

neuro·fibroma·tosis®

THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

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NNFF Representative Asks Congress to Accelerate Research To Find a Cure for NF

"The fact that I sit before you today is the greatest testament anyone could ask for good medicine and brilliant surgeons," said Michie Stovall O'Day at a recent congressional hearing. "I am living proof that the federal funds you have allocated to research into the causes and treatments for NF is money well spent."

Michie Stovall O'Day appeared before the U.S. House of Representatives Subcommittee on Labor, Health and Human Services, Education and Related Agencies on March 8, 2000 to ask Congress to direct more funds towards neurofibromatosis (NF) research. Ms. O'Day was representing the National Neurofibromatosis Foundation as part of its mission to improve the health and well being of individuals and families affected by NF. Ms. O'Day has been a member of the Foundation since 1984 and currently serves on the Foundation's Board of Directors.

As a result of NF2, Ms. O'Day has lost her hearing and has undergone four neurosurgeries for tumors on her brain and spinal cord. Ms. O'Day also lost her mother and younger brother due to complications of the disorder.

NF research has been held up as a model for "Managing Science." The overall research effort is a direct result of effective partnerships between public agencies (most notably the U.S. Congress and the National Institutes of Health), private organizations and the NNFF, and scientists

and clinical researchers in the field who have achieved their progress by collaborating to a remarkable degree. The NNFF has been instrumental in bringing together researchers who normally would be in competition with each other, and forming research partnerships that benefit both research institutions and the NF community.

Due to the continuing success in NF research, scientists now stand ready to translate basic scientific knowledge into clinical application. This means that all we have learned about what causes NF and how it leads to the development of the disorder can now be used to develop effective treatments.

However, there is still much work to be done. The NNFF believes the next steps in the NF research agenda should be continuing work in basic research, comprehensive natural history studies for NF, and beginning the process of clinical trials with innovative approaches (see article on new NNFF Director of Technology Transfer on page 5).

Given the wide variety of symptoms of NF and the significant potential of NF research for other large patient populations, cross-institute research is also an important priority. For example, the NF protein is implicated in the development of several common cancers (breast cancer, colon cancer and melanoma). Therefore, NF research stands to benefit an additional 100 million

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Innovative New Research Ideas Win Prizes from NNFF, INFA, and QXL.com

In an effort to attract outstanding young scientists to the field, the National Neurofibromatosis Foundation and the International Neurofibromatosis Association in partnership with the British QXL.com (a leading European online auction company) offered \$20,000 in prizes for new, innovative research ideas pertaining to NF1 or NF2.

The contest was open to graduate students and post-doctoral students worldwide. A panel of NF researchers reviewed all submissions, and the prizes were awarded on March 1, 2000.



NF Prize for Research Ideas

And the Winners Are...

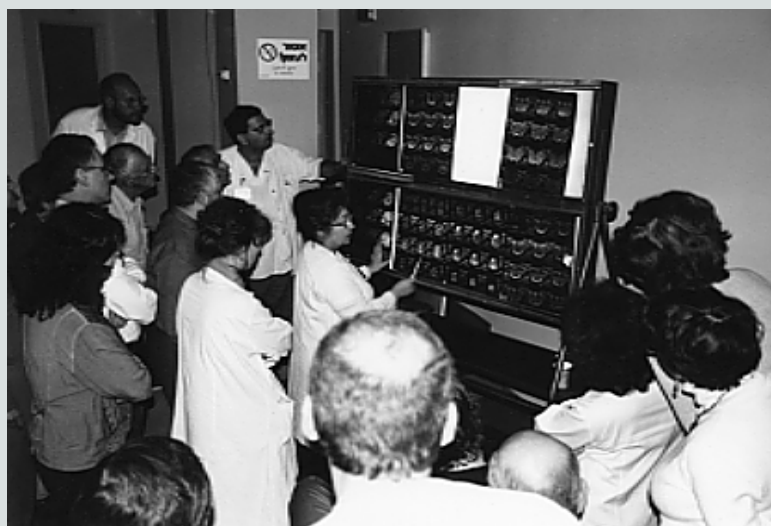
First Place (\$10,000) was awarded to Dr. Amit Etkin of Columbia University for his proposal, "Determination of mechanisms for Neurofibromatosis 1-related learning deficits." Mr. Etkin's submission is especially impressive since he is not currently doing research within the field of NF. His research idea focused on examining the potential biological causes that may relate to the high incidence of learning disabilities in persons with NF1. Approximately 40% - 50% of persons with NF1 experience some sort of learning disability. This is obviously an important area of NF research and one that the Foundation is eager to explore further.

"The experience of researching NF was rewarding in many ways aside from the honor of receiving the actual prize," said Dr. Etkin. "It served as an excellent opportunity to develop my interest and learn to bridge science in clinical medicine, which I hope to do in the future."

There were two entries tied for second place. The peer review panel decided to rate both entries equally and to split the cash awards (\$4,000 each) for second place tie. Therefore, no third place prize was awarded.

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NF 2000 CONFERENCE IN ISRAEL

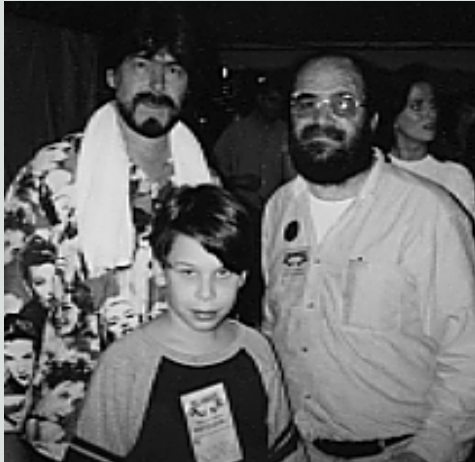


A two-day conference on NF was held in February at Tel Aviv University. Organized by Professor Amos Korczyn (Tel Aviv), the meeting heard presentations by NNFF Medical Director Dr. Allen Rubenstein (Mt. Sinai, New York), the Chairman of the NNFF's Medical Policy Committee Dr. Bruce Korf (Harvard), the NNFF President Peter Bellerman and NNFF Board Member Nate Walker. Pictured above are a group of clinical experts during a grand rounds session of the meeting, discussing MRI's and complex management issues.

CHAPTER NEWS: Waging the Fight Against NF at the Grassroots

Autographs for NF!

The South Carolina Chapter enjoyed a productive holiday meal in December. The goal of the lunch at the Myrtle Beach All Star Café was to brainstorm ideas for creative fundraisers in the year 2000. The result—an autograph auction! Autographed CDs from bands like Hootie and the Blowfish and Alabama as well as autographed pictures of other celebrities like actor Anthony Michael Hall and former President George Bush will be auctioned in April to help raise money for NF research.



Stu Wright and his son with Randy Owen of country music group Alabama.

Sticking' It To NF



One of the lucky winners with Stephan Richer of the St. Louis Blues hockey team.

The Missouri Chapter held a raffle at the Kiel Center—home of the St. Louis Blues National Hockey Team in January. Scratch-off tickets were sold for the chance to win autographed hockey sticks from NHL stars Roman Turek, Pavol Demitra, and Kelly Chase. The hockey sticks were actually used by the players during that night's game. Local TV and radio stations all helped to publicize the event as a great way to stick it to NF!

Have A Heart

Natalie Valentine of Rhode Island sold Valentine's Day Hearts to local businesses in order to raise money for NF research. The fundraiser was held in honor of her son, Harry Valentine, who was born with NF. For each heart sold, \$1 was donated back to the NNFF. Local restaurants and supermarkets in Rhode Island were Natalie's primary targets, but Pete's Tavern in New York City also joined in the effort to help make Harry's Valentines famous. Natalie was so pleased with the results from this year's effort that plans for next year are already in the works.

Doctors and Dinner

The Washington State Chapter of the NNFF held a combination Medical Symposium and Pizza Dinner at University of Washington's Waterfront Activity Center on March 6, 2000. Topics ranged from learning disabilities to occupational therapy to the latest MRI technology. Participants first came to hear the latest information in NF research and then stayed to enjoy dinner with their fellow chapter members.

NNFF Welcomes Oklahoma and Wisconsin to the Family!



Wisconsin Chapter President Elaine Pankow with Senator Kohl

Oklahoma and Wisconsin were approved as new Chapters at the January Board of Directors meeting.

The Oklahoma Chapter began with the efforts of Richard and Hilarie Hedrick of Ardmore who organized a local fundraiser with the cooperation of Wal-Mart. Richard has NF1 and has two sons with the disorder. "As soon as I found out my two sons had NF, there was only one thing to do—create a chapter," Richard said.

The Hedrick's organized on-going local meetings and developed a core group of

participants. In addition, the Hedricks worked with the NNFF to conduct local media relations to heighten awareness of NF and the Chapter throughout Oklahoma. The Chapter's first support group and educational meeting are being planned for the Spring. Interested Oklahomans can reach the Hedricks at (580) 223-3513 or via e-mail Rhedr35594@aol.com.

The Wisconsin Chapter is being led by Elaine Pankow, who's son and granddaughter have NF. She has recruited an active group of nearly 30. The

Chapter conducted its first patient education meeting in November at Children's Hospital in Milwaukee in cooperation with Dr. Mark Lubinsky of the hospital's NF clinic. Fundraising is planned and includes a sports memorabilia raffle to be held at the group's information booth at the Wisconsin State Fair in August.

A support group is planned to begin this summer. Public education outreach to Wisconsin schools is a project the group will begin to tackle in early Spring. Elaine's motto is "Here we are together, here we

stand, together we make a difference!"

Those interested in the activities of the Wisconsin Chapter may contact Elaine Pankow at (414) 438-0985 or via e-mail at epankownf@aol.com.

PEN PALS

Looking for a pen pal! Please write to: Miss B. Keyes, 209 East Broadway #6A, Seminole, OK 74868.

29 Year Old Woman with NF seeks pen pals. Write to: Linda Lisby, 2520 South 19th Street, Terre Haute, IN 47802.

27 Year Old Woman with NF1 (mother of 5 year old son with NF1 also) wants to talk to others about living with NF and raising a child with NF. Please contact: Angela at sunflwr556@aol.com **or write to:** Angela De Maria 277 Parnell St. Merritt Island, FL 32953

Pen pal wanted! Write to: Brian Marshall 772 Twin Bridge Road, Jerseyville, IL 62052

Do you want a pen pal? If so, write to: Mary Ann Redondo 12 Entrance Way, Denville, NJ 07834.

Five Clinical Experts Added to the NFFF Clinical Care Advisory Board

The Foundation has announced the addition of five new members to its Clinical Care Advisory Board (CCAB). The purpose of the CCAB is to establish criteria for comprehensive approaches to the diagnosis and management of individuals with NF 1 and NF 2. The new members are:

Dr. Stacy Nicholson

Dr. Nicholson, an Associate Professor of Pediatrics at the Oregon Health Sciences University, is the founding director of the Pediatric Neuro-Oncology Program and Program Leader for Cancer Prevention and Control for the Oregon Cancer Center. Dr. Nicholson's expertise and extensive involvement in epidemiologic studies will make an important contribution to the CCAB. He is currently working with the National Institutes of Health (NIH) in Washington, D.C. conducting clinical trials in pediatric brain tumors.



Dr. Jan Friedman

Dr. Friedman is the head of the University of British Columbia Department of Medical Genetics. Currently he is on a study leave at the Centers for Disease Control and Prevention in Atlanta, Georgia conducting an epidemiological study of NF. These types of studies generally focus on identifying or measuring the effects of risk factors or exposures for persons with a certain medical condition. Dr. Jan Friedman obtained his Ph.D. in Genetics at the University of Washington, Seattle.



Dr. Bartlett D. Moore, III, Ph.D.

Dr. Moore is an Associate Professor of Neuro-Oncology (Neurophysiology), at the University of Texas MD Anderson Cancer Center. In addition to his many scientific publications, he has developed the "Growth Curve Program". This computer software




program is used for plotting age vs. height against normal pediatric standards for patients with reported endocrine dysfunction. Dr. Moore is also a leading expert on learning disabilities and NF.

Dr. Priscilla Short

Dr. Priscilla Short currently works for the Department of Pediatric Neurosurgery, at the University of Chicago. She also works part-time at the American Medical Association. Dr. Short has NF2 and therefore brings a personal perspective to her work on the CCAB.



Dr. Abhijit Guha

Dr. Guha is an Associate Professor of Neurosurgery & Surgical Oncology and an Associate Director of the Labatts Brain Tumor Center at the University of Toronto. Dr. Guha is widely published in the fields of neurosurgery and oncology. 

RESEARCH CALLS • RESEARCH CALLS • RESEARCH CALLS

Neurofibromas Needed

Dr. Nancy Ratner at the University of Cincinnati requires neurofibromas from NF1 patients for an ongoing study of tumor growth factors, growth factor receptors, and signaling pathways in neurofibroma cells. To be enrolled in this study, tumors must be removed by the patient's own physician for medical reasons. If you are scheduled for surgery, and are interested in your tumor tissue being used for this study please have your physician and his/her nurse contact Dr. Ratner at least 24 hours prior to removal of tumors for instructions. The study requires sterile tumor tissue covered by and shipped in tissue culture medium, on wet ice. Plexiform or cutaneous neurofibromas can be used. Some patient information (age, sex, criteria used to make the diagnosis of NF1) is required. Dr. Ratner will pay shipping costs. For more information: Tel: 513-558-6079; Fax: 513-558-4454; email nancy.ratner@uc.edu.

We Need Your Tumor!

It's a simple request but an important one. If you have NF and you are going to have surgery and you would like to contribute to the research effort please let someone know. The majority of that tumor that you don't want anymore will be discarded unless a research lab knows it's available. If your own medical center is not actively researching NF, please call my laboratory and we will bank the material, use it in our own work, or donate to other collaborating labs. I can be reached at: Mia MacCollin, MD; Tel: 617-726-5725; Fax: 617-726-5736; email maccollin@helix.mgh.harvard.edu.

When you call please have available the name of your surgeon, the date of surgery,

and your surgeon's phone number. The NF community thanks you!

(Reprinted with permission from the Texas NF Foundation January 2000 newsletter Volume VII)

Researchers Seeking Families With NF1

Drs. David H. Gutmann and Michael DeBaun are requesting information regarding families with neurofibromatosis 1 and plexiform neurofibromas/malignant peripheral nerve sheath tumors (MPNSTs). We are specifically looking for families in which at least two generations of individuals with neurofibromatosis 1 harbor either plexiform neurofibromas or MPNSTs for genetic studies to determine what genetic factors might contribute or predispose to the development of these tumors. Please contact David Gutmann at Washington University. Tel: 314-362-7149; email gutmann@neuro.wustl.edu.

NF2 Patients Needed for Natural History Studies

The natural history study will measure the growth rates of vestibular schwannomas in 100 people with NF2, in order to determine the normal growth rates for vestibular schwannomas. The study will focus on patients who have been diagnosed with NF2 within the past two years. The goal of the natural history studies in NF2 is twofold:

- Develop predictive factors to determine growth rates for vestibular schwannomas in NF2
- Define all parameters necessary to conduct clinical trials for new therapies for NF2

The three-year study will be conducted at

Massachusetts General Hospital in Boston, The House Ear Institute in Los Angeles, and Mt. Sinai Hospital in New York, as well as centers in Hamburg, Germany and Manchester, England.

While no new treatments will be part of the NF2 natural history studies, patients may continue their current treatment during the study. Patients interested in participating should contact Gloria Yoon, a research assistant at The House Ear Institute. Tel: 213-483-4431; email gyoon@mailhouse.hei.org.

NF Graduate Student Is Seeking NF Parents

Ann Dylis is a Registered Nurse who is studying for her doctoral degree at Boston College. She was diagnosed with NF as an adult and has a strong desire to give back to the NF community. Her dissertation will be on the parents of children with NF. So far, the parents of NF children have only been studied in relation to validating their child's behaviors. This study will be about YOU. You can be a parent with or without NF, and your children can be any age.

If you are an NF parent and are interested in being involved, please contact Ann Dylis directly. She is currently collecting names and information for people who might be interested and then when her study starts, she will send out full information and get full consent from you. Thanks for thinking about participating in this original and significant project! Contact Ann Dylis, Boston College, Cushing Hall, 140 Commonwealth Avenue, Chestnut Hill, MA 02467. Tel: 617-552-1406; Fax: 617-479-1282; email dylis@bc.edu.

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www.nf.org

SELL IT ON EBAY FOR NF DURING NATIONAL NF AWARENESS MONTH IN MAY!

Want to clear out all that stuff in your attic and help NF research at the same time? Sell it on Ebay!

During National NF Awareness Month this coming May, volunteers from all across the country will be asked to help raise funds for NF research by auctioning items online at Ebay.com, one of the most popular sites on the Internet today. If you don't have an item to auction but still want to participate, log on during May and bid on items in the NF auction block. It's easy, it's fun and it helps further research for NF. The National NF Foundation will be organizing the effort and hopes to raise over half a million dollars towards NF Research and Programs. Log on to our website at www.nf.org/auction for user-friendly details on how you can participate in the Ebay auctions.

MOTHER'S DAY IS JUST AROUND THE CORNER...ARE YOU READY?

Your mother always told you it was better to give than to receive – this Mother's Day show her you were listening and buy her gift at the NNFF Online Store!

Make Mom proud by buying the perfect gift at any of our Shop2Give vendors and a portion of



each sale will contribute to funding NF research and programs at no extra cost to you. Send a bouquet of flowers to her door through 1800FLOWERS, surprise her with a box of chocolates from Gift Express or give her the perfect shade of lipstick from Eve.com. There are tons of categories available, from gift cards and gift certificates to clothes and jewelry so Shop2Give this Mother's Day!

Purchase mom's favorite book, movie or CD at



Amazon.com and a percentage will go towards NF research. Search any book or music category at Amazon from the NNFF Bookstore at www.nf.org/pat8-1.htm and find the perfect book for even the most discerning mom.

This Mother's Day, give Mom a great big bear hug—an E-Bear hug! E-Bears can be shipped anywhere in the U.S. and makes the perfect accompaniment to any gift from the NNFF Online Store. Log onto our secure site at <https://secure.nf.org/store/> and start shopping today!



TIME IS RUNNING OUT TO WIN A FREE VACATION!

The NNFF hopes to direct more funds toward research by reducing the cost of printing and mailing information to our members. You can help in this effort by entering our Second E-Mail Airline Ticket Sweepstakes and submitting your email address. For more details and official rules, please go to <http://www.nf.org/win/>.

No purchase necessary to enter. Entries must be submitted by May 31, 2000. Participants must be legal US resident and 18 years of age or older. Void where prohibited or restricted by law.

JOIN OUR ON-LINE COMMUNITY

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 own 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 10 pm on weekdays and 3 pm 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 then convene in the Chat Room at the designated time.

To use the NF Chat Room, all you have to do is register once. To register for the NF Chat Room, follow these simple instructions:


- Go to <http://www.nf.org/chat/chat.htm>.
- Read the "Rules and Policies" statement and click "Agree".
- On the registration page, click the "register new user" link.
- Enter your nickname, a password, password confirmation and email address. Click on the "register" button.
- Click the "Login" link on the confirmation page.
- Enter the username and password you just chose.

Congratulations! You have now joined over 500 users around the globe already in the NF Chat Room. Just type your message and click on the "post" button to let others view what you have written. 

NNFF Representative Asks Congress to Accelerate Research

(continued from page 1) Americans who suffer from these conditions. Continued NF research promises to lead to advances in understanding of cancer, tumors and learning and memory processes.

Ms. O'Day asked Congress to continue to provide clear directives to the National Institutes of Health to ensure that the level of funding to fund a cure for the thousands of Americans with NF continues to grow each year.


Ms. O'Day concluded her testimony by asking the committee, "Wouldn't it be great for the NF community to be able to look back one day and say 'I once had this genetic disorder and I thought it would be the end of me, now it is gone and I don't have to worry about it anymore?'" 

Welcome Aboard!

The NNFF's newest addition, Colette Saccomanno, Ph.D., was recently hired as the Director of Technology Transfer. As the Director of Technology Transfer, Colette, who has a family connection to NF, will be responsible for seeking sponsorship of our Clinical Trials program.

"The dawn of the age of genetic medicine holds much promise for many. It is my hope, desire and goal that the Foundation begin to lead the field in facilitating the dis-

covery of effective treatments for NF," Colette said.

Colette will be targeting large biotechnology and pharmaceutical companies that would potentially engage in NF research. In doing so, she aspires to make NF and the NNFF a significant part of multi-million dollar research projects, which such companies regularly sponsor. Colette obtained her degree at Fordham University, Dept. of Biological Sciences. 

NF PROFILE

Jordan Harlow Proud Member of the NF2 Crew

At the age of fourteen Jordan Harlow had already undergone two eye operations and it was suspected that she might have NF2. That same year Jordan developed a spinal meningioma and her diagnosis was confirmed. From that day forward she began having CT scans and MRIs every six months to monitor her condition.

"My initial reaction was surprise and a little confusion. I was a typical teenager with the philosophy of 'let's get this over with, I have a life to live!'"

Jordan's mother at first refused to believe the doctor. It seemed impossible that their beautiful, smart, popular daughter had a genetic disorder. As Jordan underwent surgery for her spinal tumor, the reality of the situation began to sink in for her and her family. The Harlow family resolved to learn as much about NF as possible since they felt this would be the key to keeping Jordan healthy.

From a young age, Jordan knew she wanted to go to college and eventually graduate school. She had always been a good listener and had a very intuitive sense of people and her dream was to become a therapist or a counselor so she could help others. Jordan knew that achieving this dream would not be easy but her strength and determination have helped her to overcome some of the obstacles that NF2 has put in her path. She obtained a bachelor's degree in sociology and a master's degree in psychology in 1990.

By the time she was ready to graduate, she knew she had a very aggressive form of NF2 and would lose her hearing in the next few years. To prepare for this, Jordan began learning sign language. In November of 1990

Jordan had the surgery that would take the rest of her hearing. After she had become deaf, many of her friends and family took sign language classes with her so they could continue to communicate. Later, when it became clear that she would also lose her vision, Jordan began to learn Braille.

NF2 has made my faith stronger, my love and appreciation of my family and friends deeper, and my gratitude for the little blessings more heartfelt

After graduation Jordan was searching for work that would allow her to use her education and talents to help others. She began volunteering in an elementary school for the hearing impaired helping to reinforce the children's spelling and vocabulary. A few years later, she served on the Board of Directors for a local independent living center and helped to set up and maintain their library.

NF2 has had a major impact on Jordan's life. In her determination to learn as much as she can and

help others cope with the disorder, Jordan helped to start the online group called the NF2 Crew. The Crew has been her biggest source of learning and investigating from links to various web pages.

A talented writer, Jordan has written about her experiences in several newsletters such as the Association of Late Deafened Adults and the *Life after Deafness* (no longer in existence) newsletter. She has also contributed to the *NF2 Review* with articles about what it is like to be deaf, finding new ways to communicate on-line, and an article musing about whether or not she would be a different person if she did not have NF2.

Jordan believes that living with NF2 has taught her many things. "The biggest impact NF2 has had on my life is to make my faith stronger, my love and appreciation of my family and friends is deeper, and my gratitude for the little blessings is more heartfelt."

Jordan's latest project has been working with a friend on a children's book called, *Missy Morgan and Polka Dot Braille*. Jordan lent her expertise and experience in psychology to ensure the book was full of positive language and images for children learning about what it is like to be blind.

The first two printings of *Missy Morgan* are completely sold out! In the future Jordan would like to see a publishing company do a large printing of the book and market it to children all over the world. "I would love to see Missy Morgan as a character on Sesame Street who teaches the children about what it is like to be blind and showing them how to read Braille like it is a cool 'secret code'."

Jordan continues to contribute to various newsletters and publications in the hopes that others can learn and benefit from her experiences.



Jordan Harlow (far right) and some Missy Morgan fans.



I Survived the NF Marathon Team!

One Team Member's Story

By Julie Craig

My daughter Holly is 2 years old and has NF1. In June of 1999 I contacted the Colorado Chapter of the NNFF to inquire



Julie and Jeff at the finish line of the Chicago Marathon.

about volunteer opportunities. I was a casual runner (at that time I had done a few 10K races) and wanted to know if there was a way to raise money by doing a marathon. That's when I learned about the NF Marathon Team.

What I thought would be the hardest part of joining the NF Marathon Team was actually the easiest – fundraising. To help raise money, I wrote a heartfelt letter about my daughter and my desire to help her and others living with NF. Then I mailed it to every friend, family member and acquaintance I could think of. I even had friends send the letter on to their friends and family to create as wide a network as possible of people who could help me. Not only

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neuro-fibroma-tosis
NF Marathon Team
racing for research

Upcoming marathons:

October 1, 2000	Portland Marathon
October 23, 2000	Chicago Marathon
October 23, 2000	Dublin Marathon, Ireland
December 10, 2000	Honolulu Marathon
January 7, 2001	Disney World Marathon, Orlando
March 18, 2001	Maui Marathon

• • • YOUR TURN • • •

Living With NF 2: A Wife's Perspective

Valerie Tucker, MA, NCC lives with her son, Noah in Davis, California. During the writing of this article, her husband Craig, who had NF2, died unexpectedly in a car accident.

Neurofibromatosis (NF). I didn't know anything about this condition before I met my husband, Craig. Twelve years later, I know it well. For the person NF embodies, it entails a life of surgeries and doctor visits. For the person who loves someone with NF, it entails a life of surgeries and doctor visits.

We chose to live life with NF, not against it

I'm not complaining. If it weren't for NF, I wouldn't have the family I have today. I met my husband because he had it. This doesn't mean that I enjoyed having NF in my life. This simply means that NF is a harsh, unyielding condition that not only invades the body but also invades the personal lives of those connected with it.

What does NF mean to a couple or families living with it? NF impacted my life socially, emotionally, and spiritually. Being a support person has helped me learn that the word "impact" can also have a positive meaning. NF isn't fun, but it has made my life complete in important ways that I never dreamed of.

The social ramifications of having NF are varied. Craig's hearing loss, his speech, and his facial paralysis effected our social lives. "How can the four of us have dinner together?" a dear friend of mine asked me.

She cared about the implications of Craig's hearing loss and speech on our ability to communicate, but she didn't care when Craig had a piece of lettuce on his cheek during dinner (he didn't know due to his facial paralysis). We quickly developed a system of signals to let Craig know about the lettuce without embarrassing him. We liked socializing with her simply because she didn't make a big deal out of Craig's differences.


I vacillated between feeling responsible for Craig's communication with others and leaving him alone. Do I interpret for him or not? This is a very personal question with no right or wrong answer. I tried to do what was most comfortable in each situation. I didn't want to see Craig isolated from his hearing family and friends. I also didn't want to be the gatekeeper of communication at each event. Surrendering to the reality that everyone isn't going to learn sign language just because I think they should was a challenge for me. The most important aspects of socializing were to discuss these potentially uncomfortable issues and realize it is okay to be picky about who we wanted to spend our social time with.

The emotional aspects of NF are significant. My husband Craig and I chose to live life with NF, not against it. Our favorite book was *Tuesdays With Morrie*, by Mitch Albom. It is the true story of Morrie Schwartz, a man living with a fatal disease (Lou Gehrig's Disease or ALS) who's positive attitude helped him to focus on the good things in his life so he could enjoy what time he had. My husband's NF allowed me to experience immense amounts of love and support. I learned that it's okay to ask for help and it's okay to accept help. These are concepts that I

had to learn for the sake of survival.

Someone once asked me if I knew Craig had NF before I married him. What difference would that have made? Yes, I knew he had it. No, I didn't comprehend what that meant. Emotionally, as his support person, I suffered from major burnout at times. As hard as I tried, I couldn't fix this condition. It was not going away. The lessons I learned about emotional strength came during our worst times, mostly during the recovery from a surgery. It is of utmost importance that support people (as well as those with NF) take care of themselves. Find a moment for yourself to sit and breathe. Take a walk. Read a book, write, laugh, or just be. Do whatever you need to rejuvenate your soul.

Spiritually, I realized that NF is a gift in some ways. It has allowed me to learn to love unconditionally; not the superficial love that judges others by their outer appearance. Craig taught me that. He was able to face each day, and each person's stares at his non-symmetrical face, with dignity and peace. A friend of mine whose husband also has NF stated "we rage, we laugh, we cry, and we go forward, sometimes weary, sometimes strong." This is so true. Whatever your spiritual belief system is, utilize it. It will help bring light within the darkest times. When I trust in the powers that be, I have more strength.

"Accept what you are able to do and what you are not able to do," Morrie Schwartz said. I couldn't change the growth rate of the tumors, but I could change how I lived each day, how I took care of myself, and how I accepted NF as part of my life. It does impact everyone's life that it touches. The social, emotional, and spiritual impacts are as real as the MRIs on the wall in the doctor's office. 

INVESTING IN NF • Where There's a Will There's a Way

By Amy Lin Parkis

(Ed. note: Making a gift to The National Neurofibromatosis Foundation through your will is called a bequest, and can allow you the opportunity to make a substantial contribution towards our ongoing efforts to find a cure and treatments for NF.)

I have been aware of NF and its affect on people's lives since I was a little girl. There are several members of my family who have NF. My mother, who had a severe case, always hoped for a cure. She and her mother both suffered with its affects, as well as one brother, an uncle, and many cousins. I remember being a small child and being out with my Grandmother, seeing people stare at her, I think it hurt me more than it hurt her. As a child it made me very angry; but as an adult it made me want to help find a cure.

I found that by making a bequest to the NNFF through my will, I could be an active part of that process. The assets that I leave to the Foundation will help to fund NF research into effective therapies and eventually a cure. Taking part in this process makes me feel as though I am helping to make a lasting difference in the NF community.

When I decided to make this gift I emailed the Foundation to get more information.

They sent me the necessary language and I worked with my attorney to create the kind of will I wanted. In addition to the good feeling that I have about making this gift I learned some things that I think you might find helpful.

It's not hard and will ensure you're able to be part of the helping process

The most important advice I can give is don't try to do it yourself! State law dictates what is and what isn't legal in drafting and signing a will. A universal will form obtained at a stationery store or a homemade will is risky, to say the least. A good estate-planning attorney can ask the right questions to help you make sure you are covering all the bases in planning the disposition of your estate.

It is important to make sure you include clear and correct information in your will. By spelling out your wishes clearly and specifically, your executor (the person who will be handling the disposition of your will), family members and other bequest

recipients (which would include the NNFF and any other charities) will know exactly what you intended. For a bequest it is important to list the full name of the organization, this case it's the National Neurofibromatosis Foundation, Inc.

Lastly, don't hide your will. Keep it in a safe place? Yes. Hide it? No. In addition to storing your will in a safe place, like a safe deposit box at a bank, make sure you tell your executor or other appropriate persons where to find it.

With a little planning and good counsel, you can also enjoy the same kind of satisfaction that I have about making this decision to help those with NF. It's not hard to do and it will ensure that you're able to keep being a part of the helping process.

(Ed. note: The Foundation thanks Amy for her generous bequest gift through her will, and for her insights into creating that will. Having a good will is important for you, for your family and for others you may want to be included. For more information please contact Andy Phillips, Vice President of Development at the NNFF (800) 323-7938 ext. 31.)

NF

Innovative New Research Ideas Win Prizes

(Continued from page 1) The two-second place winners were Dr. Karen Cichowski of M.I.T. and Dr. Glenn Cowley of Massachusetts General Hospital's Cancer Center.

Dr. Cichowski's submission, "PKC inhibitors as potential therapeutic agents for treating neurofibromas" proposes experiments that could lead to the development of a new treatment for inhibiting tumor formation in people with NF.

"As a basic scientist I regularly ask myself how can the data we generate in the lab be used to help patients," said Dr. Cichowski. "This contest for research ideas was the perfect forum to formulate and express such ideas. I hope these ideas are ultimately useful therapeutically and I am currently doing what I can to generate supporting data and bring these ideas to the attention of clinicians."

Dr. Cowley's submission, "Dopamine signaling and the NF1 disease phenotype" describes an experiment that would analyze which, if any, class(es) of dopamine

receptor(s) had an effect on NF1 phenotypes (physical manifestations of the disorder) and could therefore lead to the development of a pharmacological (drug) approach to modify the severity of NF1 phenotypes. Dopamine is a chemical that transmits messages in the brain and plays a role in movement.

An additional \$2,000 was made available to the first place winner for travel stipends to scientific meetings dealing with NF1 and NF2.

"We are absolutely delighted by the strong response to these new prizes and the high quality of the submissions we received," said NNFF President Peter Bellermann.

"On behalf of the NF community, congrat-



First place winner: Dr. Amit Etkin of Columbia University

Not pictured, second place winner: Karen Cichowski of M.I.T.



Second place winner: Dr. Glenn Cowley of Massachusetts General Hospital's Cancer Center

ulations go to the winners, who represent a new generation of brilliant scientists coming into the field or continuing in the field. Our thanks also go to Tim Jackson and QXL.com in the UK, who made the competition possible."

NF

OUR TIME HAS COME!

May is NF Awareness Month and many of our members use this time to work with the Foundation to help raise public awareness of NF in their communities. Some suggestions to help get the word out about NF:

- Provide your local library with educational materials on NF that can be distributed to the public.
- Contact your local radio station(s) about running public service announcements (PSAs) about NF. The NNFF can provide you with ready-made PSA language that you can send to the radio station.
- Distribute educational materials on NF to local doctor's offices

To let us know what you are doing in your community or for more information on how you can get involved, please contact Erica Mayer at the NNFF at 800-323-7938 ext. 39. We can provide you with ideas, materials and support to help raise awareness and support for NF in your hometown.

I Survived the NF Marathon Team

(Continued from page 6) did I receive a great response to my fundraising campaign (I raised more than \$6,000 in three months) but I also received cards, letters and phone calls from people I hadn't heard from in years offering their love and support.

Training for the marathon was a therapeutic experience for me. Being able to actively participate in something that would directly benefit Holly helped me to deal with Holly's condition. It empowered me and I felt that I was able to make a positive contribution. Physically, training was hard at times but I found that if you drink enough Gatorade it would get you through!

Running the marathon itself was a great experience. I ran with a man from New Hampshire, Jeff Brown, who was running in support of his son who had NF. We really encouraged each other and when the going got rough, we were there to remind each other of why we were doing this in the first place!

I advise anyone who is thinking about joining the team to do it! I loved the experience so much that I am already training for the next year's marathon in Chicago and have

recruited a friend to do it with me. It was an amazing experience that allowed me to help my daughter and myself while raising money for NF research. My advice is to go out there, have fun, and remember your Gatorade!



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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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