

# neuro·fibroma·tosis<sup>®</sup>

THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

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## NF Research Yields Clues to Biological Cause of Learning Disabilities and Possible Treatment

A team of scientists headed by Dr. Alcino J. Silva from the Department of Neurobiology at the University of California in Los Angeles report in the January 30th issue of the journal *Nature* that they have found a treatment for the learning deficits in a mouse model for Neurofibromatosis type 1 (NF1).

These findings are an important step towards developing a treatment for the learning disabilities (LD) often associated with NF1, as well as in the general population of the estimated 30 to 35 million Americans with LD. Learning disabilities occur at a rate of five to six times higher among people with NF1 than in the general population.

Previously, these researchers had reported that mice with a NF1 mutation show learning deficits with striking similarities to the

human condition. These scientists test spatial learning by determining how quickly mice learn to find their way in a maze. Now Dr. Silva, Dr. Rui Costa and colleagues, through research funded by the National Neurofibromatosis Foundation (NNFF), report that they have uncovered the causes for the learning deficits of the NF1 mice.

**Remarkably, researchers were able to rescue the learning deficits of the NF1 mice with a drug...**

They found that brain inhibitory signals are unusually strong in NF1 mice. During learning, excitatory brain signals are thought to

carve changes in brain structure that are needed for memory. Just as the laser-burned patterns of a compact disk are used by a CD-player to play the recorded music, the brain uses structural changes made during learning to read out the learned information.

"It is possible that in the NF1 mice and possibly in NF1 patients, the excitatory signals are simply not strong enough to overcome the abnormally high inhibition caused by the NF1 mutation, and as a consequence, a lot of information is simply lost before it can be stored" Silva stated.

Remarkably, researchers were able to rescue the learning deficits of the NF1 mice with a drug that decreases *ras* function. *Ras* is a molecule that may regulate the levels of inhibition in the brain. In the brains of

**continued on page 7**

### NF at Madison Square Garden



CIBC World Market's Annual "Miracle Day" benefits more than 300 children's charities, including the National NF Foundation. The 2001 pre-event kick-off was a skating party at New York's Madison Square Garden. **NF**



### NF at the Winter Olympics

Foundation Board Member, The Hon. Jake Garn, former United States Senator, Astronaut and Mayor of Salt Lake City, carried the Olympic torch into Salt Lake City. **NF**

## Funding for US Army's NF Research Program Reaches All-Time High

United States Congress has appropriated \$21 million for NF Research in the next fiscal year. This represents an increase from \$17 million for the program during the current fiscal year. This appropriation funds the NF Research Program of the United States Army Medical and Materiel Command.

The Army program began almost eleven years ago as an initiative of the National Neurofibromatosis Foundation. Today over 13,000 Foundation members participate annually in the legislative process leading up to the appropriations.

Commenting on the development, Foundation President Peter Bellerma said, "While the bill's primary sponsor continues to be

Rep. Jack Murtha of Pennsylvania, it enjoys wide-spread support among Representatives and Senators from both parties and in both Houses."

"The importance of these appropriations for progress towards effective treatments in both NF1 and NF2 cannot be overestimated. I urge all Foundation members and friends to express their gratitude to their own US Representative and two Senators. Our special thanks go to the members of the respective Defense Appropriations Committees in the House and Senate."

A list of all the legislators involved in the appropriations process can be found at [http://www.nf.org/contribute/us\\_army.htm](http://www.nf.org/contribute/us_army.htm). **NF**

# Flies Prove Fruitful For NF Research

## Masters of the Fly

It may be hard to believe that the bowl of fruit on your kitchen table can provide an important contribution to NF research.

Actually, it is the small black fruit flies that are buzzing around that week old banana that are truly a vital part of NF research.

Why the fly? The fruit fly (also known as *Drosophila melanogaster*) provides a model for studying the genetics and biochemistry of NF. Although the fruit fly is only approximately one-half the size of a grain of rice, this tiny organism has many important genes in common with humans, including the NF1 and NF2 genes. By using the simpler fruit fly, scientists can more easily answer questions about how genes work, information that can then be used for studies in humans. Over the years, fruit flies have provided many important clues about life processes, including cancer, and learning and memory.

And, as anyone who has left a piece of fruit out too long can attest, fruit flies are easy to come by, and they breed very fast. Scientists can create thousands of NF mutated flies in a matter of a few weeks, compared to the months or years that would be required for a more complex organism like the mouse.

What is gained is not an exact replica of the manifestations found in NF in people, but a model that has enough similarities to explore how NF mutations affect many aspects of tumor growth, development and learning and memory.

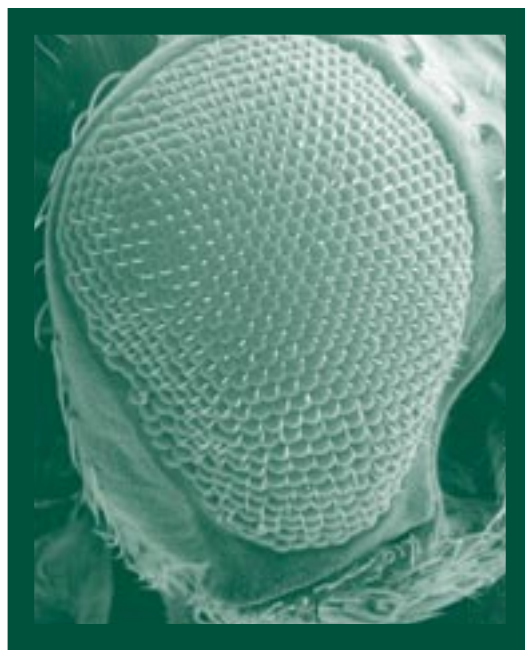
NNFF Research Advisory Board members Dr. Andre Bernards of Harvard University and Dr. Richard Fehon of Duke University are two researchers who use the fruit fly to find new pieces in the NF1 and NF2 puzzles. Drs. Bernards and Fehon came to the field with initial funding as Young Investigators of the National Neurofibromatosis Foundation.

According to Dr. Bernards, "We are trying to answer questions such as 'If you lose the proteins what happens?' and 'What pathways are involved?'"

The NF1 gene is a tumor suppressor gene. It is known that the NF1 protein, neurofibromin, interacts with the tumor suppressor gene, p53 and with a tumor-promoting gene, *ras*. When mutated, tumor suppressor genes can not stop cells from dividing out of control. If NF is mutated, the *ras* is activated, and tumors will grow.

Fruit fly studies have been helpful in understanding other pathways involving NF1.

When the NF1 gene is mutated, the result is a smaller fly with learning and memory deficits. A surprising finding was that these deficits were not corrected ("rescued") by lowering *ras* signaling, according to Dr. Bernards. However, a rise in the level of cAMP (*cyclic adenosine monophosphate*), a chemical messenger in the cell that also controls cell growth, did "rescue" size deficits, as well as learning and memory deficits in the flies. These manipulations were done genetically rather than through use of any chemical or drug.



Eye of mutated NF2 fly's eye

## The NF Fly and the Daily Grind

A group of scientists at the University of Pennsylvania reported recently at the annual meeting of the *NNFF International Consortium For The Molecular Biology of NF1 and NF2* in Aspen, CO, that neurofibromin, the NF1 protein, plays a role in the regulation of circadian rhythm in flies.

Every 24 hours the bodies of humans and animals go through a routine set of processes. This 24-hour pattern of activity is known as the circadian rhythm. This internal clock regulates hormone levels, body temperature, blood pressure and sleep cycles.

Dr. Bernards supplied the NF1 mutant flies used in the study by Dr. Amita Sehgal and Dr. Julie Williams of the University of Pennsylvania. The University of Pennsylvania researchers found that neurofibromin links the fly's circadian processes to other circadian governed cells. The NF1 mutant flies lacked a normal rest-activity rhythm.

Dr. Sehgal's work involved trying to rescue circadian rhythm deficits associated with the NF1 mutation. In this case, lowering *ras* signaling rescued the circadian rhythm defect, while changes in cAMP levels had no effect.

"Progress has been made in answering many questions about NF1," Dr. Bernards said. "The first stage was identifying the NF1 gene in the flies – that's done. The second stage was identifying the processes that are defective in NF1 mutant flies – that's also mostly done. Stage three is studying how the gene works in an intact animal – that is the stage we are in now."

## Growing Out of Control

In Dr. Fehon's laboratory at Duke University, a similar set of studies is being done to study the NF2 gene. To create a fly model that is useful for understanding the functioning of the NF2 gene, Dr. Fehon and his team inactivated the NF2 gene in the fruit fly, and the result is that cells in the insects grow at 2 to 3 times the normal rate. This is lethal to the fly, but the lethality can be 'rescued' by a normal copy of the human gene, indicating that the fly and human NF2 function very similarly.

For this reason, the basic cellular mechanisms and function of NF2 can be studied through these NF2 mutant flies. NF2, like NF1, is a tumor suppressor gene, and therefore regulates cell growth by interacting with other cellular proteins to prevent cell overgrowth.

"More recently we are beginning to understand what the gene is doing at the cellular level," Dr. Fehon said. "NF2 regulates two pathways that cause cells to divide. The first is the EGF (epidermal growth factor) pathway and the second is the TGF (transforming growth factor) pathway. NF2 negatively regulates both pathways and mutant NF2 allows cells to overgrow."

"The fruit flies with NF1 or NF2 mutations will be exciting tools for performing preclinical studies of potential therapeutic agents," said Dr. Judy Small, Director, Clinical Trials and Technology Transfer at the NNFF. "The advantages of flies, their small size and short generation time, can be used to test a large number of drugs quickly, making the fly model an important first step for deciding which promising agents should be tested in other models, such as the mouse, or in humans."

The results of the fruit fly studies are interesting and provide considerable information about the actions of the NF1 and NF2 genes. It is hoped that these exciting findings can be used as a starting point to understand the much more complex human disorder. **NF**

# A Major Milestone in the History of NF: First Chair for NF Research Is Created At Major University

NF history has taken another step forward with the creation of the Donald O. Schnuck Family Chair in Neurology for Neurofibromatosis Research at Washington University School of Medicine in St. Louis. The chair is funded by a grant from the Schnuck family, which owns and operates St. Louis-based Schnuck Markets, Inc. The Schnuck family is a long-time supporter of the NNFF and Doris Schnuck currently serves on the NNFF's Board of Directors. Neurologist David H. Guttman, M.D., Ph.D. will be the first professor to serve in this historic position.

Chancellor Mark S. Wright and William A. Peck, M.D., executive vice chancellor for medical affairs and dean of the medical school hailed the new chair and professorship. "Doris Schnuck and her family, in honoring Don's legacy, are generously helping to advance medical science

**"The creation of the world's first chair for NF research at Washington University in St. Louis is a major milestone in the history of NF."**

not only in St. Louis but for people everywhere," Wright said. "The University is extraordinarily grateful to all of them for their continued support."


"The generosity of the Schnuck family recognizes and enhances the work of David Gutmann, one of our top-notch physician-scientists," Peck said. "His groundbreaking research on neurofibromatosis makes him a natural choice for this position. Patients with NF and their families are counting on his basic and clinical studies to lead to better treatment options and brighter futures."

"The creation of the world's first chair for NF research at Washington University in St. Louis is a major milestone in the history of NF," Peter Bellermann, NNFF President, said. "All the right ingredients were in place for this development: a world-class academic institution with a long history of innovative and trailblazing research, an outstanding scientist and clinician as the first occupant of the chair, and a publicly spirited family whose philanthropic activities have improved the lives of many in St. Louis, in Missouri and elsewhere in the nation. On behalf of the NF community worldwide, congratulations and many thanks to Washington University, to Dr. David Gutmann and to Doris Schnuck and her remarkable family."

The appointment of Dr. Gutmann to this position is a well-deserved first-choice to



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

inaugurate the NF chair. Dr. Gutmann is a pioneer in research on NF. In 1990, he was part of a research team that discovered the gene for NF1. Dr. Gutmann and his colleagues study three of the most common nervous system tumors—astrocytomas, meningiomas and schwannomas. Dr. Gutmann's research applies to both NF1 and NF2. Dr. Gutmann directs the NF Program at St. Louis Children's Hospital and shares a patent on the NF1 gene. Dr. Gutmann also serves as the co-chair of the NNFF's Clinical Care Advisory Board. 

## Michigan Entrepreneur Funds Foundation's Technology Transfer Program

The NNFF research program received a substantial boost through the generous gift of more than \$1.4 million dollars from The Gilbert Family. The gift funds the recently established Technology Transfer Institute of the National Neurofibromatosis Foundation over a three-year period.


The Technology Transfer Institute was developed in an effort to accelerate the pace with which the results to date of basic science are applied to improved diagnostic procedures and rational treatments of individuals with NF1 and NF2.

The Foundation's Technology Transfer Institute's scope includes Technology Transfers and Clinical Trials, Pre-Clinical

**"With his magnificent gift to the Foundation, Dan continues to show exceptional leadership in a new arena, namely NF clinical trials..."**

Trial Models, and a Clinical Imaging Database/Patient Archives.

The Gilbert Family of Michigan made The Gilbert Fund gift possible. Daniel Gilbert, the founder, President and CEO of Quick-Loans is a member of the NNFF Board of Directors.

"Dan Gilbert has a remarkable record of entrepreneurship in his industry" said NNFF President, Peter Bellermann. "With his family's magnificent gift to the Foundation, Dan continues to show exceptional leadership in a new arena, namely NF clinical trials. These trials have propelled us into an entirely new field requiring vastly greater resources than anything we have ever attempted before. The Gilbert Family gift could therefore not come at a better time. We thank the Gilbert Family on behalf of all individuals in the world with NF and their families. Their chances for a better quality of life have changed greatly for the better as a result of this gift." 

# NF Marathon Team: Races For Research

The NF Marathon Team Program is a wonderful way of supporting NF research and NNFF programs. Individuals sign up to participate in an established marathon as part of the NF Marathon Team. Participants receive training in fundraising and have goals to raise a certain amount for the NF cause. The program also provides training and nutrition programs designed to help each person achieve his/her walking or running goals.




NF Marathon Team

Each walker/runner can qualify for free transportation, lodging and more for the marathon weekend by raising a minimum amount in donations. In addition to raising

much-needed funds for NF research and NNFF programs, becoming a member or donor on the NF Marathon Team helps spread NF awareness.

Each participant is paired with an "NF Hero," in whose honor the Marathon is completed.

The NF Marathon Team Program also needs volunteers in the marathon cities to help with NF Team transport and to provide support during the marathon.

For more information call toll free 877-NF-Races or visit the Team at <http://www.nf.org/marathon/> 

## neuro-fibroma-tosis<sup>®</sup> NF Marathon Team — racing for research

### Upcoming Marathons — next 6 months

5/5/02	Vancouver, BC
6/2/02	Rock N Roll Marathon San Diego CA
6/22/02	Mayor's Midnight Sun Anchorage AK
9/01/02	Rock N Roll 1/2 Marathon Virginia Beach, VA
9/22/02	Maui HI
10/06/02	Portland, OR
10/13/02	Chicago, IL
10/13/02	Long Beach, CA
10/20/02	St Louis, MO
10/28/02	Dublin, Ireland
12/1/02	Seattle, WA

## Please Join Us for a "Spot of Tea"



Last year Margie Feinberg and her daughter, Nettie, co-chaired the first annual "May Tea Party" to benefit the National Neurofibromatosis Foundation.

The response to the program was overwhelming. More than 450 hostesses participated raising over \$153,000 for the Foundation.

The concept behind the "May Tea Party" is basic. On Mother's Day, or any day during the month of May—which is also National NF awareness month—ask your friends, neighbors, relatives and co-workers to "have a cup of tea" on behalf of anyone who has NF. No one even has to

leave their home to participate in the May Tea Party—it's make believe!

The Foundation will send you beautiful, newly designed, pre-printed invitations, envelopes and even the symbolic tea bags for your mailing. You personalize the invitations and send them out with the tea bag and envelope for a return contribution in support of NF research.

That's it! It's an easy, elegant and heartwarming way to help the NNFF—bringing attention and raising funds for NF.

For more detailed information about the May Tea Party and to sign-up log onto the NF Web Site at [www.nf.org](http://www.nf.org). We'll provide you with everything you need so you can send out your May Tea Party invitations.

## NNFF- Unidos Para NF Announces New Chat Room!

**This new chat room, beginning early May 2002, will be conducting online chats in Spanish.**

We invite all to spread the word and log on! This is part of our ongoing efforts to meet the needs of our Spanish Speaking NF Community.

For more information visit [www.nf.org/espanol/](http://www.nf.org/espanol/)  
For comments, please write to [NNFF@nf.org](mailto:NNFF@nf.org)

## NNFF- Unidos Para NF !Anuncia Nuevo Salón de Charla!

**Este nuevo salón de charla será conducido en Español y comenzara charlas a principio de Mayo 2002.**

Invitamos a todos que compartan la noticia y comiencen a charlar! Esto es parte de nuestros continuos esfuerzos para alcanzar las necesidades de nuestra Comunidad de NF del habla Hispana.

Para mas información visite a [www.nf.org/espanol/](http://www.nf.org/espanol/)  
o para hacer comentarios email: [NNFF@nf.org](mailto:NNFF@nf.org)

## PEN PALS

*(Editor's Note: Another great way to connect with other individuals and families whose lives have been touched by NF is via The NF Web Site [www.nf.org](http://www.nf.org) on the NF Your Turn Bulletin Board or the NF Chat Room, both are at [http://www.nf.org/goto/online\\_community](http://www.nf.org/goto/online_community))*

Mom with NF (and her two children as well) seeks pen pals. Will write to all who respond. Contact Tammy Rossi, 666 Casanova Street, Atlanta, GA 30315.


Please write! I have NF1. Contact Ronald Boose 611 Gentry Road, Hickory, MS. 39332

Mother of three (all have NF1) seeking pen pals. Please write to Ms. Jaqueline Bluit 7111 South Wentworth Avenue, Apt. 4G Chicago, IL 60621.

Hi! I'm Gale. I am a 40 year-old married woman (no kids) with NF1. My interests include reading, walking, and talking on the computer. I am looking to meet other people with NF to exchange stories. I was diagnosed about three years ago and all my

tumors are internal. Please write soon. Gale Spector 1169 East 73rd Street, Ground Floor, Brooklyn New York 11234.

Want an international pen pal? Please write to: Justyn Adderley Flat 4 103, Park Lane Kidderminster, Worcestershire DY11 6TB England

Only person with NF in family seeks pen pals from anywhere overseas. Write to Jodie Nolan 220 Borton Road, Tullera NSW 2480 Australia. 

## CHAPTER NEWS

# Waging the Fight Against NF at the Grassroots

### Todd Mozer Earns Top Volunteer Honor: Brian Behrens National Volunteer of the Year Award 2001



Todd Mozer is a dynamic role model, and a caring father of a child who has NFI. As a concerned parent and a skilled athlete he decided to get involved with the Foundation's Marathon Team. Todd has participated in several marathons and also ran in the Iron Man Triathlon competition last year in Florida in honor of NF.

In addition to the usual fundraising for the marathon team, Todd has gone above and beyond by setting extraordinary personal fundraising goals. He accomplished this through a swim-a-thon event in April 2001 and several parties given in his hometown to raise money and awareness. Todd has contributed towards public education efforts through several local media articles and through a special appeal to the entire Connecticut NF community in an effort to raise awareness and increase donations for the cause.

### Patti Lettich Voted NNFF Chapter Volunteer of the Year Award 2001

Patti Lettich has been a long term Washington Chapter volunteer and two-term board member who has made a substantial commitment to



NNFF. Patti's involvement with the Washington Chapter has spanned over fifteen years and has carried the Washington Chapter with grace, dedication, a much-needed sense of humor and a great deal of courage. The annual Garden Sale, countless hours of work on the annual Harvest Dinner and Auction, medical symposia, support group events, and numerous other activities are examples of her tireless efforts and the reasons why many people have cited Patti as the reason they joined the Chapter. Her positive energy has sustained many members' involvement over the years. A public bench with a plaque in her son Tim's memory has been erected in Seattle's historic Fremont district with a view of the Fremont Bridge, Tim's favorite spot.

### Key Club Car Wash Fundraiser

In the spring of 2001, an amazing group of young volunteers rolled up their sleeves and pitched in to raise money



and awareness about neurofibromatosis. In Hazelton, Pennsylvania, the local high school's Key Club made NF a special cause to aid, through their community service efforts. This group organized a car wash fundraiser which was greatly supported by their school. The Deiter family brought NF to the forefront of public consciousness in their Pennsylvania town. Their efforts and that of the Key Club resulted in an assembly with visiting members of the NNFF staff and mention in their local newspaper. Great job!

### New England Volunteer Organized Hockey Event for NF

On November 18th, the Boston Bruins Alumni team played the coaches of the Nashua Panthers in a charity game to benefit the National Neurofibromatosis



Foundation. Kevin McGowan organized this very unique and spirited charity event that took place in the Tsongas Arena in Lowell, Massachusetts.

The hockey game and banquet that followed, were well attended and helped bring awareness of NF to a larger audience.

### Maryland Golf Tournament

The First Annual Julie Ann Robertson Cashour Memorial Fund Golf Tournament was held at the Whiskey Creek Golf Club on June 5th. Julie's brother Jeff Robertson organized the event. The tournament was intended to raise awareness about NF while continuing Julie's legacy to courageously struggle against the disorder. Jeff welcomes those individuals who would like to participate in this year's tournament to contact him at 301-607-8001. He anticipates that the second tournament will be even bigger and better than last year.



### Oregon Group Getting Off the Ground



Local volunteer Jean Fitzgerald organized an NF Family Picnic on September 29th. This group that met for fun in the sun at Champoeg Park, originated as a support group that meets at Good Samaritan Hospital. The Oregon group hopes to reach out to other families and eventually become an official Chapter of the NNFF. Interested patients and families can find out more about joining this group through the official NF website at [www.nf.org/oregon](http://www.nf.org/oregon)

### Florida Golf Tournament


The Florida Chapter set the tone for the future. On October 1st they held their



2001 Charity Golf Tournament in Orlando, which was an outstanding success. Planet Hollywood and a

devoted group of Chapter volunteers supported the event. This event not only surpassed the net profit of previous golf tournaments run by the Florida Chapter, but also gave uplifting reassurance to NNFF that the fundraising activities of the Chapters would remain strong and consistent in the coming years.

### Tri-State Region

A heartfelt "thank you" to Lydia LoPrimo and the LoPrimo family. The Second Annual NNFF Benefit Golf Classic was held April 26, 2001 at Silver Lake Golf Course on Staten Island. The day was a complete success — great weather — great crowd — lots of money raised for the Foundation. Again, thank you Lydia & family & co-workers for all your hard work! This year's date is Thursday, April 25, 2002. 

### Shop for NF Research

Our shopping mall, courtesy of GreaterGood.com, allows our web site visitors to shop at all of their favorite stores at the click of a button. As an extra bonus up to 15% of all purchases goes towards funding NF research at no additional cost! Simply click on the "GreaterGood.com" icon located on our home page and shop to your heart's content! Its as easy as 1-2-3!

It doesn't matter if you are looking for a dress from the Gap.com or a subscription to a favorite magazine from ValueMag.com the NNFF/GreaterGood.Com online mall will meet all of your shopping needs. There are too many stores to tell you about all of them. Check it out for yourself! Simply go to [www.nf.org](http://www.nf.org) and click on the "GreaterGood" icon. Remember up to 15% of all purchases goes towards funding NF research!



Purchase your favorite book, movie, or CD from Amazon.com and a percentage of your order will go towards NF Research and programs. Browse through Amazon's amazing music selection and pick out those titles that stir up memories. And let's not forget what made Amazon great in the first



place – their outstanding selection of best selling novels. When you shop at Amazon, don't forget to check out these

other categories as well: Electronics, Toys & Games, Health & Beauty, Travel, and much more! Remember, when you shop at Amazon.com a percentage of what you purchase goes to NF Research at no additional cost to you!

### Helping to Spread NF Awareness Just Got Easier!

The NNFF's online store has been redesigned to make it easier to find and purchase all of our great NF gifts. Now our web site visitor's can help spread NF awareness with greater ease. Seamlessly browse through our selection of NF clothing, books, and accessories. Spread awareness with our NF license plate frame or key chain. Or maybe wear an NF t-shirt to your child's next softball game. There are many items to choose from. Come and help us spread NF Awareness!

The store is located here:

[https://secure.nf.org/cgi-bin/web\\_store/web\\_store.cgi](https://secure.nf.org/cgi-bin/web_store/web_store.cgi) or you can go to the "Shopping for NF" button on the home page. Then select "The NNFF Store" option.

### Become an e-member for NF Awareness Month in May!

When you add your name to our roster of e-members you help the NNFF advocate on your behalf to other public, private, and government agencies that are interested in funding programs for NF. The larger our membership, the louder your voice! What's that? You're already an e-member. Then show your support for the NF community by giving someone you care about a gift of membership in the NNFF. The recipient will receive a personalized card notifying them of your gift, along with a membership card. They will receive all of the national and local benefits listed below, and you will have the satisfaction of giving a gift that contributes to the efforts to find treatments and a cure for NF. To find out more visit our web site at



<http://www.nf.org/contribute/emember.htm>.

#### BENEFITS OF MEMBERSHIP

- National newsletters and chapter newsletters; \*
- **(NEW!)** Handsome NF logo pin
- Be a part of the team to help find treatments and a cure for NF;
- Strengthen our roster of members as we advocate on behalf of all those affected with NF throughout the U.S.;
- Receive a personalized NNFF Membership Card;
- Automatic Membership in your local State Chapter;\*
- Invitation to the NNFF Annual Membership Meeting;
- Notification of special patient support services;
- Notification of special publications and events;
- Enjoy a 10% discount on Bookstore items, educational materials, and national symposia;
- Your Membership is a fully tax-deductible contribution as allowed by law.

\*Not all states have active chapters and/or newsletters.

## 20,000TH MESSAGE MILESTONE REACHED ON NF BULLETIN BOARD

### Join our On-Line Community

As an online NF resource, the NF "Your Turn" Bulletin Board (BB) is a place for people with NF and their loved ones to share personal experiences, ask questions, post current events relating to NF, and make friends. The BB features ongoing general discussions about NF1 and NF2 as well as a special monthly topic designed to initiate a productive exchange of ideas. To date, more than 22,000 messages have been posted on The BB.

You have a voice. Let it be heard! You can jump right into the mix by replying to what someone previously wrote or you can start a new discussion. Tell your story. Find a pen pal. Stay up on current NF news and research. Get important announcements from the NNFF. There's simply no reason not to join!

To use the NF "Your Turn" Bulletin Board, all you have to do is register once. To register for the NF Bulletin Board follows these simple instructions.

- Go to <http://www.nf.org/bb2/bbentry.htm> and click "register."
- Read the "Rules and Policies" statement and click "Agree."
- On the registration page enter your username/nickname and your email address. These two are required for successful registration. Completing the remaining fields is optional. Click "submit registration" when finished.
- Your password will be sent to the email address you submitted in step 3.
- Once you receive your password you are free to participate in all Bulletin Board discussions. Enjoy!

### NF "Your Turn" Bulletin Board Highlights

When we posted the question "Who is your NF hero" on The NF Website's Bulletin Board we received a variety of inspiring and touching responses. A few are shared with you below:

*"I would have to say that my dad is my hero. He has NF1, as do I and my oldest son, Phillip. My dad has shown me that no matter how bad he feels he is going to help anyone in our area. He has given to me so many memories and so much love that I will never forget the good times and the bad that we have shared.*

— BB

*"Our daughter is so courageous with everything she has been through. Her constant smiles just make my day. She is a very loving and giving child. My son also gives me great joy. He is too young to realize he has NF. But he comes up to me every day and says 'Mommy, I have a furprize for you!' Not a surprise, a 'furprize' and he gives me the biggest hug and kiss."*

— K

## www.nf.org (continued)

"I would have to say my first ophthalmologist, who diagnosed my condition when I was five. Second would be the neurosurgeon (my first surgery at age 12) who was in the profession to serve humanity. He was the doctor who discovered I was born without a right eye socket, so he put one in--and a plate. True, my eyes are asymmetrical, but I still have my sight."

— BM

### Meet Others in Real Time

Hundreds of people from around the world have joined the NF Chat Room

and the number continues to grow! The chat room allows you to have live discussions about issues pertaining to NF right from your computer.

The NF Chat Room does not require any special software or any specific browsers (such as AOL, Prodigy, etc.) Anyone, anywhere that has an internet connection can use it anytime – all you need is access to the World Wide Web.

The NF Chat Room is open 24 hours a day, 7 days a week, for the convenience of

people in international time zones. Although the NNFF has scheduled 10pm on weekdays and 3pm on weekend afternoons (Eastern Standard Time) for discussions, we urge you to establish chat sessions of your own at times that are practical for you. Just schedule a meeting with your buddies online whenever you want and convene in the chat room at the designated time.

Go to <http://www.nf.org/cgi-bin/nfmainchat/mainchat.cgi> and you'll be chatting it up in no time! **NF**

## NF PROFILE Joshua Dingeman Teen Soars With The Eagles

*(Editor's note: Life with NF can be hard, but many people with NF manage to do extraordinary things. The purpose of the NF Profile feature is to highlight persons with NF who are doing exciting things with their lives and serve as role models and inspiration for others living with these challenging disorders.)*

What does 16-year-old Joshua Dingeman have in common with Astronaut James Lovell Jr, Steven Spielberg and retired CIA Director Robert Gates? They have all earned the rank of Eagle Scout – the highest level of achievement a member of the Boy Scouts of America can receive.

Joshua received his Eagle Scout badge one year ago after the completion of a public service project where he and a few friends sanded and painted benches for the Leader Dogs for the Blind in his hometown of Shelby Township, Michigan.



Not only is it impressive that a 16-year-old boy would choose to devote his free time to helping others in his community, but Joshua has achieved this honor while living with learning disabilities that are a part of his NFI.

Since the age of 5 Joshua has known he has NFI. His father, Peter, has been an active member of the Foundation for years and serves as the Michigan Chapter President. Joshua says that he has always known he had NF and was always encouraged by his family not to let it limit him in any way. Peter, who also has NF, has been a great example to Joshua in this respect.

It's been one year since Joshua received his Eagle Scout badge and his efforts haven't ended there. He continues to earn additional "PALM" awards (awards for earning merit badges in addition to the badges required to become an Eagle Scout) for his community service work. Joshua's future goals include going to college to study psychology.

With his determination it is clear that he will continue to soar no matter what path he chooses. **NF**

## NF Research (continued from page 1)

NFI mice there is too much *ras* activity, which leads to detrimental increases in inhibition.

Thus, to treat the learning deficits, researchers gave the NFI mice a drug commonly referred to as FTI or farnesyl transferase inhibitor. This drug decreases the activity of *ras*. Clinical tests are currently under way to test the efficacy of FTIs as anti-tumor agents. Thus, it is possible that molecular malfunctions that cause

the tumors in NFI, also are responsible for the learning deficits. One day a single drug may be used to treat these two different symptoms of NFI.

"We are all very excited about this discovery, but there is a lot of research to be done before these discoveries can be translated to the clinic" Silva cautions. "But we can see the way ahead clearer than ever before."

"While billions of dollars are spent on special education programs to ameliorate the effects of learning disabilities experienced by millions of Americans, comparatively little has been spent to discover the molecular biology and biochemical processes involved in LD," Peter Bellermand, NNFF President said. "The work of Dr. Silva and his colleagues represents a groundbreaking advance in understanding the root causes of learning disabilities and how to treat them." **NF**

# The 6th annual NNFF International Summer Camp. Don't Delay!

Two sessions available on a first come first served basis.

## First Session—July 17–July 26, 2002

Send your child for a week of fun and learning at the NNFF Camp where they will visit the Grand Canyon, camp under the stars in Moab, Utah and raft down the Colorado River. Campers will also spend a few days at Camp K enjoying the ropes course, arts and crafts as well as fun day trips to see AAA baseball games, visit 12,000 foot Snow-bird mountain, lots of swimming, hiking, horse back riding, camp fires, dances, talent show, fishing and more.

A unique feature of our camp is the visit to the University of Utah's Eccles Genetic Science Learning Center to take a tour of a working genetics lab, perform hands-on experiments and have the chance to talk one-on-one and ask questions of an NF researcher. The kids always enjoy being scientists for a day and learn about NF and genetics in a fun, interactive way.

This session is designed for new campers or for returning campers who have attended only one other camp session.

Price: \$600.00 plus Airfare

## Second Session—July 26–August 2, 2002

This camp is a great opportunity for the kids to reconnect with their friends and spend time together. This summer we have



added a rafting trip for the campers to enjoy. In addition to the rafting trip, campers will be spending a few days at Camp K enjoying swimming, hiking, horse back riding, camp fires, dances, a talent show, fish-

ing, and AAA baseball. Reunion campers also take a trip to the University of Utah's Eccles Genetic Science Learning Center.

This session is our reunion camp and is open to campers who have attended two or more NNFF summer camps.

Price: \$575.00 plus Airfare **NF**

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THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

95 Pine Street  
16th Floor  
New York, NY 10005

Telephone: 1-800-323-7938  
or 212-344-NNFF

Fax: 212-747-0004

E-mail: [NNFF@nf.org](mailto:NNFF@nf.org)

On the Web: [www.nf.org](http://www.nf.org)

Managing Editor: Michelle Messinger

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.*

## MEETING ANNOUNCEMENT

**NNFF Annual  
Membership Meeting**

**Hotel Jerome  
330 East Main Street  
Aspen, CO 81611**

**Saturday, June 8, 2002  
8:00AM**

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