can match you with one or more doctors who can best answer your questions or concerns. They will be able to help with topics such as genetic testing; a sudden decline in function; significant increase in dystonia or other recent changes; current medications and trying new medications; DBS — what is done, how does it work, when should it be considered; Baclofen pump; botox; changes in vision and eye problems; and any other concerns you might have regarding NBIA. Please contact [pwood@NBIAdisorders.org](mailto:pwood@NBIAdisorders.org) as soon as possible if interested in one of these appointments. This is a unique opportunity to meet with a leading NBIA expert.

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## You can help send a needy family to the NBIA conference in May

Some NBIA families very much want to attend our family conference to be held next May in Cincinnati, but they can't afford to go on their own. In past years, some families have attended the conference thanks to the generosity of our donors.

**If you would like to help sponsor a family or an individual, please return the Family Conference donor slip inside the contribution envelope included with this newsletter.**

We have families from as far away as India, Australia and South America who already are wondering if there will be scholarship assistance for them to attend. We also have many families in the United States who, because of high medical costs and the financial burdens of this disease, are too depleted to add one more cost. Yet, they desperately need to be around others who are coping with this difficult diagnosis.

We often hear from our families that they never met anyone else with the disease until they came to one of our conferences. Your donation, regardless of the amount, could make a world of difference to them.

## Cincinnati fundraiser brings in \$10,000 to help support the 2007 NBIA family conference

*By Susan Laupola*

A dinner and silent auction in Cincinnati netted \$10,000 for the NBIA Disorders Association and launched the 2007 NBIA Family Conference on a healthy path. All of the proceeds from the fundraiser will go toward the conference, which also will be held in Cincinnati.



*Master of ceremonies Richard Kelly congratulates Mary Tapke on winning a raffle basket. Committee member Gail Kelly is on the right and attendee Su Truman looks on.*

The fundraiser was organized by NBIA Disorders Association board members Mary Tapke and Susan Laupola. Board president, Patty Wood, was in attendance at this first fundraiser held in her hometown Oct. 21.

For the \$20 price of admission, participants feasted on a lasagna dinner and a large assortment of homemade desserts. They also bid on silent auction items, bought raffle tickets on a variety of gift baskets and took chances on our grand prize electronics drawing which included an IPOD, DVD recorder, and multi-phone set. Throughout the evening volunteers sold split-the-pot tickets, NBIA 10-year anniversary cookbooks, T-shirts, and pins. We also had so many donated desserts that our MC even began to auction them off.

Although we were not fortunate enough to have any NBIA children or adults present, we know they were with us in spirit. A table was set up with NBIA posters, newsletters, and brochures and a DVD was shown during the evening that gave our guests a chance to see the wonderful families they were there to support.

*(see Cincinnati on pg. 4)*

## Cincinnati

*(continued from page 3)*

The DVD was narrated by Patty Wood who told us the names and hometowns of each of the individuals as they went by on the screen. Many thanks to Patty and Davida Strauss for putting this DVD together in time for the event.



*Patty Wood narrates video showing NBIA individuals at Cincinnati fundraiser Oct. 21.*

It could not have been such a success without the generosity of our many donors. Individuals who have no connection to NBIA (or in fact have never even heard of the disease) were more than willing to support it. Private donations covered our food expenses, raffle items, hall rental, liquor license fee and all of our auction items and gift baskets.

As anyone who has held a fundraiser knows, it takes several dedicated individuals who are willing to give many hours of their time to plan and organize such an event. Mary and I would like to give special thanks to all of our family and friends who joined us on this occasion and especially to our fellow organizers: Gail Kelly, Vicky Stapleton, Patty Bunke, Gary Hampton, and Gina Moore — we couldn't have done it without them!

We would also like to thank our volunteers who either helped in the kitchen, assisted in decorating the hall, provided wonderful musical arrangements, sold raffle tickets, served drinks at the bar, took pictures or helped in other ways: Diane Murdock, Tony Venuto, Diane King, Sarah King Tamsuhkin, Melanie Seta, Sam Laupola, Katie Laupola, Max Laupola (and his girlfriend Ashley), Derek Scott, Ed Kelly, Alex Moore, Anna Bunke, Melissa Farrell, Holly Kahles and Ron Stapleton.

Finally, thanks to our master of ceremonies — Richard Kelly. His unique sense of humor and generosity had everyone entertained until the last minute and all were pleading with us to hold the event again next year (which we definitely are considering).

## Cincinnati Fundraiser Donors

Bob Ronkers Running Spot	Ellie Fabe
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Cappel's	Melissa Fabe
Cincinnati Art Museum	Georgetta Gambetta
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Cincinnati Zoo	Gary & Barb Hampton
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Dillard's Hair Styling	Holly & Mike Kahles
Domino's Pizza	Gail & Rich Kelly
Esquire & Mariemont Theatres	Vicky Kelso
Frisch's Restaurant	Bob and Ann Knodle
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Patty Bunke	Chris Taylor
Dorothy Burks	Vicky Weiner

## Fun walk engages friends and community; raises \$30,000 for research grants

*By Veronica & Gaetano Bonfiglio*

Our first event fundraiser since our son, Brent, was diagnosed with NBIA in 2003 was daunting to think about, but once we got going, it far exceeded our wildest expectations. We set a goal of raising \$20,000 by holding a Fun Walk at a local park in Fremont, Calif. Oct. 14, and ended up with over \$30,000!

Once before we had raised money for the NBIA Disorders Association by way of a direct letter campaign to close friends, but after reviewing the association's fundraiser package, and with guidance from Kris McGourthy and Patty Wood, we decided to try a Fun Walk. A two-mile paved path around a local lake seemed to be the perfect setting, so we sent invitations to our closest friends asking for volunteers to help organize the event.

With helpers on board, we brainstormed and generated letters

*(See Fun Walk on pg. 5)*

## Fun Walk

*(continued from page 4)*



*Gaetano Bonfiglio collects pledge sheets for Fun Walk at local park in Fremont, Calif. that raises \$30,000 for NBIA Research Fund.*

that could be customized for each business. We split up the workload and agreed to contact certain merchants for prizes and donations. We also signed up walkers and sponsors, and sold raffle tickets. We didn't advertise in the newspaper but we distributed fliers at friends' workplaces, schools, and a few local businesses.

We spoke to Brent's school principal who not only allowed us to set up a table during Back to School Night, but also encouraged the Merit Club to adopt the project. The kids sold ice-cream for three weeks and raised \$2,217 for the event!

Brent's former Montessori teacher allowed the kids to sell raffle tickets for two days. We recruited high school students needing community service hours to sell raffle tickets outside our local video store. The sales were so good there we decided in the future we should sell outside other stores with lots of foot traffic for at least three or four weekends.

We wish we had started planning earlier. It took longer to get the proper permits from the city recreation department than we had thought. Also, several businesses told us that their allowance for charitable donations had been reached and we should have applied earlier. Nevertheless, we were fortunate to get wonderful prizes and contributions.

Our good friend Pilar Bonilla, who is employed by Commercial Casework Inc., rallied friends and coworkers to sponsor the event. Her wonderful boss, Bill Palmer, encouraged his employees by offering to match their donations. Their generosity translated into \$4,920.

Another NBIA family, Donna, Ron and Jon Stretter joined us, all the way from the Napa Valley. It was very special to meet another NBIA family for the first time.

We also saw friends we had not seen in a long time, and many of them stayed the whole day, enjoying snacks and many of the activities, including crafts, board games, soccer and face-painting. Play-Doh turned out to be a surprise hit with kids and adults alike. Everyone had so much fun they asked if we'd do it again next year.

We owe a debt of gratitude to our wonderful core volunteers, Gladys Adra, Paresch Bhakta, Giuseppe Bonfiglio, Pilar Bonilla, Julia Cerna, Sherry Ghassimien, Norma Iglesias, Kuldeep Kalonia, Ali & Parvaneh Khymehdooz, Mabel Moreno, Henry Pegueros, Minnie Uppuluri and Robin Yarmovsky.

Also, special thanks to our gold sponsors: Commercial Casework, Inc., Gifford Foundation, Santa Barbara Travel Bureau, Centerville Junior High School, Mabel Moreno & Kuldeep Kalonia; and to our Silver sponsors: Minnie & Venkat Uppuluri, Paresch & Kuki Bhakta, Vahe Sarkiss, Behrooz Shishegar, Kami and Eva Shishegar, Trader Joe's, City Beach, and Harmonious Healing Center, Angela and Aaron Allen, Ignazio and Enza Bonfiglio, Meheran Atae, Patricio and Norma Dauguet, Show and Sell Realty.

And a million thanks to all of our volunteers, merchants, walkers and their supporters.

### Food & Gift Donors

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## Fun Walk Fundraiser Donors

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## Fun Walk Fundraiser Donors

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## Queen Bee Golf Marathon raises \$25,000 for research

By Rich Leap

One of the cardinal rules of fundraising is to build the event around something you like. Outside of family time, golf is my favorite pastime. So, we planned the Queen Bee Golf Marathon at Piedmont Country Club in Northern Virginia for Oct. 9.

The Golf Marathon was a new concept to all who played. The goal was to play 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. Each golfer committed to try and raise \$1,000.

Part of the sponsor process was an option for a hole sponsorship. This was a very successful endeavor as every hole on the course ended up with a sponsor. We had a goal of \$20,000 for the event.

Quest Diagnostics came on board as the marathon sponsor and picked up the entire cost of the event. This ensured that 100 percent of the money raised went directly to the research fund. In addition, we were able to obtain a number of prizes for the event

through local sponsors to help keep the play interesting throughout the day.

The volunteers were out before sunrise, setting up the registration table and preparing the course for the event. They also filtered throughout the course making sure the players had enough drinks and snacks.

The day turned out perfectly: 70 degrees, sunny and no wind — a golfer's dream. Eighteen golfers (17 men, 1 woman) and one clever tag team were on the course. For the tag team, four guys played 25 holes apiece to support one injured golfer who had signed up for the event. This allowed him to reach the 100-hole goal and maximize the pledges. Play began at 7:30 with twosomes on every other hole.

During the day, my daughter, Brittany, who has NBIA, was able to make her way around the course to meet the golfers and take a photo with each group as they passed by the clubhouse. Brittany is no stranger to golf carts (she likes to ride along with me), but zipping around with her Aunt Nadine and Cousin Samantha was probably the highlight of her day.

The golfers played diligently. By the end of the day, 1,526 holes had been played — an average of 85 holes per person. David Eliot and

(see *Queen Bee Golf Marathon* on pg. 8)

## NBIA 10th anniversary cookbooks flying out the door like hotcakes

The association's 10th anniversary cookbooks have been moving as fast as the plates at the newest trendy restaurant in town. We met our goal of selling 1,000 books in just seven weeks and faced a dilemma. How many more should we order? We settled on 300, the number of recipes in each cookbook.

The books are here, just in time for holiday gifts for friends and family. They also would be great ways to thank the teachers, aides, nurses, hairstylists and many others on your list!

Cookbooks with recipes provided by NBIA family and friends across the world can be purchased at our Web site at [www.NBIAdisorders.org](http://www.NBIAdisorders.org) for \$12. Shipping and handling costs are \$3.50 per book in the United States and Canada and \$11 per book anywhere else in the world.

For orders in the United States of 15 books or more, please contact Patty Wood at [pwood@NBIAdisorders.org](mailto:pwood@NBIAdisorders.org) or call (619) 588-2315 to make arrangements with no shipping fees.

Many of our NBIA families chose to sell cookbooks as their fundraiser for the year (we asked all NBIA families to have one fundraiser in their community this year) and that contributed heavily to our success. We thank everyone who participated and helped us raise more than \$12,000 in sales so far for our organization. It is not too late if you also would like to sell cookbooks as a fundraiser in your community. Just let Patty know how many books you'd like to try and sell.

## Queen Bee Golf Marathon

*(continued from page 7)*

Kevin McDonald reached the 100-hole goal along with the tag team put together by John Moore. Dinner and awards were handed out at the end of the day, with a tired but supportive group of golfers vowing to play again next year.

We collected more than \$25,000 in pledges. The players averaged more than \$1,000 each, allowing us to surpass our goal.

Thanks to Betty Ann Senf (Eye of the Needle) for doing such a fine job with our event shirts, Peg Sherwood for creating the Hole Sponsor signs and Candice Helmlinger for designing the golfer packet.

Also, thanks to the golfers, sponsors, volunteers and prize donors for making the Golf Marathon a great success and for contributing to our goal of finding a cure and future prevention.

Special thanks to marathon sponsor, Quest Diagnostics; Hole-in-one sponsors, Solid Foundations; Hole Sponsors, Eye of the Needle Embroidery; Jim Joyce and Matt Malloy; Pittsburgh Police - Zone 2; Pittsburgh Police - SWAT; MaryDawn Miller; Cindy and Allen Melton; Washington Courier; Quest Diagnostics - Specimen Processing Department; Data Systems Hardware; J & K Moving and Storage; Creative Direct Response; North Texas Pan American Soccer and Tender Heart Enterprises.

We are grateful to our volunteers, Charo Aguirre, Michelle Ayala, Debbie Files, Robin Firestone Patti Freeman, Candice Helmlinger, Judy Leap, Rita Leap, Nadine McDade Samantha McDade Casey Parker and Gine Portnoy and our prize sponsors, Red Fox Inn, My Haberdasher, Piedmont Country Club, El Tio Restaurant, Ruby Tuesday, Golf Tour Trailer, Bubbles Hair Salon, Sunnybrook Golf, Designer Fitness, Sodexho and Modell's Sporting Goods.



*Queen Bee Golf Marathon in Haymarket, Virginia*

*Golfers Pictured: (Front Row kneeling l-r)  
David Eliot, Kevin McDonald, Rob Seaman,  
James Penn, Bob Guiney, Rich Leap*

*(Second Row Standing l-r)  
Sid Vikram, Jay Stewart, Mike Leap, Chris Kase, Mitch  
Russell, Mike Knapp, Florinda Russell, Tom Huard, Frank  
Wood, Rich Erikson, Kevin Rollison, Jay Portnoy, John Moore*

*(Not Pictured)  
Mike Jones, Bruce Weyrick,  
Len Vincent, Bryan Firestone*

## Queen Bee Golf Marathon Fundraiser Donors

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*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

**Barbiero Family**  
Paul Sherman, Jr.

**Becky Belcher**  
Lois Clifford

**Brent Bonfiglio**  
Nancy Misra

**April & Tracie Flinn**  
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Mr. & Mrs. Charles Waniak

**Ken Stromsta**  
Mr. & Mrs. Charles Sprackling

**Kim &/or Patty Wood**  
Jill Kosen  
Georgetta Poston  
Mary Ann Roser

### In Memory Of

**Alyssa &/or Sabrina Barbiero**  
Arlindo Calado  
Deborah Ellinger  
Don & Madeline Norman  
Christopher Roberts  
Michelle Ryan-Rivers & family  
Bob & Pat Sweeney  
Peter Tarantelli

**Bruce Belcher**  
Douglas & Joy Lamos  
Hugh Schrader

## Stretter Family Fundraiser Donors In Honor Of Jonathan Stretter

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### Stretter Family Fundraiser

The Stretter family sent out a letter this fall to 400 family members and friends asking for their help in the fight against NBIA. Over \$5,000 for our Research Fund has come in so far, in honor of Jonathan Stretter, who has NBIA.

Jonathan Stretter's story will be featured in our April 2007 newsletter.

## MESSAGE FROM THE PRESIDENT



*Patty Wood*

As another year comes to a close and we prepare to celebrate the holidays with our families, I am grateful, more than ever, to all of the families who held fundraisers this year. I am especially cheered by the children who took the initiative to hold a bake sale or donate money because they know a child affected by NBIA.

We told several of those stories throughout the year in our newsletter. I also recently received this letter that I would like to share with you:

Dear NBIA Disorders Association,

This year, our friend Brittany Leap, whom we have known for five years, was diagnosed with NBIA. We met Brittany in a program our moms taught at church. Because we are all home-schooled, we got to spend more time together and we became great friends. Our moms are close friends, too.

After finding out that Brittany had NBIA, my brother, sisters and I wanted to do something to help. Every year, my siblings and I celebrate all of our birthdays with one big birthday party. This year, we decided that we would not ask for gifts, but would instead ask for donations to NBIA. Together, my brother Biaggio (6), my sisters, Elly (8), Lia (2) and myself, Josie (10), collected \$650. This helped us understand that opening gifts gives you joy for a moment, but opening your heart to help a special friend gives you joy forever.

Sincerely,  
Josie Corrado

When I think about the future of our organization, I don't worry too much when I see children like this. They already have a spirit of compassion and giving. May the special moments of this holiday season inspire you to make a difference in someone's life.

*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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| Marisa Barnes           | Microsoft Giving Campaign  |
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- |                           |                         |
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## Tykes riding their trikes raise \$950 to fight NBIA

Thanks to Wonderland Nursery School in Schenectady, N.Y., whose toddlers once again pedaled 50 laps on tricycles and two-wheelers, netting \$950 this year for NBIA. This is the fourth year the school has donated to the NBIA Disorders Association through their yearly fundraiser.

The donation is in memory of Sabrina and Alyssa Barbiero of Schenectady who both passed away in 2004. A teacher at Wonderland, Leslie Leo-August, is a friend of the Barbiero family.



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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

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

Visit our Web site at

[www.NBIAdisorders.org](http://www.NBIAdisorders.org)

*from discovery to cure*