

# neuro·fibroma·tosis®

THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

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## Meeting Held for First International Natural History Study of Plexiform Neurofibromas in NF1

An important organizational meeting of the participating researchers and clinicians in the Natural History Study of Plexiform Neurofibromas in NF1 was held for two



Dr. Bruce Korf

and a half days in February at the Banbury Center of the Cold Spring Harbor Laboratory, New York.

The multi-million dollar study, underwritten by the NF Research Program of the United States Army, is the first of its kind in NF. It is designed to establish normative data for plexiform neurofibromas. A second purpose of the study is to create the infrastructure for clinical trials in NF. A similar study, also funded by the U.S. Army, is underway for vestibular schwannomas in NF2.

The plexiform study is headed by Dr. Bruce Korf (Harvard/Boston Children's Hospital) as principle investigator and includes 22 NF centers in the United States, Europe, South America and Australia.

The first session of the Banbury meeting led to a surprisingly animated discussion about the issue: "what should be included

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## Few Americans Aware of NF According to National Survey

For years, it has been anyone's guess how many people know about neurofibromatosis. Our experience tells us that few people are aware of NF. But hard data was non-existent. That is why taking a valid measure of the public's awareness of NF has been a wish of the NNFF for many years. This wish came to fruition when a friend of the NNFF made possible a pro-bono survey via Roper Starch Worldwide Inc. A brief, two-question survey was conducted by this world renowned research firm, to measure public awareness of NF.

Eight percent of those surveyed had both heard of neurofibromatosis and could correctly identify it as a genetic disorder.

**"Eight percent of those surveyed had both heard of neurofibromatosis and could correctly identify it as a genetic disorder"**

Roper Starch surveyed a nationwide cross section of 1005 men and women 18 years of age and older in face-to-face interviews in their homes. The sample interviewed in this study is a representative sample of the populations of the Continental United States, exclusive of institutionalized segments of the population.

"While eight percent may seem small, it represents 21 million Americans who know about the existence of NF and who can correctly identify it as a genetic disorder," NNFF President Peter Beller-mann said. "This gives us a firm and accurate base from which to measure future public education efforts."

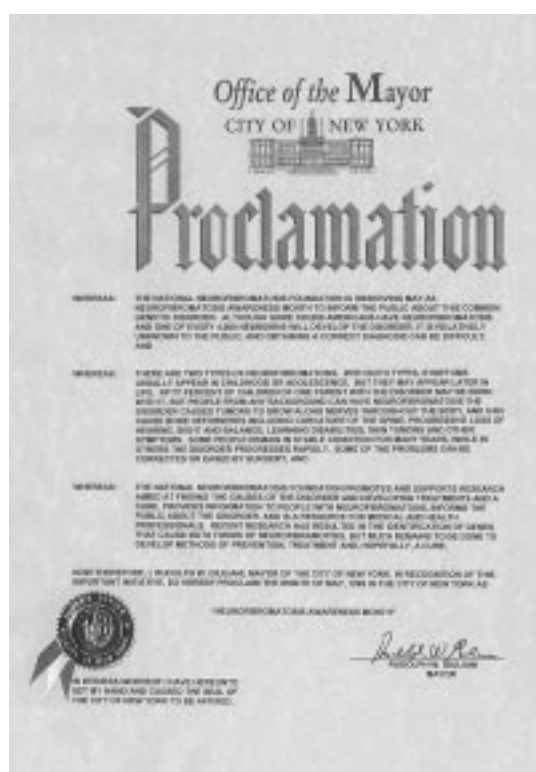
(In accordance with the NNFF agreement with Roper Starch, these results can only be released, reproduced or shared publicly by either the NNFF or Roper Starch. All press releases that cite these findings must be reviewed and approved in advance by Roper Starch Worldwide.)

NF

## National NF Awareness Month

Each year the National Neurofibromatosis Foundation initiates the month of May as NF Awareness Month. We encourage volunteers around the country to raise awareness of NF through a variety of activities, including proclamations by public officials, generating media coverage, dissemination of public service announcements and NF educational materials, as well as holding fundraising events.

In addition to a letter from President Clinton recognizing May as NF Awareness Month, the Foundation has received numerous proclamations from around the U.S. At press time, proclamations have been received from the following public officials: Governor Gray Davis, California; Mayor Richard Riordan, Los Angeles, CA; Mayor Joe Serna, Jr., Sacramento, CA; Mayor Susan Golding, San Diego, CA; Mayor Guy Houston, Dublin, CA; Mayor Diane Howard, Redwood City, CA; Governor Thomas Vilsack, Iowa; Governor Mel Carnahan, Missouri; Mayor Clarence Harmon, St. Louis, MO; Mayor Kaye Barnes, Kansas City, MO; Governor Christine Todd Whitman, New Jersey; Mayor Rudolph W. Giuliani, New York, NY;



Governor James Hunt, Jr., North Carolina; Governor Frank Keating, Oklahoma; Governor William Janklow, South Dakota; Mayor Gary Hanson, Sioux Falls, SD; Governor, Michael Leavitt, Utah; Governor Gary Locke, Washington.

NF

# Major Cancer Meeting Sheds Light on Promising Tumor Research

By: Frank Lieberman, MD, NNFF Clinical Trials Coordinator; Department of Neurology & Division of Neoplastic Diseases, Mt. Sinai School of Medicine, NY

The information presented at the meeting of the American Association for Cancer Research (AACR) in April included several promising avenues in cancer treatment that may prove relevant to NF. In addition, there were several NF-related presentations at this important meeting.

**Presentations included information about three different types of drugs that are approaching or in clinical trial for NF1-related tumors.**

The AACR meeting was exciting on many levels. Most significant was the increase in the number of presentations about translational research that applies information learned about tumor growth on the molecular level to identifying promising new drug therapies.

One of these approaches is the use of immunotherapeutic strategies for cancer treatment. These now include:

- Monoclonal antibodies, directed against the receptors for tumor growth factors, used in combination with chemotherapy for patients with breast cancer.
- Novel vaccine strategies employing genetically modified tumor cells or immune stimulating cells.
- Monoclonal antibodies carrying radioisotopes or toxins to the cancer site, in combination with chemotherapy.

Presentations included information about three different types of drugs that are approaching or in clinical trials for NF1-related tumors:

- Tyrosine kinase inhibitors (TKI) — TKIs are designed to block the growth stimulatory signals that are sent through receptors on the tumor cell surface.
- Farnesyl transferase inhibitors (FTI) — FTIs block signalling through the RAS receptor pathway, which appears to be an important signalling system in NF1 related tumors. FTIs block a step in which the RAS protein interacts with other proteins that send the growth stimulatory signal to the cell.

Schellens et al reported on the first Phase I study of an oral FTI (R15777) in adults with cancer. No patients with NF1 were included. The drug is given orally, twice a day. This drug does cause low white cell and platelet

counts when the dose is raised. A patient with colon cancer had tumor shrinkage while taking the drug. This FTI will proceed to Phase II trials in Europe.

A Phase I trial of a different oral FTI is currently ongoing at the NCI, in children with progressive plexiform neurofibromas or malignant peripheral nerve sheath tumors. This drug will probably begin a Phase II trial in the fall of 1999 in the U.S.

- Antiangiogenesis drugs – These drugs which block the formation of blood vessels that growing tumors require, are being tested in a variety of animal models of human cancer.

Angelov et al demonstrated that a new angiogenesis inhibitor SU-5416, caused tumor regression in mice implanted with neurogenic sarcomas from patients with NF1. This drug blocks signaling through the vascular endothelial growth factor (VEGF) pathway and is in Phase I trial for other solid tumors. VEGF is produced by a wide variety of human tumors, and Angelov et al demonstrated VEGF is produced by human malignant peripheral nerve sheath tumors. SU-5416 should be a promising agent for patients with malignant peripheral nerve sheath tumors. The role of antiangiogenesis drugs for plexiform neurofibroma patients is less clear, since benign neurofibromas seem not to produce the high levels of VEGF which are associated with the malignant peripheral nerve sheath tumors.

TKIs and antiangiogenesis drugs are also candidate agents for treatment of NF2 related meningiomas.

The drug SU-101 may have an application in patients with NF1-related astrocytomas and NF2-related meningiomas. SU-101, a drug which blocks signaling through the platelet derived growth factor receptor, is currently being tested in adults with recurrent malignant brain tumors in a Phase II study. Adamson reported on a phase I study of SU-101 in children, the initial step in preparations to test the drug in pediatric brain tumors. NF2 patients with meningiomas would be potential candidates for such a study. The toxicities and the breakdown of the drug seem similar in children and adults.

Two molecular studies implicate the dysfunction of the NF1 gene in the development of astrocytomas and perhaps medulloblastomas. In the first, Li et al studied the expression of variant forms of the neurofibromin gene message, as it is transcribed into RNA of different sizes, in pediatric brain tumors. These investigators found that cells lines derived from medulloblastomas, a common type of pediatric brain tumor, express a different

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## RESEARCH CALLS

### Schwannomatosis Study

Drs. Bruce Korf and Gerald Cox of Children's Hospital Boston are researching the genetic basis of schwannomatosis. They are interested in receiving clinical samples from affected individuals and families whose schwannomatosis is not caused by mutations in the NF2 gene. They are performing genetic linkage and loss of heterozygosity studies to identify these other genetic causes.

From singly affected individuals, the doctors are interested in receiving (1) purified DNA from blood samples or a sample of blood (5-10 cc in a purple top tube and 3 cc in a green top, sodium heparin tube) and (2) purified DNA from schwannomas or whole tissue from one or more schwannomas (fresh frozen, paraffin embedded, etc.). From families, they are interested in receiving the same samples as above from both affected and unaffected family members. Also requested is documentation of the pathological diagnosis of the tumor and any relevant medical records. The doctors would like to speak directly with interested individuals beforehand to discuss the research study, answer any questions and review the informed consent form, and make arrangements for shipping and handling of specimens. Dr. Cox can be contacted at (tel.): 617-355-5800 or via e-mail: [coxg@a1.tch.harvard.edu](mailto:coxg@a1.tch.harvard.edu).

### NF2 Patients Needed for Natural History Studies

This natural history study will measure the growth rate of vestibular schwannomas in 100 people with NF2, in order to (1) develop predictive factors to determine the normal growth rates for vestibular schwannomas and (2) define all parameters necessary to conduct clinical trials for new therapies for NF2. The study will focus on patients who have been diagnosed with NF2 within the past two years.

The three-year study will be conducted at Massachusetts General Hospital in Boston, The House Ear Institute in Los Angeles, Mt. Sinai Hospital in New York, and centers in Hamburg, Germany and Manchester, United Kingdom.

While no new treatments will be part of this study, patients may continue their current treatment during the study. Patients interested in participating should contact Gloria Yoon, research assistant, The House Ear Institute: telephone: 213-483-4431 or via e-mail: [gyoon@mail.house.hei.org](mailto:gyoon@mail.house.hei.org).

# CHAPTER NEWS: Waging the Fight Against NF at the Grassroots

There are many ways to raise funds for NF research programs and promote awareness of neurofibromatosis with your community. Recently several state Chapters and individual members of the Foundation organized activities and fund raising campaigns that are excellent examples of ways to support the fight against NF.

## Gather Friends and Dine for a Good Cause



Donald Trump and Adam Goodkind at the Mar-A-Lago luncheon in Palm Beach, FL

## Lunch at Local Landmark

Over 200 people attended a luncheon at Donald Trump's exclusive Mar-A-Lago members-only resort in Palm Beach, FL to support neurofibromatosis research. Volunteer Simone Lipton, and her friends, Shirley and Milton Gralla sponsored this new event. Adam Goodkind, Lipton's grandson spoke during the luncheon about what it is like to live with NF2. The luncheon generated funding for the Foundation's NF2 research program and will be held annually.

## Sample Local Cuisine

The Annual Crab Cioppino Festival was hosted by Jodi and Fernando Rocha for 450 of their friends and neighbors in Gilroy, CA. The event now in its seventh year provides funds for the Kamilla Rocha Family Fund which supports NF research and programs.

## Enlist Support from a Local Organization

### Make a Cultural Connection

Theater-goers in St. Louis, MO supported NF as they attended the opening night performance of Beckett's "Waiting for Godot" produced by the Black Repertory Theatre. This partnership enabled local students to see a top-notch performance and learn about NF.

### Shop for a Good Cause

Belk Department Stores in South Carolina provided the local NNFF Chapter with discount coupons to sell to the store's customers. Shoppers benefited from mer-

chandise discounts, contributed to a good cause and learned about NF.

## Use Flower Power for Fundraising

### Make Your Garden Grow

The NNFF Washington Chapter held their Annual Flower & Garden Sale. Proceeds from the sales grew when they were matched with a gift from PEMCO Financial Center.

### Make a Heartfelt Donation

Valentine's Day carnations were sold to romantic NNFF supporters in Wisconsin.

## Honor Young NF Ambassadors Across America

Breanna Robinson of Darlington, SC was named as an Ambassador of Children & Families by the March of Dimes Walk America.

Mary Margaret Seay from North Carolina was chosen as "poster child" of the local Wal-Mart's benefit concert for the Children's Miracle Network.

Charity Hodson, was chosen to represent Iowa in the National Special Olympics.

## Involve Classmates

Children at the Joseph C. Caruso Elementary School in Keansburg, NJ saved their snack money to raise funds in honor of their schoolmate, Christopher Faler. NY/NJ Chapter volunteer Nina Koridek involved a local business and donor to match the funds raised by these children.

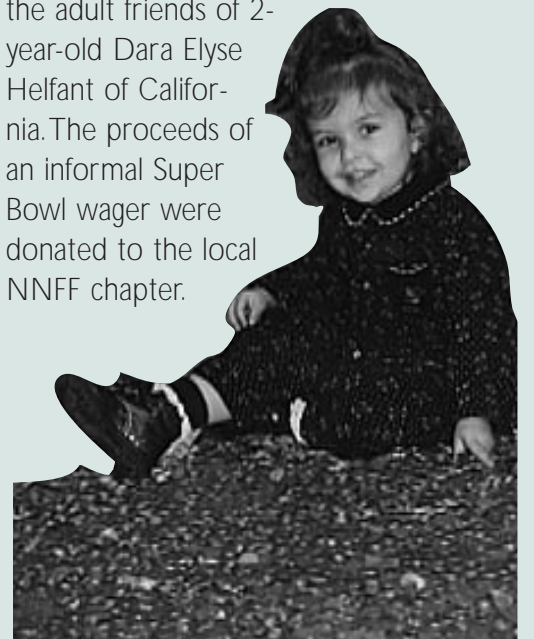
Teacher Sally Ward encouraged seventh and eighth graders at the Petros-Joyner

School to save their pennies and donate to the NNFF Tennessee chapter in honor of classmate Sara Summer. Ward also generated local media coverage of the penny drive.

Fellow nursing school students of NNFF Chapter President, Lisa Rogers of Ft. Knox, KY, adopted NF as their charity of choice for the Nightingale Project, during their final year of school. The student nurses held a series of fundraisers during the year to benefit the NNFF. Their activities culminated at graduation when NNFF President Peter Bellermann was invited to bestow upon each graduate her nursing school pin.

## Turn a Wager into a Windfall for NF

One thousand dollars worth of dimes are in the bag for NNFF programs thanks to the adult friends of 2-year-old Dara Elyse Helfant of California. The proceeds of an informal Super Bowl wager were donated to the local NNFF chapter.



Dara Elyse Helfant sitting atop the donation of dimes

NF



NNFF Missouri Executive Director Debbie Medbury and daughter Chelsea (standing 1.) are joined by (standing l. to r.) Waiting for Godot Director Joneal Joplin, Actor Wayne Salomon, Producing Director Ron Himes, Belois Davis and Ed Davis of BKE Toys, Inc., Robin Jones, NNFF MO Board Member and daughter Alexandra. Recipients of benefit tickets to the opening night performance are (seated l. to r.) Tylisha Anthony, Calina Abernathy, Nikki Anthony, Teresa Hughes and Roshanna Anthony. These students are holding teddy bears donated to the event by BKE Toys, Inc. The bears spread the word about NF through their buttons donated by Buttons By Wilson.



### Is This Your Lucky Day?

Would you have imagined that your e-mail address could have the power to direct more funds to NF research? When you send the Foundation your e-mail address, you can help the organization reduce printing and mailing costs by providing you with materials via e-mail. And there is a special incentive for participating.

Interested? For more details and official rules, please see the following web address: <http://www.nf.org/win/>

No purchase necessary. Entries must be submitted by July 1, 1999. Participants must be legal U.S. residents 18 years or older. Void wherever prohibited or restricted by law.

### The NF Bulletin Board – Connects People Everywhere From Anchorage to Zaire

An exciting new online resource is now available for patients and families on *The NF Web Site*. The NF “Your Turn” Bulletin Board is a free electronic forum where people can share information, personal experiences and stories, ask questions, post NF current events, and make new friends. Even if you live in an area far away from an NF support group you can still connect with the global NF community twenty-four hours a day from the comfort of your own home.

The Foundation encourages you to visit and participate on the bulletin board by going to *The NF Web Site* at <http://www.nf.org> and clicking on the words “Bulletin Board” to the right of the center photograph.

“The rise of the internet has brought several benefits to the NF community: rapid access to an enormous amount of information, improved communication between NF researchers and healthcare professionals, and, perhaps most importantly, an opportunity for people to connect with each other,” says NNFF President, Peter Bellermann. “Unlike many general-interest bulletin boards and chatrooms where users can feel lost in the cyber-sea, The NF Bulletin Board helps bring people together with a common sense of purpose.”

The bulletin board consists of several discussion forums where online visitors can view and post messages. Each month special topics or forums appear on the bulletin board in addition to the ongoing forums – “General Discussions,” “Pen Pals,” and “NF and Children.” Special topics have included “NF Awareness Month,” “Clinical Trials,” “NF and Hormones,” “NF and Older Adults,” “Insurance,” “Learning Disabilities,” “When

to Tell Your Partner?,” “Upcoming Surgery,” and “Plexiform Neurofibromas.”

Bulletin board visitors have a choice of responding to special topics or to previous messages, or they may create their own topics within a forum. Messages remain visible on the bulletin board for twenty days after being posted, but older messages can be viewed by selecting a time period from a pull-down menu on the bulletin board. Newer replies to a topic are added to the “thread” (a “thread” refers to the chains of dialog created by new topics being posted).



In the first two months since its inception in late February, the bulletin board has seen more than 700 postings from over 400 registered users from around the world. “NF and Children,” one of the most frequently visited forums, has generated a number of supportive “threads” between concerned parents. Many parents begin topics by sharing some background on their child and expressing their concerns. Other parents with similar concerns or whose children are facing similar problems will join in a discussion on the bulletin board and offer support, sometimes in the form of information or suggestions, but often just being there for each other online.

### e-member



#### E-members Can Save 15%

Beginning June 15, you can become a Foundation *e-member* with a 15% discount off regular membership. Enjoy the same benefits as regular members while receiving newsletters, updates, and other materials in an electronic format via e-mail (see related article on this page). *E-memberships* are offered at this discounted price because corresponding by e-mail reduces costs to the Foundation. Visit *The NF Web Site* at <http://www.nf.org/join/> to join. You may also renew your membership online and receive 15% off.

#### Grand Opening – The NF Online Store

Now a new feature on *The NF Web Site* allows you to drop in and shop from the comfort of your own home while helping in the race to find a cure. Web site visitors can purchase a wide array of NF-related merchandise in **The NF Online Store**. Items include t-shirts, sweatshirts, nightshirts, tote bags, key chains, buttons, calendars, and greeting cards. And, there are plans to expand the store in the near future to include books, brochures, video material and more. All proceeds go to support the work of the Foundation. The online store can be reached at the following web address: <http://www.nf.org/store/>



### Reach for a Cure with Donna



Kudos to Donna Oettinger, Chapter vice president of the New York/New

Jersey region, who was instrumental in establishing **The Online Store** and in promoting sales of “Reach for a Cure” products. Donna has been a Foundation member since 1978 and involved in New Jersey regional activities since 1980. When not working as a medical assistant, Donna tirelessly advocates for NF awareness, raises funds, organizes support group meetings and participates in the online NF community. In addition to selling the emblazoned t-shirts, sweatshirts, and other “Reach for a Cure” items, Donna has done a tremendous job coordinating NF walk-a-thons in New Jersey for the last five years. Keep an eye on *The NF Web Site* for an expanding “Reach for a Cure” selection, because with Donna there’s no telling what’s in store next.

# NF PROFILE

## Joe Lewin: *Born to Run*

Like his hero Bruce Springsteen, Joe Lewin was born to run. In fact, it is hard to keep up with him as he races from one activity to another. When he is not covering a sports event, this 30-year old sports writer from central New Jersey puts on his other hat as a console cowboy exploring the cyber-frontier, studying to be a technical support specialist, and participating in various online NF communities. After interacting with Joe online, one is unequivocally impressed by his upbeat attitude, commitment to the internet as a resource for the NF community, and concern for accurate NF information on the internet.



Diagnosed with NF1 as an infant, Joe has been aware of having NF for as long as he can remember. In addition to a number of visible small tumors, Joe has a large tumor on his left hip, which was very tender as a child but became less sensitive after adolescence. To this day, Joe maintains a healthy dose of skepticism when health care professionals tell him he cannot do something. As a child Joe developed a speech impediment and speech therapists told his parents he would never speak "normally." His determination to prove them wrong enabled him to overcome this and go on to pursue professions which require strong verbal abilities.

As a freshman in high school, Joe decided to go out for the track team. At first, other team members discouraged Joe from joining the team. Joe weathered rough times while running track, but his perseverance and dedication to being the best runner he could be soon earned him their respect and acceptance.

To this day, Joe remains a remarkably even-keeled individual, not taking negative comments to heart. Joe acknowledges how high school experiences like this can shape a young person. So, he offers the following words of advice for adolescents with NF, "The high school experience is determined more by what an individual chooses to make of it rather than those around him/her."

While still in his junior year studying journalism at Trenton State College, Joe accepted a position covering high school sports for the Trenton Times, one of the leading New Jersey newspapers, where he has been for 9 1/2 years. His favorite sport to cover is basketball. Joe is proud to note that one of the players he wrote about, Greg Grant, went on to play in the NBA for the Phoenix Suns, New York Knicks, and several other teams.

A typical workday involves picking the best match-up of the day and then showing up for the pre-game warm-up, checking the line-up, keeping statistics during the game, conducting post-game interviews with the coaches and players, and writing the story and submitting it to his editor. The last step is to check on scores and highlights from other games in the region.

Recently, Joe has been taking computer classes and hopes to move into the technical support field. He believes this will be a welcome change of pace from the long evening hours required of journalism that can put constraints on his social life.

In his precious spare time, Joe is an active participant on NF bulletin boards and cha-

rooms, always offering a friendly word of encouragement and sharing information. He views the growth of the internet as a powerful means for people with NF to connect across the country and around the globe. Joe sees the tangible benefits of connecting and talking with other people for support and advice. Online he urges people to consult their doctors about drugs and other treatments rather than relying solely on internet postings.

Joe has also written freelance pieces for other publications, including one for the Arizona Republic, the state's largest daily newspaper, on the National Junior College Soccer Finals. But his all-time favorite story was about another form of entertainment – Rock 'n' Roll. In 1995, he wrote an article to commemorate the 20th anniversary of Bruce Springsteen's launch to fame in New York's Bottom Line Nightclub. The piece, published in a Springsteen fan magazine, featured an interview with the club's owner, Alan Pepper, about Springsteen's performances there and his subsequent stardom.

Joe has been a Springsteen fan for over half his life and has attended over twenty of his concerts, including one concert where he was able to raise substantial funds for NF research and promote NF awareness by auctioning a ticket on the internet. Joe has gotten close enough to Springsteen to shake his hand. Joe sees him as a New Jersey icon embodying the can-do, gritty spirit of the state.

It is that spirit that Joe possesses as well. Asked what advice he would offer other people with NF, particularly children, Joe responded, "Don't let it bother you. Take one day at a time, keep going. Try to stay as knowledgeable as you can."

NF

## Major Cancer Meeting

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pattern of neurofibromin message than normal brain. They showed that treatment with a differentiation inducing drug, phenylbutyrate, can modify the pattern of neurofibromin message expression in one of the cell lines.

Further studies will be needed to clarify whether the pattern of gene expression in the cell lines is contributing to the abnormal growth behavior of the cells.

Guttman et al, demonstrated that mice carrying one mutated copy of the NF1 gene demonstrate abnormally high astrocyte pro-

liferation. Elucidating the mechanisms by which NF1 gene mutations disrupt cell growth control may lead to better treatments for brain tumors associated with neurofibromatosis and sporadic astrocytomas and medulloblastomas as well.

Perhaps the most exciting laboratory advance was the report in the "Late Breaking Results" session from Parada and Jacks, describing a transgenic mouse model of NF1 in which the animals develop peripheral nerve sheath tumors. These animals should provide a better model for the

human disease and to evaluate antitumor therapies.

The AACR meetings conveyed the excitement of the cancer research community as translation of molecular and cell biologic discoveries into new treatments begins in a systematic manner. Compounds that target specific growth signalling molecules, such as the FTIs and TKIs, or which target the molecular signals that stimulate blood vessel growth, are promising agents for the treatment of NF1 and NF2 related tumors.

NF

# Pen Pals

- **NF1 family would love to hear from others.** – Lynne Stockman; 823 N. 600 W., #4; Provo, UT 84604.
- **Looking for others with NF1 children who have optic gliomas/optic chiasmal gliomas and central precocious puberty. Need to find support from someone who understands.** – Bonnie Crist; 319 W. 9th St.; Anderson, IN 46016; crist3b1j@ameritech.net
- **I am 18 years old and would love to write to others.** – Angie Muncy; 33201 Vine St., D157; Eastlake, OH 44095
- **24-year-old Canadian with NF1 seeking support from other young adults.** – Brandon Marsh; 10-536 College St.; Kingston, Ontario, K7L4M5, Canada
- **I love music and the outdoors and would love to hear from other NF1 teens.** – Elizabeth Gilliam; 507 Wakonda Beach Rd., Waldport, OR 97394; gecko\_babe@hotmail.com
- **55-year-old man seeking others with NF.** – stasiui@bnbcomp.net (Stanley F. Wolf)
- **Mother of a 5-year-old (both have NF1) would like to hear from others.** – Deborah Beck; 893 N. 14th Place; Cornelius, OR 97113
- **28-year-old college student would like to connect with others who understand having NF.** – tlgreen\_98@yahoo.com (Terry Green)
- **Looking for families who are dealing with NF and ADHD.** – Dona Guyer; 101 S. Madison St.; Stoughton, WI 53589; xemena@excite.com
- **Would like to get in touch with anyone who with NF2 and has had spinal surgery using gamma knife.** – rab1941@aol.com
- **I would like to have a penpal who has NF and has a child with NF also.** – Katie Simms; simms@nku.edu
- **I'm 31 and have NF1. Would like to hear from others with NF1 or 2.** – bockleymary@hotmail.com (Mary Bockley)
- **24-year-old woman would like to write to someone with NF1.** Angela Vicuna, 11502 Basye St., D; El Monte, CA 91732; AXV8358@mail.paccd.cc.ca.us
- **I am 21 years old and have a brain tumor caused by NF. I would love to talk to others.** – Holly Van Barg; 2314 Plumbrook Circle, Sandusky, OH 44870-6080; hollylove\_96@yahoo.com
- **I'm a 36-year-old female and the 3rd generation in my family to have NF1 with plexiform neurofibromas and malignant peripheral nerve sheath tumors. I would like to correspond with others who don't mind talking about their NF. I am hoping to give and receive inspiration, understanding and friendship. Please**
- **write.** – Robin Suarez; 464 S. Anza; El Cajon, CA 92020
- **I'm Melissa. I'm 25 and have NF. I would like to talk via e-mail.** – BigRed222@hotmail.com
- **42-year-old mom with NF1 and son Kenny (age 13) would like to talk to others.** – Susan Clifton and Kenny; 525 Smedley Ave; Media, PA 19063; or e-mail: Sue-BCLif525@aol.com; Kenny-Kwcli525@aol.com
- **Would like to hear from anyone with NF.** – Rosie Agro; 531 Canon Ave., Manitou Springs, CO 80829
- **I welcome anyone to write to me about NF. I'm 29 and just been diagnosed and know very little.** – Lisa Campagna; 43387 Citation; Novi, MI 48375; Acampa5646@aol.com
- **Woman from Belgium has a 2-year-old son with plexiform surrounding his eye, she would like to hear from others.** – Corinne.GATTEGNO@SG.cec.be
- **My name is Robert Scott. I have NF1 and have had many surgeries for plexiforms. I wear a brace to help me walk. But I will never give up. Please write – I will answer any e-mails.** – rls3947@aol.com
- **I'm 19 and want to write to other people with NF1.** – Cheryl Smith; 4695 Castle Circle; Lester Prairie, MN 55354

## Plexiform Study

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under the term plexiform neurofibroma?"

The second session was devoted to the creation of a protocol for MRI's which are integral to the study. Particular interest was generated by new imaging technologies - especially for soft tissue tumors - which Dr. Jay Tsuruda from the University of Utah presented.

The third session dealt with the clinical and pathological data which must be generated for the study. The fourth session covered issues involved in creating and maintaining a tissue bank. It also covered a number of

issues in cell biology relevant to the natural history study. The final session dealt with a myriad of administrative and managerial matters attendant to such a complex study that involves so many centers spread throughout the world.

The Banbury meeting, funded by the U.S. Army and the National Neurofibromatosis Foundation, was judged by all who attended to be a successful beginning to one of the most significant current undertakings in neurofibromatosis research.

NF

## Kid's Council

### Do You Know A Child With NF?

If you know a child between the ages of 6 and 17 with NF 1 or NF2, the Kids' Council is a great program for him or her. With more than 100 members to date, the Kids' Council is the place for young people from around the world to get to know each other better. The Kids' Council Newsletter and Pen Pal Buddies programs help kids connect. New members get a special Kids' Council pin, personalized Membership Certificate and Pen Pal Buddies List. For more information contact the Kids' Council Coordinator at NNFF@nf.org or 800-323-7938 ext. 28.



### SPONSOR A CAMPER

Enrollment to the 1999 NNFF International Summer Camp for Teens has reached capacity with 57 teens from across the U.S., Belgium and Japan participating. With such high attendance we need your help more than ever. Your donation will underwrite the expenses of campers and support the many planned activities. Your contribution is tax deductible, but more importantly, you will be providing a teenager with an experience he or she will always remember. For more information on ways you can support the 1999 NF Camp or a camper, please call 800-323-7938 x32.

High atop Snowbird Mountain near Salt Lake City, UT during the 1998 NNFF International Summer Camp (l. to r.) Lizzie Stonberg, Angie Disney and Amanda Biddle enjoy a moment together.

# Viewpoints on NF

## Older Adults: Perspectives on NF

(Note: The following is another in an occasional series about issues of importance to older adults. This article reflects the personal experiences of Bobbie Colgan of Sioux Falls, SD. Bobbie is the president of the NNFF Northern Plains Chapter. Bobbie's attentiveness to her health is an example to us all. – Ann Porter Colley, Column Editor, Older Adults: Perspectives on NF)

Becoming a senior with NF has created a whole new set of problems for me than in the first four decades of my life. I have had some pretty personal choices to make. I am not sure if I have made the right choices, but I have made the ones that are the most comfortable for me.

I am aware that certain features should be watched for, whether you have NF or not, such as hypertension, unexplained numbness, weakness, tingling, pain, bowel or bladder problems and appearance of new masses, particularly if rapidly growing or hard. This I do on a daily basis. Every two years I have an audiometric screening and also an ophthalmologic examination. Some of the things I do are not because I have NF, but because I feel they are an

important part of anyone's health program. A yearly mammogram and blood panel is also part of my health package.

I have made the personal health decision not to take Premarin or any estrogen replacement. I was on Premarin in a low dose. Although it did not aggravate my neurofibromas, and I agree it may never have, I balanced the risks versus the benefits and decided that with a well-balanced diet including dairy products, I would rather not take estrogen.

This past summer I developed pain in my feet and was alarmed that it might be caused by several small neurofibromas on the bottom of my feet. My doctor did a x-ray to make sure there was nothing impacting the bone structure of my feet. The x-ray was negative and Dr. Michaels made a very simple suggestion to me - that is that I start wearing orthopedic shoes. So upon my return to Sioux Falls, I purchased a pair of these shoes. In a matter of days, I experienced no more pain. Better yet, seven months later, I am pain free and back to taking long walks with my two beagles. I




Bobbie Colgan

guess it is normal for someone with NF to attribute all health problems as being associated with NF, and I have learned that this is not always true.

During my physical exam this past summer, I also found out I had high cholesterol. I am sure this is a general health issue not related at all to having NF. So now I join the thousand of Americans who watch what they eat and follow the American Heart Association diet.

I have been very lucky not to have health-related problems with my NF. The only problems I have are cosmetic ones. I have had a few neurofibromas removed that were irritated by my clothing. About two years ago, I had some removed from the chin area of my face. This was done not for health or out of necessity, but purely for the sake of vanity.

Using common sense and having check-ups by a doctor knowledgeable about NF is part of my total program. The choices I have made are purely personal with no guarantee they have been the right ones. But, I have followed my head and my heart. What more can a person do? 

## • • • YOUR TURN • • •

(Ed Note: This feature of *Neurofibromatosis News* was developed to encourage patients and their families to share their concerns, questions and perspectives with others. The answers to medical questions can only cover generally applicable situations, and cannot take the place of consultations and specific medical care. If you would like to share your views or raise any questions, please submit them in writing Editor, *Neurofibromatosis News*, 95 Pine St; 16th Fl; NY, NY 10005 or via fax: 212-747-0004 or email: [nnff@nf.org](mailto:nnff@nf.org))

### Telling A Partner

The NNFF invites readers to share how they have handled the following situation: I am a 29 year old male with mild NF. I have never really seen the issue addressed of how people go about telling a partner that the person they love may become deformed – or at least significantly less fetching. I believe the prospect of eventually becoming "less attractive" greatly inhibits my ability to pursue and maintain a loving relationship. It seems like a deception to withhold the

NF information, but revealed too soon would likely frighten away even the most stalwart suitor.

–A.E.R., Akron, OH

### Resources for Special Education

My child has NF and learning disabilities. How have the changes in IDEA regulations affected his access to services in the schools?

– W.G., Syracuse, NY

*Parents of children with disabilities have a wonderful resource in their state's Parent Training and Information (PTI) programs to answer this and other questions. According to Exceptional Parent magazine, PTI programs are funded by the Office of Special Education Programs in the US Department of Education. Their mission is: "To provide training and information to meet the needs of parents of children with disabilities living in the area served by the center." PTIs can help parents understand their children's specific needs; communicate more effectively with professionals; participate in the educational planning process; and obtain information about relevant*

*programs, services, and resources.*

*For more information, contact the Technical Assistance Alliance for Parent Centers, 4826 Chicago Ave. S, Minneapolis, MN 55417; (888) 248-0822 (Toll-free nationwide); E-mail: [alliance@taalliance.org](mailto:alliance@taalliance.org); Web site: [www.taalliance.org](http://www.taalliance.org).*

### College Scholarships

Are there any college scholarships available to students with neurofibromatosis?

– C.L., Costa Mesa, CA

*The NNFF is not aware of any scholarships specifically for college students with NF. However, many scholarships exist based on a range of criteria. There are directories of available scholarships that can be found in the reference section of many public libraries. Enlist the assistance of your local library's reference librarian to help you locate these directories. In addition, the following web site has information about a number of online college scholarships databases:*

*<http://www.gilbertschool.org/teched/witit/sc.h.html>.*



## NF Before Congress



Spreading The Word: Testifying before the House Appropriations Subcommittee for Labor, Health and Human Services, and Education in April were Rep. Fred Upton (l.) and his constituent Dr. Fred Matthews (r.). Both Are Michigan residents who supported increased appropriations for the National Institutes of Health (NIH) and asked that the Committee urge the NIH in turn to increase funding for neurofibromatosis research. The full text of Dr. Matthews' testimony, which includes praise for the NNFF and its work in NF research, can be read on The NF Web Site at [www.nf.org](http://www.nf.org).

### MEETING ANNOUNCEMENT

#### NNFF Annual Mem- bership Meeting

New York Marriot  
Marquis  
1535 Broadway  
New York, NY

Saturday, June 5, 1999  
8:30AM

Remember you can donate to  
NF research, public education  
and patient support services at  
your workplace through your  
employee giving campaign

Combined Federal Campaign (CFC)

NNFF designation #0550

Or Community Health Charities  
(formerly NVHA)

### *In Memorium*

Dr. Karl Lisch

The National Neurofibromatosis Foundation mourns the passing of Prof. Dr. Karl Lisch. Dr. Lisch was the Austrian ophthalmologist who in 1937 identified the "clumps of pigment cells" on the iris as diagnostic indicators of NF1. The "Knoetchen," as Dr. Lisch called them in his native German, have been called Lisch nodules ever since. In 1987, the Lisch nodules were formally recognized as one of the diagnostic criteria for NF1 by the NIH Consensus Conference. Dr. Lisch died at the age of 91 in his hometown of Woergl, Austria in February.

**neuro·fibroma·tosis**  
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Managing Editor: Francine Morris

The purpose of the National Neurofibromatosis Foundation, Inc. (NNFF) is to improve the well-being of patients and families affected by NF1 and NF2. The Foundation therefore sponsors scientific research aimed at finding the causes and cures for the neurofibromatoses, promotes the development of clinical activities, works to create public awareness and provides patient support services.

*The National Neurofibromatosis Foundation is a founding member of the International Neurofibromatosis Association.*



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Make New Friends.....Share a Story.....Take Your Turn  
On the *New NF Bulletin Board* at:  
[www.nf.org](http://www.nf.org)