

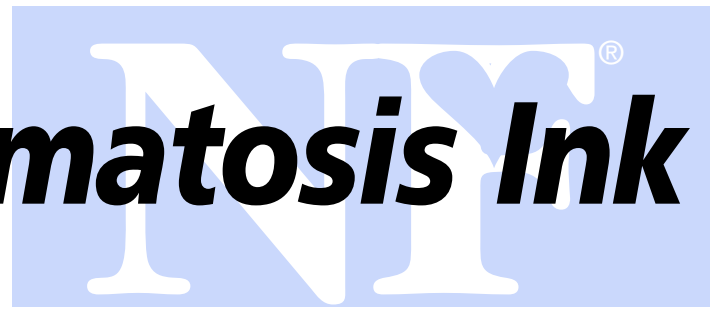
# Neurofibromatosis Ink

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## NF Gains Attention in Washington: More Research Funds Sought



The U.S. House of Representatives and the U.S. Senate Appropriations Committees have included neurofibromatosis in their reports commending the National Cancer Institute, the National Heart

Lung and Blood Institute, the National Institute of Neurological Disorders and Stroke, the National Institute of Child Health and Human Development and the National Institute on Deafness and Communicative Disorders of the National Institutes of Health for their involvement in NF research and encouraging them to continue to make NF basic and clinical research and clinical trial grants available to investigators interested in NF. The report language for FY2006 has the strongest emphasis given to NF in the 15 years of working with Congress. For the first time, the National Institute of Child Health and Human Development is called upon to issue grant proposals (RFAs) in NF because of learning disabilities connected with NF.



The NF Research Program of the Department of Defense administered through the Department of Army continues to be quite a success story because of the small investment made over the last 9 years and the tremendous progress toward treatments

for NF and numerous other conditions associated with NF. We are asking Congress for \$25 million again this year for the Army's NF Research Program to support the Army's NF Clinical Trials Consortia which has been created to conduct clinical trials on pharmaceutical treatments for those with NF, genetic mechanisms, and other innovative investigations into the cause of the many symptoms of NF and several cancers.

For all these years, our champions in Congress have been Congressman John Murtha (PA) and Senator Tom Harkin (IA). We give our continual gratitude to these tireless supporters of NF research and all who are affected by NF.

### What you can do help:

**NF Families and Friends** write your Congresspersons and Senators thanking them for their past support and asking their continued support of NF research at the National Institutes of Health and the NF Research Program in the Department of Army.

**NF Researchers** — Aggressively seek NIH and Army grants, bring new researchers into the NF field, and continue to pursue new avenues that could lead to effective treatments for NF and eventually a cure for this complex and unpredictable disorder.

## New Officers of NF, Inc.



John, Rosemary, Barbara and Miguel.

**Miguel Lessing, President** (right), brings to NF, Inc. 25 years of experience working on consumer products' multinational companies in general management, finance and operations, with firsthand exposure to multi-cultural environ-

ments and start-up organizations. He grew up and obtained CPA and MBA degrees in his native Argentina and has lived in various countries before settling in the USA in 1983. He resides in Wellesley, Massachusetts. His elder son has NF1.

**Barbara L. Brush, Secretary**, lives in San Diego, California. She holds an MFA in Creative Writing and teaches in the Rhetoric and Writing Studies Department at San Diego State University.

**Rosemary Anderson, Vice President**, is from Grand Rapids, Michigan and is the mother of a 24-year old son with NF1. She is also president of the NF Support Group of West Michigan which recently celebrated its 20-year anniversary.

**John Everett, Treasurer**, is the Executive Director of Community Involvement Programs, a nonprofit organization that provides support for 1,000 individuals with developmental or mental health disabilities in Minneapolis, Minnesota. He holds a Masters degree in Administrative Science from Johns Hopkins University and has a 9 year old son with NF1.

**Brenda Duffy received an engraved crystal plaque commemorating her seven years of service as President of NF, Inc. She currently holds the position of Immediate Past President of NF, Inc.**

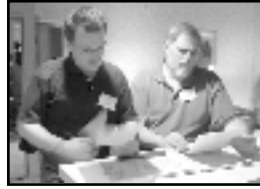


**Penny J. Schwartz, DSW, with her parents when she received the 2003 Distinguished Service Award from the Brookdale Center on Aging at Hunter College in New York City.**

We want to welcome Penny J. Schwartz, DSW, of Mount Sinai Hospital in New York City to the NF, Inc. Board of Directors. Dr. Schwartz has been associated with NF since 1979 when she was the social worker for the Department of Neurosurgery at Mount Sinai. She teaches in the Department of Community Medicine of Mount Sinai School of Medicine and is an Adjunct Professor at the Hunter College School of Social Work.

## NF2 Hospital Orientation Packets Now Available

*NF2ers review the Hospital Orientation Packet at the NF2Con in Las Vegas, April 2005*



NF, Inc. has put together a packet of information/aids designed to answer many questions, give tips, and provide a little specific assistance especially for the hard of hearing or deaf patient who is about to go to the hospital for surgical procedures, imaging, etc.

Included in the packet are many helpful websites dealing with everything from disability services, deafness, signing, patient advocates, and Social Security denial to a site where you can keep everyone with internet access up to date on the patient's condition with one entry.

"How to Make the Medical System Work for You" is a booklet authored by Donna Getz. There is also information on Mercy Travel, Angel Airlift, and the Association of Hospitality Houses, that might be of help if you have to travel for medical care.

Signs for your door or above your hospital bed are included. They read "Hard of Hearing" or "Deaf - Please Sign; Write; Speak Slowly." There is also a little sticker to put at the Nurses' Station to remind them you are deaf/hard of hearing; that way, when you ring the buzzer for assistance, they don't come over the intercom and expect a reply!

NF, Inc. has distributed this packet to 86 physicians listed in the NF2 section of their National NF Medical Resource Directory encouraging them to distribute this information to their patients, particularly those anticipating surgery.

If you need a copy of the NF2 Hospital Orientation Packet, please e-mail the NF, Inc. NF2 Representative at Marie. Drew@nfinc.org, providing your complete postal mailing address. It would be helpful for us to know where you have your surgery scheduled. If you do not have computer access, you may phone toll free 1-800-942-6825. A donation of \$5.00 to help cover the cost of postage and handling would be greatly appreciated.

## NF2Con 2005, Las Vegas



*Some of the attendees at the Las Vegas NF2Con in April visited Red Rock Canyon. They are shown releasing balloons in memory of friends who have died from NF2. "It was a very moving experience and watching these colorful balloons float away while choking back tears was possibly the highlight of the trip." The 2005 NF2Con was supported by*

*generous donations from the NF Support Group of West Michigan, NF, Inc. and NF, Inc.-Mid-Atlantic. Thank you!!*

## Daytona Beach Weekend – NF2 Crew Holiday, May 18-22, 2005

*Pictured are Beverly, Cindy, and Marie (right) on the beach.*



Some members of the online NF2 support group, the NF2Crew, like to travel a bit.

Our latest "adventure" was a long weekend in Daytona Beach, Florida. Does it look like we are having fun? Because we were! The weather was beautiful, the timing was perfect as it was not crowded, and we had a fun weekend at the beach! On Saturday the group traveled to the home of member Mike Ashley, who lives in Jacksonville. Mike is a superb cook, and we decided to make him prove it! He did!! The Ashleys were wonderful hosts, from their deaf Dalmatian to the colorful parrot – and everyone had a ball in the pool!

*by Marie Drew for The Crew*



[www.nf2crew.org](http://www.nf2crew.org)

## NF2 References

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Dunningham CD, Friedman RA, Brackmann DE et al. Neurologic skull base surgery in pediatric patients. *Otol Neurotol* 2005 Mar;26(2):231-236.

Evans DG, Moran A, King A, et al. Incidence of vestibular schwannoma and neurofibromatosis 2 in the North West of England over a 10-year period: higher incidence than previously thought. *Otol Neurotol* 2005 Jan;26(1):93-97.

Utermark T, Kaempchen K, Antoniadiis G, et al. Reduced apoptosis rates in human schwannomas. *Brain Pathol* 2005 Jan;15(1):17-22.

**NF2  
Advocure**  
advocates for a cure

Advocure is a working advocacy group for the NF2 Crew. Recent advances in our understanding of NF tumorigenesis and signal transduction have taken us into the era of translational research whereby it is possible to screen and identify existing drugs or compounds that act on key targets, potentially curing both NF1 and NF2.

Advocure is an international coalition committed to ensuring the rapid translation of this knowledge into targeted therapy for the NF community. They monitor relevant research and drug developments world-wide and lobby to achieve their goal of expediting much-needed systemic therapy for this devastating central nervous system disorder.

*Advocure, P.O. Box 1273, McMurray, PA 15317*

*contact@advocurenf2.org*

*http://advocurenf2.org/*

## CAMP NEW FRIENDS

Camp New Friends in Sunshine, Maryland was the first camp on the East Coast for children with NF1 and NF2. It was established in 2004 by Children's National Medical Center in Washington, DC in collaboration with NF, Inc. The wildly successful 2005 camp doubled the number of campers and counselors from last year. They came from California, Arizona, Texas, Mississippi, Michigan, Illinois, Indiana, New Hampshire, Massachusetts, New Jersey, Pennsylvania, Virginia, Maryland, the District of Columbia and even China!

You can see more pictures on [www.nfinc.org](http://www.nfinc.org). Camp New Friends 2006 will begin registration in January for the week-long camp July 22-28. For more information call Sandy Weinstein, MSW at Children's National Medical Center at 202-884-5142 or e-mail [scushwei@cnmc.org](mailto:scushwei@cnmc.org).



*Carnival Day brought visitors Katie Vandingham (right) and Becca Magnone from Capitol Associates in Washington, DC pictured with Justin Nesmith, a veteran NF counselor from Arizona.*

*For this camper, catching a fish in the lake was a new experience that had to be caught on film!*



*On Carnival Day campers went fishing for ducks and fun prizes.*



*The inside sport of billiards was very popular on all of the hot weather days at camp.*



*Col. Janet R. Harris, M.S.N., Ph.D., Director of the Congressionally Directed Mandated Research Program, is pictured with Roger Packer, M.D., Chairman of the Department of Neurology at Children's National Medical Center, who has a grant to study NF from the Department of Defense; and Mary Ann Wilson, a Board Member of NF, Inc. Col. Harris spent an afternoon at the camp watching the outdoor games, walking with the horses and campers, and having dinner in the cafeteria with everybody.*



*Awards were given to campers and counselors during the closing program at the Frog Playhouse.*

## Gillian Anderson Fans Raise \$23,000 for NF, Inc.



What could possibly make a pen and ink caricature worth more than \$10,000? The answer is obvious to fans of the long-running TV series, "The X-Files" – the autographs of both Gillian Anderson AND David Duchovny on a one-of-a-kind drawing. Resuming a tradition from previous years, actress Gillian Anderson's official

website, [gilliananderson.ws](http://gilliananderson.ws) (nicknamed GAWS), hosted an on-line auction to raise money for NF, Inc. During the three-week event, which ended on May 8th, 61 autographed items were bid on by devotees from around the world.

The fiercely fought-over caricature was one of four hand-drawn cartoons by gifted Italian caricaturist, Maurizio "The Hand" diBona. Two were of Gillian as herself, and two depicted Gillian as FBI Agent Dana Scully, Gillian's character on "The X-Files." Among other sought-after offerings were personalized autographed photos, gowns Gillian wore to award shows, a script from the soon-to-be released film, "The Mighty

Celt," Gillian's childhood violin, and the most unusual – a white plaster mold of Gillian's face. The winning bids came from all over the globe. Everyone who participated had an opportunity to learn about neurofibromatosis. And why raise money for NF, Inc? Gillian's dedication to improving the lives of all those living with NF is inspired by her brother, Aaron, 24, who was diagnosed with NF1 at age three.

California college senior Becca Sherrill, GAWS administrator, photographed all items, posted them on eBay, and packaged and shipped them to winners. Her partner in the auction's success was volunteer, Mari Garcia, of San Francisco, who promoted the auction, provided item descriptions, handled all communications, kept records, and handled countless other behind-the-scenes tasks.

NF, Inc. wishes to thank all auction donors, bidders, winners, promoters and onlookers, most especially Gillian and Rosemary Anderson, Maurizio diBona, David Duchovny, Mari Garcia, Becca Sherrill, Diane MacDonald, Cheri and Rob Stewart, June M., the members of HAL and the late Paul Gallagher.

## NF, Inc. Member Organization News

### ARIZONA

Teen Team and Adult Support Groups started again this summer. Plan to participate in our annual Golf Classic in October. Preparations are being made for an international NF camp in Arizona next summer. For more information, call Nicole Nicks at 480-945-9650 or e-mail [nfaz1@cox.net](mailto:nfaz1@cox.net).

### CALIFORNIA

Our first year was a tremendous success!! Our first educational meeting was held in February 2004 in Vacaville with geneticist Samuel Yang, M.D. as the featured speaker. To honor May as NF Awareness Month, a small group participated in our first walk for NF in May 2004 in Woodland and Kim Bischoff from the Illinois/Midwest NF, Inc. talked to the group about NF. Michael Edwards, M.D. spoke at the October 2004 educational meeting. Ms. Cynthia Soloman of Access Strategies was the guest speaker at the January 2005 educational meeting. More than 80 walkers participated in the First NF Walk in Vacaville in March and Alcino Silva, Ph.D., from UCLA, a pioneer scientist in NF and learning disabilities, spoke at our May educational meeting in May. Tena Rosser, M.D., child neurologist from Los Angeles Children's Hospital and Camp New Friends resident physician, was our guest speaker for our first meeting in Los Angeles.

#### **Do You Already Recycle? Or Do You Toss Out Your Items In The Garbage? Why Not Recycle For Neurofibromatosis?**

NF, Inc. California started saving old cell phones and empty cartridges in February 2004. Since then we have been able to collect almost \$6,000.00. Can you help us collect more? It is really easy to do. Contact the California office for some flyers and then just start asking family, friends, neighbors, co-workers and businesses that you visit. You will be surprised on how easy and fast you can start collecting these items.

There is no cost to you or the busi-

ness collecting them. The businesses can mail the items in or you can collect them and mail them in. Once they are returned, then we get credit for them. More information can be found on our website <http://www.nfnocal.org/recycle.htm>.

The California office can be reached at 707-469-0467 or by emailing [info@nfnocal.org](mailto:info@nfnocal.org)

#### **Successful Meeting in Southern California**

On Saturday, June 4, NF, Inc.-CA held its first Southern California meeting in Los Angeles at UCLA's Gonda Center. One of the highlights of the event was an "Ask the Doctor" session with guest speaker Dr. Tena Rosser, child neurologist and director of the NF Program at Children's Hospital in LA. Dr. Rosser gave an informative Power Point presentation on NF1 and NF2, followed by a very helpful question-and-answer period. Many thanks to Dr. Rosser for sharing her time, knowledge, and experience with us!

NF, Inc.-CA would also like to express our appreciation to Dr. Alcino Silva and his wife Tawnie for graciously arranging the UCLA meeting space, and to Ms. Tara Gentile for opening her home to the NF families and friends who spent the afternoon brainstorming ideas, wishes and plans for the organization. Thanks to Debbie Bell for her tireless leadership; to all those who offered assistance before, during, and after the meeting; and to the many individuals and families who attended. We hope to see everyone again at future events and activities!

#### **Winner of National Doodle Day Contest**

California resident Jennifer Evans' artwork won first place in the 17-24 age group category of the National Doodle Day competition. The Doodle Day contest is a UK-based fundraising event that aids two charities: The Neurofibromatosis Association and Epilepsy Action. Jennifer became involved with the contest in honor of a close friend who has NF. She shared her winning artwork with the group and encouraged everyone to participate in future contests. Program



details and winning Doodles, including Jennifer's, may be viewed online at [www.nationaldoodle-day.org.uk](http://www.nationaldoodle-day.org.uk)

Congratulations, Jennifer!

The next Northern California educational meeting is scheduled for Saturday October 15 in Vacaville. The next Southern California educational meeting will also be in October, 2005. For more information, visit the website [www.nfcalifornia.org](http://www.nfcalifornia.org) or e-mail [info@nfcalifornia.org](mailto:info@nfcalifornia.org) or call Debbie Bell at 707-469-0467.

### ILLINOIS/MIDWEST

Mark your calendars for the Fall Symposium to be held Saturday, October 22nd, at the beautiful McDonald's Campus in Oak Brook, IL. Join us for an exciting day in which you will meet other families dealing with NF and hear specialists tell us about the latest progress in NF research, current treatment options and practical advice for living with NF. Some of this year's speakers will include David H. Gutmann, M.D., Ph.D., NF Clinic, St. Louis Children's Hospital; James Tongsgard, M.D., NF Clinic, University of Chicago Hospitals; and Dr. Derald E. Brackmann, Otologist/Neurotologist, House Ear Institute, Los Angeles, CA. Paul Mendelsohn, past President of NF, Inc. and formerly with the Center for Medicare & Medicaid, will talk about Insurance and NF. We will have a break out session for NF 1 and NF 2 in the afternoon and finish the day with an NF Family Panel. If you are interested in Moving Forward and Reaching Out, give the IL NF, Inc. office a call for further details at 630-932-8111 or email [ilnfinc@sbcglobal.net](mailto:ilnfinc@sbcglobal.net).

On June 4th, over 600 individuals enjoyed a warm spring morning together while raising much needed funds for NF Research. After turning in our donations, we put on our new orange Great Steps T-Shirts and enjoyed a continental breakfast. Mayor Pradel and Pat Simmons started our day with fun facts – then the 2.5 Mile walk began. After the walk the Music Men entertained us with the latest hits while we had pizza, hot dogs and ice cream for lunch. Then the much

anticipated raffle began. This year's top fundraisers were awarded two tickets on United Airlines. This event at the Naperville Riverwalk is one of our favorites and will be back again the first Saturday in June 2006.

This year's Golf Outing once again took place at the beautiful Klein Creek Golf Club in Winfield, IL on Friday, August 5th.

Many thanks to our Presenting sponsor LaSalle Bank as well as Professional Business Consultants, Inc., Dr. and Mrs. Jeffrey Visotsky, The Private Bank, Curtis R. Imel, D.D.S., P.C. and our many other sponsors.

Brian Korf's passion to help NF has kept this Golf Outing strong for the past 7 years. It will be held again next year the first Friday in August.

## INDIANA

We would like to Thank and say "Great Job!" to all of the counselors-in-training (CITs) at Camp New Friends in Sunshine, Maryland. The camp director and activities director couldn't say enough good things about these kids, including Skylar from Indiana. They were very proud of how responsible and hard working all of them were.

Recently there have been several new contacts and we are hoping the new families and friends will get involved with the organization. We are undergoing restructuring in Indiana. If you are interested in serving as an officer or want to volunteer and commit to making a difference in the lives of those affected by NF, please e-mail [gtDavis@peoplepc.com](mailto:gtDavis@peoplepc.com). For more information about the NF group and resources in Indiana, contact Pam Davis at 765-339-7206.

## KANSAS AND CENTRAL PLAINS

In May an Ice Cream Social was held at Zion Lutheran Church in Hutchinson where Nancy Prieb is a member. The event raised \$165 for NF and was matched by Trievent Insurance. On May 4th and 5th the Chapter had a booth at the Kansas Public Health Conference and in July the NF exhibit was displayed at the Kansas School Nurses Conference. Both conferences were held in Wichita and drew nurses from all over Kansas. On Sunday August 28, St. Paul's Lutheran Church in Wichita, where Gordon Prieb is a member, had an Ice Cream Social

with the proceeds going to NF. On October 6th the NF exhibit will be at the Kansas State Nurses Association in Topeka.

**For more information, call toll free 1-800-942-6825 or e-mail [nprieb@southwind.net](mailto:nprieb@southwind.net).**

Kansas and Central Plains continues to staff and finance the 800 number for NF, Inc. Phone calls come from all over the United States and recently a call came from Israel. Any donation to help support the 800 number would be appreciated.

**Please send donations to NF Kansas & Central Plains, PO Box 1792, Hutchinson, KS 67504-1792. Thank you!**

## MID-ATLANTIC

*Tom Paxton performing the powerful song he was commissioned to write for the 9/11 ceremonies held in New York City.*



Another successful "Afternoon Delight at Mimi's" with

Tom Paxton, international folk singer/composer, was held June 12 after the NF1 Symposium "What's New In 2005" at Children's National Medical Center in Washington, DC. An update on the NF1 research being conducted at Children's was presented by Roger Packer, M.D., and others with Ludwein Messiaen, Ph.D., from the University of Alabama explaining the NF1 DNA test as the featured speaker.

Penny Freeman, right, secretary of NF Mid-Atlantic, presented Sandy Weinstein, MSW, Director of Camp New Friends, with a check for \$3,500 for the 2005



NF camp. The funds were raised by her son Matthew's school in Glen Burnie, Maryland. NF Mid-Atlantic provided counselors, counselors-in-training, volunteers, host families, transportation for some out-of-towners who attended the camp, as well as campers and funding. We are already making plans for the 2006 camp.

Upcoming informational meetings are scheduled for Fairfax Hospital on September 25 for an update on NF research with investigators from the National Institutes of Health, some funded by the Department of Defense, and the 2004 and 2005 research conducted at Camp New Friends;

Hackensack, New Jersey on October 25 and in Virginia Beach, Virginia at the end of February 2006.

The 6th Annual "Italian Night for NF" benefiting the 2006 NF camp is being held on Saturday November 12 in Baltimore. A new fundraiser is being planned in Hagerstown, Maryland by Andrea, who has NF2, and her mother. Federal employees, military personnel, state employees and retirees, donors through the United Way, please designate Neurofibromatosis, Inc.-Mid-Atlantic in your 2005 workplace campaigns. Our organization is listed under the federation Local Independent Charities of America. Thank You!

For more information, visit our new website at [www.nfmidatlantic.org](http://www.nfmidatlantic.org), e-mail us at [nfmidatlantic@aol.com](mailto:nfmidatlantic@aol.com) or call toll-free at 1-866-261-1271.

## MINNESOTA

On September 18 we will be holding our "Steps for NF" walk-a-thon in Minneapolis. To participate in this event visit [www.walkforjustice.org](http://www.walkforjustice.org) and click on "groups" and you will see NF Minnesota.

The Neurocutaneous Syndromes Clinic Without Walls opened on August 1 at the Children's Hospitals and Clinics of Minnesota in St. Paul. For more information, call Elizabeth Siqveland, MS, RN, CNP at 651-220-6745 or e-mail [elizabeth.siqveland@childrenshc.org](mailto:elizabeth.siqveland@childrenshc.org).

The Chapter informational meeting is being held on Saturday November 5, 2005 from 1 to 4 pm. Representatives from the NF Clinics at Mayo Clinic, the University Fairview Genetics Clinic and the Neurocutaneous Syndromes Clinic Without Walls will participate on a panel. For more information, call 651-225-1720 or e-mail [johne@cipmn.org](mailto:johne@cipmn.org).

## NEW ENGLAND

### Trustee Program:

NF, Inc. New England Board member Naomi Stonberg recently hosted a Trustee Reception for over 60 guests. The purpose of the Trustee Program is to introduce new people to neurofibromatosis and to enlist their help in the fight to cure NF. After Naomi welcomed her guests, President Mike Harrington gave an overview of our mission and our many events and programs. Mike introduced Dr. Scott Plotkin from the Massachusetts General Hospital NF Clinic and the Harvard Medical School Center for NF and Allied Disor-

ders (CNFAD), who gave an update on research and clinical trials. Dr. Plotkin was followed by NF mom, Kristen Day, who told the group about her son Max and the many ways she works to create awareness and raise funds for NF.



*Shown in the photo left to right: Dr. Scott Plotkin and Dr. Anat Stemmer-Rachamimov from the CNFAD, with Lizzie Stonberg and her mother Naomi Stonberg.*

#### Upcoming:

The 4th Annual Mini Golf Event will take place on **Sunday, September 25th**. Begin with a round of golf at Golf Country on Rt. 114 in Middleton, MA between 9:00 AM and 3:00 PM. Then join us at The Prince Restaurant on Rt. 1 South in Saugus, MA for pizza, face painting, a raffle and fun!

Friends Bike Ride for NF, **October 1st and 2nd**. Andres Lessing and his dad Miguel Lessing will bike 180 miles from Provincetown on Cape Cod to Wellesley, MA in order to raise funds for Neurofibromatosis research. They are inviting Friends of NF to join in their annual fundraising ride. The funds raised will go to the Center for NF and Allied Disorders ([www.cnfad.org](http://www.cnfad.org)) of the Harvard Medical School. For more information visit their site at <http://www.friendsrideforNF.org/>.

**Monday, October 3rd**, The Annual Hickory Hill Golf Tournament, Methuen, MA, Sunday, October 9. Fun, golf contests, great food and prizes.

**Sunday, October 9th** a team representing NF, Inc. NE will run in the LaSalle Bank Chicago Marathon. To find the runner's pages go to [www.Justgiving.com](http://www.Justgiving.com) and enter the runner's name.

2nd Annual "Faces of NF Dinner" - **Friday, October 21, 2005** - American Legion, Medfield, Massachusetts. Contact Kristen Day @ [KCDay234@msn.com](mailto:KCDay234@msn.com) with any questions.

## Sweet Deal for NF



NF, Inc. is delighted to announce a very sweet deal with one of the Internet's most successful online food retailers, CoffeeCakes.com. Thanks to the generosity of CoffeeCakes owner and founder and mother of a child with NF, Sherry Comes, a percentage of every sale is donated to NF, Inc. Besides exquisitely delicious coffee cakes, you can order gourmet teas, coffees, cheesecakes, tortes, truffle cakes, teapots, travel mugs and more. All items are of the highest quality and make great gourmet gifts!

CoffeeCakes.com is the proud recipient of a customer-voted "Top Service Five-Star Award" for superlative quality and received a "Best Overall" rating by the *Wall Street Journal* in 2002.

You may also order the blue NF, Inc. wristbands through the CoffeeCakes website in packages of 10 for \$10. Visit [www.coffeecakes.com](http://www.coffeecakes.com) to view their high quality and varied products.

Take advantage of our NF 10% off any item coupon from CoffeeCakes.com. Call anytime 1-800-830-2696 and mention this NF coupon code or enter NF in the coupon field when ordering online. The 10% coupon offer expires December 31, 2005.

## Helpful Resources

### Neurofibromatosis: A Handbook for Patients and Families, 2nd Edition

Authors: Bruce Korf, M.D., Ph.D., Allan Rubenstein, M.D.  
(2005) 264 pages \$79.95  
Thieme Publishers 1-800-782-3488 or e-mail [customerservice@thieme.com](mailto:customerservice@thieme.com)

### A Parent's Guide to Learning Disabilities Associated with NF1

British Columbia Neurofibromatosis Foundation  
(2005) 45 pages \$5.00 (US dollars)  
1-800-385-2263 or e-mail [bcnf@bcnf.bc.ca](mailto:bcnf@bcnf.bc.ca)

### 14 Stories: A Guide for Patients and Families Living with Neurofibromatosis

Texas Neurofibromatosis Foundation  
(2005) four-color booklet, 40 pages \$10.00  
1-800-942-8476 or visit [www.texasnf.org](http://www.texasnf.org)

### A Consumer Guide for Getting and Keeping Health Insurance

(51 guides – one for each state and the District of Columbia)  
Georgetown University Institute for Health Care Research and Policy  
[www.healthinsuranceinfo.net](http://www.healthinsuranceinfo.net)

### National Patient Travel Helpline

Help is available to sort through details of your travel needs and then refer you to the best source of help. Call 1-800-296-1217 or visit [www.patienttravel.org](http://www.patienttravel.org)

### National Library of Medicine [PubMed]

(medical journal articles articles)  
[www.nlm.nih.gov](http://www.nlm.nih.gov)

### National Organization of Social Security Claimants Representatives (NOSSCR)

(If Social Security Benefits have been denied, they can help locate an attorney in your state.) 1-800-431-2804 or visit their website at [www.nosscr.org](http://www.nosscr.org)

**Bullying and the Young Child** visit [www.childhealthalert.com](http://www.childhealthalert.com)

## Honoring Loved Ones

We want to express our sincere gratitude to the following individuals who have honored a loved one by making a donation to NF, Inc. The memorial donations are designated to the NF Research Fund to provide a living legacy in search of a cure for NF.

### In Memory of...

Billie Anderson  
Eugenia Carlisle

Barbara Coleman  
Sam Fisher  
Mary Ana Geres  
Michael Glasscock, M.D.  
William Hancock

Elizabeth Holdt  
Ania Radzimkiewicz  
Betty Russi  
Mark Schlott  
Edward Sowinsky

### In Honor of...

Gillian Anderson

Zachery Tyler Fleming  
Friends  
Daughter  
Brittany James  
Miguel Lessing  
All with NF2

### Contributor

Broan-Nutone  
Vernon Burnes, Faculty & Staff Midlakes School, Lee & Helen Hawkins, Donald & Barbara Outhouse  
Sherry C. Brooks, William L. Motley, Jr.  
Shirley Mendell  
Hans & Phyllis Geres  
John & Lynn Woodman  
Jeanette & Scotty Mixon, Piney Forest Baptist Church, Robert & Mary Staton  
Fran Goldberg-Cohen  
Travel Deals, Inc.  
Helen E. Martin  
NF, Inc.-Indiana  
Miguel Lessing, Nancy Prieb,  
Irene Sowinsky

### Contributor

Patricia Brabham, Sharon Fetter, Elizabeth Koenig, Bonnie Mann, Judith A. Scheets  
Francis R. Neal Rev. Trust  
Genny Allard  
Leon Gelman  
Floyd Cornell, Jr.  
Susana Lessing  
Lucia B. Perez

We also want to thank all of the employees at Allstate, The Gap, and United Airlines for participating in the Employee Matching Gift Programs and making donations to NF, Inc.



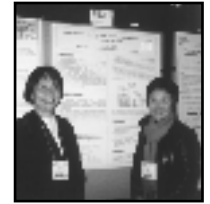
## Meet Some NF Researchers

**Gareth Evans, M.D.**, from the United Kingdom, a longtime investigator of NF2, stopped by the NF, Inc. booth at the American Society of Human Genetics (ASHG) 2004 annual conference in Toronto.



**Michael Baser, Ph.D.**, from California is a member of the international NF2 research team and had several posters at ASHG.

**Dr. Lee from Brazil and Dr. Park from Korea** collaborated on NF1 research in Korea and had posters at ASHG.



**Dusica Babovic-Vuksanovic, M.D.**, from the Mayo Clinic in Rochester, Minnesota pioneered the pifenidone studies for NF1.



**NF, Inc. invites all researchers interested in NF attending the ASHG meeting in Salt Lake City, Utah October 24-29, 2005 to stop by the NF, Inc. booth #622.**

## Participate in NF1 Research

Douglas Stewart, M.D., a medical geneticist at the NIH National Human Genome Institute (NHGRI), is investigating differences in disease severity among individuals and families with NF1. The purpose of the study is to look at the genetic differences among individuals with NF1 to understand why some people with NF1 have more severe disease than other people also with NF1. Individuals age 16 years and older diagnosed with NF1 may be eligible to participate in this study. Participants can either be the first member of their family affected or have a family history of NF. Parents and affected siblings will also be invited to participate. The study will include a two-day visit to the NIH Clinical Center in Bethesda, Maryland for a genetics evaluation, MRI of the spine, pictures taken and blood will be drawn. Medical evaluations will be free of charge and funding is available for travel expenses. For more information, please contact Jennifer Sloan, Ph.D., Protocol Coordinator and genetic counselor at NHGRI/NIH at 301-451-9145 or e-mail [jsloan@mail.nih.gov](mailto:jsloan@mail.nih.gov)



**For a listing of other NF research projects needing participants, visit the NF, Inc. website at [www.nfinc.org](http://www.nfinc.org).**

## OTHER NF CENTERS

These NF Centers (listed from East Coast to West Coast) see and treat children and adults with NF1 and with NF2.

**James Gusella, Ph.D.**, Director  
Harvard Medical School Center for  
Neurofibromatosis And Allied Disorders  
13th Street, Building 149, Room 6220  
Charlestown, Massachusetts 02129  
617-724-2365  
[administrator@cnfad.org](mailto:administrator@cnfad.org)  
[www.cnfad.org](http://www.cnfad.org)

**Kaleb Yohay, M.D.**, Director  
Neurofibromatosis Center  
The Johns Hopkins Hospital  
600 Wolfe Street, Jefferson Room 123  
Baltimore, Maryland 21287-1000  
410-855-3806 fax: 410-614-2297  
[www.hopkinsmedicine.org/neuro.nf](http://www.hopkinsmedicine.org/neuro.nf)

**Gene Barnett, M.D.**, Head  
Brain Tumor Institute  
Cleveland Clinic  
9500 Euclid Avenue Desk R 20  
Cleveland, Ohio 44195-5045  
216-444-5381 fax: 216-444-0924

**David Gutmann, M.D., Ph.D.**, Director  
Neurofibromatosis Center  
Department of Neurology  
660 So. Euclid Ave, Campus Box 8111  
St. Louis, MO 63110  
314-362-7379 fax: 314-362-2388  
[www.neuro.wustl.edu/infcenter](http://www.neuro.wustl.edu/infcenter)

**Bruce Korf, M.D., Ph.D.**, Director  
Neurofibromatosis Center  
University of Alabama – Birmingham  
1530 3rd Avenue South, Kaul 230  
Birmingham, Alabama 35294-0024  
205-934-9411 fax: 205-934-9488  
[www.uab.edu/genetics](http://www.uab.edu/genetics)

**John Slopis, M.D.**, Director  
Neurofibromatosis Clinic  
M.D. Anderson Cancer Center  
Box 87  
1515 Holcombe Blvd.  
Houston, TX 77030  
713-792-2454 fax: 713-794-4373

**Stefan Pulst, M.D.**, Director  
Neurofibromatosis Clinic  
444 So. Van Vincente Blvd. #1001  
Los Angeles, CA 90048  
310-423-9914 or 310-967-1644  
fax: 213-651-5381

For a listing of medical professionals familiar with NF, visit [www.nfinc.org](http://www.nfinc.org) and click on your state.

## NF Center in St. Louis



**David H. Gutmann, M.D., Ph.D.**

A comprehensive Neurofibromatosis (NF) Center has recently been established at the Washington University School of Medicine in St. Louis, Missouri. This Center focuses on promoting groundbreaking laboratory research and accelerating the pace of scientific discovery aimed at improving the care of persons with NF. "Our goal is to develop effective therapies for individuals with NF. To achieve this goal, we must understand the function of the NF genes in health and disease," says David H. Gutmann, M.D., Ph.D., director of the Comprehensive NF Center and a leader in the area of NF research and patient care.

The mission of the Washington University NF Center is to stimulate and promote research on NF and to achieve significant

breakthroughs in the diagnosis and treatment of people living with NF. The cross-disciplinary NF Center eliminates traditional barriers to laboratory and clinical research progress by establishing a framework for new scientific partnerships among researchers using cutting-edge research and advanced medical technologies.

In addition, the Washington University School of Medicine in association with St. Louis Children's Hospital has broadened their longstanding commitment to providing outstanding care for people with NF. Using a team of physician subspecialists dedicated to the care of children and adults with NF, the complex medical needs of each individual with NF can be met.

Through a combination of excellent clinical care, innovative laboratory research, and novel clinical research, the Neurofibromatosis Center at Washington University School of Medicine is actively working to improve the lives of people affected with NF. To learn more about the Comprehensive NF Center, please visit their website at [www.neuro.wustl.edu/nfcenter](http://www.neuro.wustl.edu/nfcenter).

## NF Member Organizations

Neurofibromatosis, Inc. 1-800-942-6825

Neurofibromatosis Association of Arizona  
PO Box 2718  
Chandler, AZ 85244-2718  
602-315-9676

Neurofibromatosis, Inc. – California  
PO Box 1234  
Vacaville, CA 95696-1234  
707-469-0467

Illinois/Midwest Neurofibromatosis, Inc.  
PO Box 1923  
Lombard, IL 60148-8923  
630-932-8111

Neurofibromatosis, Inc.-Indiana  
PO Box 221  
Linden, IN 47955-0221  
765-339-7206

Neurofibromatosis Kansas and Central Plains, Inc.  
PO Box 1792  
Hutchinson, KS 67504-1792  
316-669-8453

Neurofibromatosis, Inc.-Mid-Atlantic  
8855 Annapolis Road #110  
Lanham, MD 20706-2924  
301-577-8984

Neurofibromatosis, Inc.-Minnesota  
PO Box 18246  
Minneapolis, MN 55418-8246  
651-225-1720

Neurofibromatosis, Inc.-New England  
9 Bedford Street  
Burlington, MA 01803-3702  
781-272-9936

## LEND YOUR SUPPORT Neurofibromatosis, Inc.

I am interested in supporting NF, Inc. Date \_\_\_\_\_

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NF, Inc. Campership Fund: \$ \_\_\_\_\_

Helen Filak Memorial Fund: \$ \_\_\_\_\_

NF2 Support: \$ \_\_\_\_\_

John Petito Memorial Travel Fund (for NF2): \$ \_\_\_\_\_

Memorial  In Honor Of: \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone (\_\_\_\_\_) \_\_\_\_\_ E-mail \_\_\_\_\_

Child

Other Relative

Friend

Health Professional

Educator

Physician

I have NF1

I have NF2

Other \_\_\_\_\_

Please make check payable to **Neurofibromatosis, Inc.** and mail to **PO Box 18246, Minneapolis, MN 55418-8246**. All monies received by NF, Inc. are tax deductible and support education, research and support services for those affected by NF and their families.

**NOTE:** Neurofibromatosis, Inc. encourages and promotes local support services to NF families. In providing services to people requesting information, we frequently make referrals to local support groups such as NF Clinic Association, Pittsburgh, PA; Oklahoma INFO, Oklahoma City; Texas NF Foundation, Irving; and NF Support Group of West Michigan, Grand Rapids. These referrals do not indicate an endorsement of or formal relationship with NF, Inc. by these organizations.

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