

neuro·fibroma·tosis®

THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

WINTER 2000

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Over \$1 Million Raised for NF in a Single Night!

\$1.15 million was raised on November 15 by the National NF Foundation at its 20th Anniversary Awards Gala in New York City. The event was the culmination of a yearlong celebration by the Foundation and its

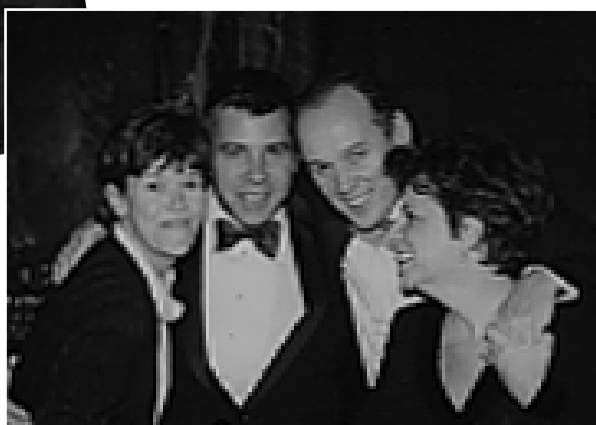


Above: NNFF President Peter Bellermann with Harold Ramis and the evening's honorees Dr. George Milne and August Busch IV.

Right: The Feinbergs and the Gallaghers take time out from the fun to pose for a picture.

Chapters of their work over the past two decades. More than 400 supporters turned out to celebrate and help raise money for NF.

Among the honorees at the dinner were August A. Busch IV, accepting the Distinguished Leadership Award on behalf of Anheuser-Busch Companies and the Busch family in recognition of their longstanding



support of NF and their dedication to improving the quality of life in the community, especially for children and families. George M. Milne Jr., Ph.D. accepted a Distinguished Leadership Award on behalf of Pfizer, Inc. in recognition of Pfizer's acclaimed research activities and shared commitment to children and their health.

The event generated \$1.15 million dollars, the most money raised by a Foundation event to date. Special thanks go to Board member Thomas Gallagher and Peter Feinberg, who spearheaded the event and whose generous donation of both time and money helped to make the night such a success. The proceeds from the event will go to fund NF research as well several Foundation programs that provide support to persons living with NF.

NF

Coping with Neurofibromatosis 1: A Study of People Living the Disorder

An Interview with Dr. Joan Ablon

(Ed. Note: Joan Ablon, Ph.D. is Professor Emerita, Medical Anthropology Program, Department of Anthropology, History and Social Medicine, School of Medicine, University of California, San Francisco. Dr. Ablon is the author of the new book, "Living with Genetic Disorder: The Impact of Neurofibromatosis 1.")

Q. How did you become interested in NF1 as an area of study?

A. As a medical anthropologist, I am particularly interested in the personal, family, and social issues that confront persons with health conditions that may be little known to the general public and, in many cases, even to health care providers. In 1986 I met an NF support group member whose husband and daughter had NF 1. She described some of their concerns, and talked about the issues that her daughter faced in her decisions about childbearing. I felt that an investigation into NF1 promised to open many windows on how individuals and families cope with chronic health conditions, uncertainty, and sometimes stigma, caused by physical differences that are negatively valued in this society. At that time, I

was not yet aware of the complex array of the many possible symptoms of NF1. As I learned about the condition my resolve grew to carry out this research.

When I started my research, I found there was very little information on the psychosocial dimensions of the condition — how people with NF1 actually live their lives, and what personal problems they may confront as a result of their condition.

"Good copers know that their disorder doesn't control them or their future."

Q. Why did you decide to write this book?

A. To this day there is no other book that medical personnel who work with affected individuals and families can read to learn about the special kinds of life experiences that help to shape their patients' or clients' lives and perceptions about themselves as totally functioning individuals. Further, there is no other book that affected persons and their families can read to give them an understanding of the kinds of life

experiences and problems related to NF1 that they or their families might anticipate and hence effectively plan for. I have attempted to address many of the issues of daily life that persons with NF1 frequently encounter in the social, educational, and medical dimensions of their lives. In addition, persons with other genetic conditions may share many of the concerns experienced by persons with NF1 and I would hope this book might be of value to them also.

Q. How did you find your research subjects?

A. I recruited subjects through three sources: 1) the population of persons who attended support groups in Northern California sponsored by the NNFF and the California Neurofibromatosis Network (no longer in existence); 2) those who responded to notices I placed in local mailing announcements of these two organizations; and 3) the caseloads of the genetics departments of two major metropolitan hospitals.

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Puzzling Relationship Between Cardiovascular Disease and NF1 Leads to the Creation of New Task Force Committee

Committee Charged with the Exploration of Causes and Potential Treatments

(Ed. Note: The following article is based on an interview with Dr. J.M. Friedman, Head of the Medical Genetics Department at the University of British Columbia. Dr. Friedman is the chair of the NNFF's new Task Force Committee on Cardiovascular Disease and NF1.)

As part of the Foundation's continuing effort to advance NF research, another task force committee was created in June 1999 to address cardiovascular complications and their relationship to NF1. This taskforce is a subcommittee of the "NNFF Task Force on Treatment of NF1" which was created in 1995 to consider the need for additional information on the natural history of the disorder and to recommend directions for development of models for experimental therapeutics for NF1.

"Medical literature suggests the NF1 gene contributes to cardiovascular disease..."

The goal of NF1 Cardiovascular Taskforce is to gather all current knowledge on cardiovascular disease as it relates to NF1 and to identify pressing research issues that need to be addressed.

Raising Awareness

The two most common causes of premature death in adults with NF1 are cancer and cardiovascular disease. Although cardiovascular disease is the leading cause of death in the general population as well, there seems to be a higher rate of cardiovascular disease among younger NF1 patients. The reason for this is currently unknown.

Assignments for the NF1 Cardiovascular Task Force

Each member of the taskforce has been charged with researching a specific area related to cardiovascular disease and NF1. Listed below are the areas currently being researched by the committee. The knowledge gained by this initial information gathering will serve as the basis for the creation of research goals and clinical trial programs in the near future.

- The importance of cardiovascular disease in NF1
 - Frequency in NF1 patients compared to the general population
 - Effect on mortality
 - Secondary effects of neurofibromas on the cardiovascular system
- Cardiovascular biology in NF1
- Cardiovascular disease in patients with NF1 (e.g., hypertension, cerebrovascular disease, cardiac malformations and cardiomyopathy)
- Recommendations for management (screening, evaluation and treatment) and setting research priorities*

*This represents the second phase of the taskforce's work

"Cardiovascular complications are not a well recognized feature of NF1 mainly because it does not have anything to do with the skin or nerves," says Dr. Jan Friedman, Head of the Medical Genetics Department at the University of British Columbia and Chair of the NF1 Cardiovascular Task Force. "I think both physicians and patients need to be made more aware of the connections between cardiovascular problems and NF1 since these complications need to be carefully monitored in people with neurofibromatosis."

By creating this taskforce and subsequently raising awareness among physicians and other medical professionals, the Foundation hopes to attract researchers into this important area of study.

There is already evidence in the medical literature that the NF1 gene contributes to cardiovascular disease in persons with NF1. Mice that had been given a double dose of the NF1 gene mutation died of severe heart disease as embryos before they were born.

Common Problems

Hypertension (unusually high blood pressure) is the most common cardiovascular problem in adult NF1 patients. Hypertension has also been found with some frequency in children with NF1. It is uncommon to find hypertension in children in the general population.

An unusual kind of vasculopathy (constriction of blood vessels which can lead to hypertension and other problems) also seems to occur with increased frequency in persons with NF1.

Pulmonic stenosis (narrowing of the major blood vessel that leads from the heart to

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RESEARCH CALLS

Exploring the Link Between NF and Cancer

We are looking for individuals with NF1 who have had solid tumors, sarcomas such as rhabdomyosarcoma, neurofibrosarcoma, fibrosarcoma, or osteosarcoma; malignant peripheral nerve sheath tumors; central nervous system malignancies excluding optic gliomas; or pheochromocytomas.

We are investigating the process by which specific changes in the NF1 gene leads to cancer. We will review medical records and arrange to obtain a small blood sample (a little painful) and/or swabs from the inside of the mouth (not painful at all).

Please contact Dr. Virginia P. Sybert at (206) 543-5290, email fk101@u.washington.edu if you think you might be suitable for this study. Thank you for your help in our research efforts.

NF 1 Tumor Study

Dr. Peggy Wallace and Dr. David Muir at the University of Florida have federal funding to continue their research of NF1 tumors. They are studying benign tumors (neurofibromas, both small and large) and malignant tumors (often called neurofibrosarcoma, or MPNST). The goal of this work is to understand the changes that cause growth of these tumors, to help develop better treatments. If you or a family member or friend is arranging surgery to remove any tumors for clinical reasons (preferably at least the size of an average marble), and would like to contribute extra surgical tissue to this research, please contact Dr. Wallace. She will discuss the research with you and help make arrangements to recover any extra tumor material (not needed by your physicians), if you wish to participate. It helps to make arrangements ahead of the surgery you schedule, as we need the tissue treated in a special way. A small amount of blood (1-3 teaspoons) will also be needed, which can be obtained at the same time or another date. Dr. Wallace and Dr. Muir thank you very much for your help!

Margaret (Peggy) Wallace, Ph.D.
Associate Professor, Pediatric Genetics
University of Florida
Box 100296, 1600 SW Archer Road
Gainesville, FL 32610-0296
PH (352) 392-3055
FX (352) 392-3051
email: peggyw@cmg.health.ufl.edu

NF Cell Study

Dr. George H. De Vries at the Loyola University School of Medicine and the Hines VA Hospital needs neurofibromas from NF patients for an ongoing study of altered signaling pathways in neurofibroma cells. The neurofibroma can be shipped in tissue-culture medium on wet ice. Either plexiform or cutaneous neurofibromas are useful. Limited information concerning age, sex, and criteria used to make the diagnosis of NF1 would also be useful. Please contact Dr. De Vries at least 24 hours prior to the removal of the tumors. Dr. De Vries will pay all shipping costs. For more information, please telephone (708) 202-2262; fax (708) 202-2703; or email gdevrie@orion.it.luc.edu.



CHAPTER NEWS: Waging the Fight Against NF at the Grassroots

Rollin' Along

For the second year in a row Roger Piacentini laced up his skates and completed a 100-mile trek across Long Island on October 10. This year, Roger recruited others volunteers to join him in his efforts and help raise money and awareness for NF

research. Roger is pictured here with his ten year old son Anthony (who has NF1) and singer Billy Joel whom they met up with at the finish line!



Singer Billy Joel shows his support for the NNFF Skate-A-Thon.

The Wig Master, a popular disc jockey from 99 Rock WPLR, was entombed in ice for 48 hours as part of a promotion to raise money and awareness for NF. In preparation for the event, WPLR spent two weeks explaining what NF is to listeners in Connecticut and Long Island, NY. Curious listeners were invited to come down and see the frozen tomb and NF information was distributed to all spectators.

their home to help raise money for NF. The young philanthropists donated half their earnings to the Foundation and the other half to help the homeless in New York City.

Walking for Research

50 members of the First Baptist Church in Lumberton, NC took to the streets for a five-mile walk-a-thon in honor of two-year-old Erin Johnson. Ms. Johnson was recently diagnosed with NF. All of the proceeds from the walk were donated to the Foundation to be used for NF research.

17 Years and Counting!

Lynne Murphy of Lawrence, MA held her 17th annual NF fundraiser on November 13th. The fiesta theme party drew more than 400 people including a few New England Patriot cheerleaders who were on

hand to sign autographs and pose for pictures.

Baseball Fever

The NNFF's Washington Chapter honored Dan Wilson, catcher for the Seattle Mariners baseball team at their dinner/auction in October. More than 300 people packed the brand new

Benaroya Symphony Hall in downtown

Seattle for an evening of good food and fun. In addition to attending the dinner, Dan spent a day playing baseball with some kids from the local chapter and "co-starred" with them in a video about what it is like to be a kid growing up with NF.

Frozen Alive!

Toyota of Wallingford, CT and WPLR radio joined together to "put the freeze" on NF!

Halloween Party

Squid Country Safari (a design company in Boston that creates interactive computer programs for museum patrons) held a Halloween party in October to benefit children with NF. The party was so successful they are planning on making this an annual event. Proceeds from the party will go to fund four NNFF camp scholarships this summer!

A Taste of Fall

The Northern Plains Chapter held their "Taste of Fall" fundraiser in October. Guests enjoyed wine tasting, hors d'oeuvres and a silent auction where they could bid on items ranging from hockey tickets to a day at spa. All proceeds benefit the NNFF.

Never too Young to Help Out

On October 16th two kids from Guilford, CT rolled up their sleeves to do their part in supporting NF research. 16 year-old Adam and 11 year-old Leane organized a tag sale at



Top left: WPLR Radio helps put "the freeze" on NF. Top right: Scene from the Squid Country Safari Halloween Party. Below: Members of the First Baptist Church Walk-A-Thon.

Keep the Marathon Momentum Going!

Thanks to the energy and enthusiasm of our NF Marathon Team members we have more than 100 members from 22 states so far! People of all ages and situations have been participating in the marathons. Some are running in honor of an NF hero and some are NF heroes themselves!

No more excuses... anyone can do it!

EXCUSE # 1 – I am not an athlete so I can't participate.

The idea of participating in a marathon can be overwhelming but you don't need to be an Olympic athlete to participate. All you need is the desire to raise awareness and bring hope to the thousands of Americans with NF.

EXCUSE # 2 – I should have signed up earlier. It's too late to join the team.

It's not too late to get involved. (See list of races still open to walkers/runners.)

EXCUSE #3 – I don't live in any of the cities where the marathons are taking place so I can't get there.

Participants can qualify for free transportation, lodging and more for marathon week-end by raising a minimum amount of pledges.

EXCUSE #4 – I don't know how to fund raise or how to get started.

We have information available to help you with your fundraising efforts (sample letters, informational materials, donor sheets, etc.). And of course our NF Marathon Team Coordinator is always available to give help and advice!

To get involved please call Anita Carter at our Marathon Team Race Headquarters office (toll-free) 877-NF-RACES (637-2237). Email: RaceForNF@aol.com.



neuro-fibroma-tosis[®] NF Marathon Team — racing for research

Upcoming marathons:

June 17, 2000	Anchorage Marathon Anchorage, AK
October 23, 2000	Dublin Marathon Dublin, Ireland
December 10, 2000	Honolulu Marathon Honolulu, HI
January 7, 2001	Disney World Marathon Orlando, FL
March 18, 2001	Maui Marathon Maui, HI
April 28, 2001	Country Music Marathon Nashville, TN

Join the NF Chat Room!

The NF Chat Room is a new interactive resource on the NNFF website that allows people to have "live" discussions about issues pertaining to NF right from their computers. People across the nation and around the world can now communicate with each other, ask questions and discuss NF news online. The responses are instantaneous!

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.

Coming in the Year 2000 – Two NNFF International Summer Camps

Due to overwhelming demand since the first NNFF International Summer Camp was established three years ago, the National NF Foundation has decided to hold two camps in the year 2000. One camp will be held for new applicants, those who want to experience the adventure of rafting down the Colorado River, making new friends and learning about the genetics of NF from an actual NF researcher. A separate reunion camp will be held for those returning from previous camps to see old friends and relive the excitement.

Check out the new Summer Camp Section of our website at <http://www.nf.org/camp99/summercamp.htm> for more details and applications. In this section, you'll also find the 1999 International NNFF Summer Camp Photo Album as well as bonus pictures not found in the book.

Deadline for submissions of applications for both camps is March 3, 2000. Participation for each camp is limited to 60 teens. Applications are taken on a "first come, first serve" basis so we urge you to send in a completed application (including medical form) as soon as possible. A limited number of scholarships will be available for campers based on financial need.

Need an Idea for Valentine's Day? – Send an NF E-Bear

Valentine's Day is just around the corner and what better way to show someone you care than by sending an E-Bear? This plush teddy bear comes complete with a cowboy hat, National NF Foundation

Button and bear grin. Best of all, with each \$14.99 purchase (plus shipping and handling), a contribution is made to the work of the Foundation. Each additional E-Bear only costs \$10, so send all the people you love the gift that gives. Order today! Supplies are limited.



To order your NF E-Bear, please call the National NF Foundation at 1-800-323-7938 or order online at the NNFF Online Store: <http://www.nf.org/store>. All online credit card transactions take place on a secure server.

Winter Getting You Down? Let the NNFF Take You Away

Does the snow and ice make you long for sun and sand? Or maybe you like to take advantage of the cold weather with a fun ski vacation? Let the National NF Foundation pay for your ticket to any destination in the Continental U.S. All you have to do is send us your e-mail address.

By reducing the costs of printing and mailing, the National NF Foundation hopes to direct more funds towards NF research. You can help by entering our Second E-mail Airline Ticket Sweepstakes and submitting your e-mail address. For more details and official rules, please go to <http://www.nf.org/win/>.

No purchase necessary. Entries must be submitted by May 31, 2000. Participants must be legal U.S. residents and 18 years of age or older. Void where prohibited or restricted by law.



Cardiovascular Task Force

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the lungs) and multiple café-au-lait spots characterize Watson syndrome. Medical evidence suggests that Watson syndrome results from mutations on the NF1 gene. Recent studies indicate that pulmonic stenosis also occurs with increased frequency in persons with NF1 who do not have Watson syndrome.

Questions to be Answered

"The cardiovascular taskforce is the largest taskforce created by the Foundation so far because we are not starting out with a lot

of knowledge in this area," observes Dr. Friedman. "Therefore we had to assemble a large group of experts in cardiology, vascular disease and NF to work together to gather all that is known and to start to make the connections between cardiovascular disease and its manifestations in persons with NF1."

Some of the important questions the taskforce will need to address are:

- What is the best way to test for cardiovascular disease in persons with NF1?
- How much surveillance is needed?
- What is the best way to monitor these conditions?

- Does cardiovascular disease manifest itself the same way in persons with NF1 as it does in the general population?
- Do persons with NF1 react the same way to current medications and treatments used to treat cardiovascular disease?

"I have two hopes for this taskforce," says Dr. Friedman, "to gain a better understanding of the nature of cardiovascular disease in NF1 and identify a clear direction of how to address these issues from a research standpoint."



NF PROFILE

Dennis Chipollini: No Excuses, No Limits

If you had to use one word to describe to Dennis Chipollini, it would be energy!

This 46-year old father of two from Philadelphia has faced many obstacles his life and has not only triumphed over them, but has emerged even more determined and optimistic than he was before.

“I want Nicholas to learn by example not to let anything get in the way of achieving his dreams.”

Ten years ago Dennis lost both his legs in a car accident. Before the accident Dennis was an athlete running 5 miles a day and playing a competitive game of golf or tennis. He underwent 13 surgeries (one in which his severed right leg was reattached) but an aggressive bone infection led to his left leg needing to be amputated just below the knee. His doctors said he would never walk again. During his time in the hospital Dennis's wife Suzanne gave birth to their first child, Nicholas.

Determined to regain the use of his legs, Dennis began his own program of vigorous exercise and healthy eating. At first Dennis would literally drag himself up the stairs to exercise in his home gym on the third floor of his house. But it didn't take long until Dennis proved the doctors wrong and began the road to recovery.

Just 10 months after the accident Dennis was able to walk with a cane, in one year he was driving and in three years he was back at work at UPS. Four years after the accident Dennis ran in his first 5K race.

Then in 1996 Dennis' young family faced yet another challenge, their son Nicholas (then only 6 years old) was diagnosed with NF1.

“My wife and I were devastated at first. The more we learned about NF the more afraid we became,” said Dennis. “At first the doctors thought Nicholas had Noonan's Syndrome and then they told us he had NF. I decided to educate myself on the disorder and turned to the Internet and the NF Foundation for information.”

Not being a man to give up easily when life's complications became too great, Dennis decided to turn his personal triumph over his injuries into a way to help his son. This past September Dennis ran a half marathon in Philadelphia and began his campaign to raise public awareness of NF.

His inspiring story caught the attention of newspapers and television stations in the Philadelphia area and Dennis has been interviewed many times about his commitment to raising money and awareness for NF research in support of his son.

Dennis joined the NF Marathon Team in August 1999 as a way to get involved with the Foundation and be proactive in his efforts to help his son. Dennis will be running in the San Diego Marathon this spring and hopes to raise more than \$10,000 for NF research. His employer, UPS, got him

off to a great start by donating \$3,000 to the NF Marathon Team.

The decision to openly join in the cause for NF meant telling Nicholas about his condition. Dennis said the media attention surrounding the September race meant it was time to be honest with Nicholas about the disorder.

Dennis says he wants to be role model for his son.

By using himself as an example he tries to instill in Nicholas a sense of self esteem and confidence that will help him deal with the challenges he will face in living with NF.

“Sometimes Nicholas is ashamed of having NF. Recently at a swimming party some kids were teasing him about his café-au-lait spots and the freckling on his arms. I told him NF was nothing to be ashamed of. In the past I would not go swimming because I didn't want to take off my prosthetic leg because I felt embarrassed. Now I make a conscious effort not to do that or be embarrassed. I want Nicholas to learn by example never to be ashamed of who he is and not to let anything stop him from achieving his dreams.”



Dennis pounds the pavement as part of the NF Marathon Team

NF

The Stuff in Your Attic Can Help Fund NF Research – Join Our On-Line Auction

Is your attic or garage full of things you don't need but can't bring your self to throw away? You may have something that could bring you a tax deduction, help further research in NF and make you feel good at the same time! How is this possible? By donating it to the NNFF on-line auction.

How does it work?

During NF Awareness Month in May the NNFF will be holding a month-long auction on E-Bay (www.ebay.com). You can participate in two ways (1) donate an item to be sold in the auction and/or (2) log on to our website during the month of May, click on the E-Bay icon and bid on items in the NNFF auction block!

If you are interested in donating an item to the auction or for more information visit our auction web page at: <http://www.nf.org/auction/>

What type of items are we looking for?

Anything! Remember the old saying “one man's junk is another man's treasure.” Nothing is too big or too small. Auction items can be anything from an old painting you have in your house to that exercise equipment that gathering dust in your basement to hand sewn napkins your grandmother gave you but you never use! People can donate cars, boats or even real estate. Some common items that people donate for auction include



baseball cards, trading cards, rare coins, stamps, old records, books, and musical instruments.

Be as creative as you want. If you are unsure as to whether an item would be appropriate for the auction, please feel free to contact the Foundation at 800-323-7938.

Stay tuned...

As the auction draws nearer we will be providing you with more information and updates on items that will be available for bid. Tell your friends, family and co-workers. Anyone can donate an item and EVERYONE is invited to bid!

NF

Dr. Ablon Interview

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Q. How did you conduct your research for this book?

A. Interviews with fifty-four adults in their homes (some repeatedly over many years) formed the basis of this book. I also interviewed eighteen families wherein the parents were unaffected but a child had NF1. I asked participants to tell me their life stories and how in their perceptions NF1 had affected their lives. While I had a list of topics I hoped we would cover, participants were urged to bring up any other topics they wished to discuss. Thus, they taught me about how it is to grow up and live with NF1. The participants were generous in sharing their life stories and many told me they had never talked to another person before about these experiences. When writing the book I was very careful to protect the anonymity of persons who spoke with me.

Q. Why do you think the psychosocial aspects of NF have not been adequately addressed?

A. Doctors see their patients briefly and do not have the time, or often the inclination, to ask about the personal issues or experiences of their patients' lives. Also, clinicians ordinarily do not give their attention to such issues as cosmetic concerns and yet those may be of the most importance to patients despite what other more clinically serious physical symptoms exist.

The research on NF1 has systematically gone into the directions of laboratory science or clinical care. The closest area that has been addressed deals with learning disorders in children. In the past 12 years or so, a significant literature has developed on the cognitive problems of children. However, no attention has been paid to these problems in adults. In fact, the one pervading symptom of NF1 that I found to be most devastating to subjects' lives was learning disorders. Learning

problems contributed to poor self-image, poor educational experiences, and later diminished opportunities for satisfying or well-paying jobs. Had these learning disorders been attended to in subjects' early lives, as hopefully is more the case now, the personal, social, and economic problems they had experienced might have not existed.

Q. What do you feel are the positive ways in which persons found to cope with their disorder?

A. Persons who have coped effectively with their condition have a number of elements in common. First and central, they have "attitude," that is, knowing that you are a valuable person who happens to have a genetic disorder. These persons believe that their disorder doesn't control them or their future in life, they control it and what happens to them. Good copers, usually with the aid of their families, were persistent in seeking good medical care and doctors who were knowledgeable about NF1 and showed them respect and concern. Also, they early on sought assistance for their educational needs and training that would result in employment that would be satisfying to them. They have a social support system of family and friends who care about them and their welfare. Neither severity nor visibility of subjects' conditions dictated their lives. For example, one third of the persons who had highly visible conditions had positive, proactive approaches to their lives. The major message that emerges from subjects' life stories is the significance of a strong, supportive family in early life that could imbue confidence and security to the individual. For those who had a parent with NF1, the importance of positive parental communication and the providing of emotional and practical support cannot be overemphasized.

Q. What advice would you give to parents of a child who was recently diagnosed with NF1 or a recently diagnosed adult?

grandmother who is 84 years old and living with NF was born in 1915). Shorty La Comb has four siblings – Mac (who may have had NF); Ethel; Ashton (who had one son named Melvin); and Gary (who had two sons, one named Gene).

If you are out there some where and would like to contact some distant relatives to share stories, support and anything else, please write to us. – Robin Suarez 464 South Anza, El Cajon, CA 92020.

• I am making a NF quilt! If you would like to help please send a square of fabric with your name on it to me and I will include it. Once I have completed the quilt I will be sending it to the NNFF. – Regina Werth; 1426 Summit, Racine, WI 53402.

• I am a man with NF 1. Do you want to be my pen pal? If so, please email me at – docdo1@juno.com.

A. I would advise them to seek out the best medical care in their area for themselves or their child. Contacting one of the national foundations for information about NF clinics or NF specialists would be a good way to begin. Children should have an early assessment of their cognitive abilities to determine if they have learning disorders or associated problems. If this is the case, parents should be prepared to aggressively pursue the needed testing and special educational services that are mandated by law to assist children with learning disorders. In the case of an adult with learning disabilities, assistance for special educational and employment needs may be available through community colleges under mandated disability regulations.

Further, I would urge them to contact the national NF organizations to learn about support groups in their area. Through these groups, they will be kept aware of the latest scientific and clinical advances and also have the benefits of sharing others experiences.

If they are fearful of seeing other persons with NF1 who may be more severely or visibly affected, persons should remember that although they share this condition, no one case follows the exact path of someone else's. Take advantage of the commonalties to find strength in the support of others. Also seek out any other organizations that may be relevant for the condition. For example, support groups for adults with learning disorders or other special problems may be available in their community.

Finally, if the person is of reproductive age, it is important for them to consult a genetic counselor or geneticist to learn about the issues around childbearing that should be considered.

To purchase a copy of Dr. Ablon's book please contact the NNFF at 800-323-7938. The cost is \$59.95 plus \$3.20 for shipping and handling.



Pen Pals

• **NF support group started in Mexico! Interested?** Contact: Tammy Keller, Horacio 1805-1101, Los Morales Polanco, 11510 Mexico, D.F. Mexico; phone (525)580-2618

• **26 year old man with NF2 wants to talk to others dealing with NF.** Write to: Neil Thom at 3843 Lancaster Drive, Eugene, OR 97404 or call Neal at (541) 607-3120.

• **I am a single 33 year old female. I have NF 1 and would like to have pen pals. I will respond to all that write me. My email address is: kitty-cuddle@aol.com.**

• **I am the fourth generation in my family to have NF and am looking for some distant relatives who may also have NF 1. I live in San Diego and have the following information: My great-grandfather was Kearny (Shorty) Joseph La Comb, born in Louisiana. He married Lilly Luella Nichols and they had two daughters who were both born in Kansas City, Missouri – Juanita (born 1913) and Rheba Aline (my**

• **Would like to talk to anyone who has NF1 or NF2.** Write to: Besty Imholte, 5936 Newton Avenue South, Minneapolis, MN 55419

• **I am a 31 year-old man living in Bloomington and would like to meet other adults with NF living in Indiana.** Please write to: David Drutt; 2202 N. Browncliff Lane, Bloomington, IN 47408.

• **36 year-old woman with NF1 seeking pen pals.** Please write to: Karen Manuel; 702 N. Crocker, Sulphur, LA 70663.

• **38 year old female with NF1 would like to talk to others with NF, email:** LGreen3487@aol.com

• **20 year old female with NF1 would love to talk with anyone.** – Angela Russow, 301 East Main Street #112, Barrington, IL 60010.

INVESTING IN NF

Family Funds – Helping to Build a Better Future

When one person in a family is affected with NF, everyone in the family is effected. Families are therefore a big part of the NF picture, as we search for a cure and effective treatments for both NF1 and NF2.

Families and their friends have a great way to join in moving the work ahead by establishing an ongoing partnership with the Foundation, through “Family Funds”. Created by an individual or a family, they are usually named by the creators of the fund and are often named after the family itself. Some are named in memory of, or in tribute to, a particular family member. Family Funds are maintained by the NNFF to accept gifts from your family members, friends, and business associates. The gifts received through these funds provide support for the Foundation’s extensive range of programs (from research and medical collaborations to public education and patient services).

The Foundation already has 29 Family Funds. The following are related comments from some of the individuals who started these funds.

“I started the Keller Research Fund three years ago because I wanted to be an active part of the solution. I have confidence that a cure, or at least effective treatments, will be found and I feel strongly that the way to get that to happen is by supporting The National Neurofibromatosis Foundation and the various scientific and research initiatives that it coordinates”.

-Cornelia Keller Biddle

Some families do a Holiday card appeal requesting gifts to the Family Fund in lieu of presents. Others chose to write to their

prospective donor lists each year requesting a contribution.

“Not so long ago, before NNFF existed, there was little my family could do about NF2, which had changed our lives but we knew so little about. Now we can do something. As a person with NF2 and a member of the NNFF Board of Directors, I am proud to tell my friends and family about this outstanding organization. It’s a privilege to give others the opportunity to join me in supporting the Foundation. I include a pledge form with my year-end letter so that they can commit up to five years of funding. It’s working well and the positive response is the best Christmas gift I could ask for!”

-Michie Stovall O’Day

Still others hold special events and fundraisers in the name of their Family Fund.

“Nothing is more important than finding a cure for NF2, for my son Adam. Last year my mother, her friends the Grallas, and I, held a fundraising event in West Palm Beach, FL. We were thrilled with the turnout and the generous donations made before and even during the event, as well as being able to increase awareness of NF to hundreds of people. The NF Foundation announced the Adam Goodkind NF2 Research Fund at this event, dedicating 100% of the money to researching a cure for NF2. We encourage our family and friends to make donation to mark important occasions. We are proud that we have already been able to fund three projects in our first year! This year we are going to host an event in New Jersey and hope to raise as much as it takes to cure this disease!”

-Barbara Franklin

New Developments in Family Funds

We have seen a steady growth in the creation of and activity within Family Funds and want to encourage this growth throughout the NNFF family. In recognition of this growth, we are now offering two levels of funds (Family Funds that begin at \$5,000 and Leadership Funds that are new and begin at \$25,000). Both provide the opportunity to name a fund and support NNFF’s work. They can be started with gifts of cash or securities and they can include gifts from family and friends. They require annual contributions at the levels indicated, with the idea that the annually contributed funds will grow over time. In fact, as a fund grows to the \$25,000 per year level, it will receive the “Leadership Fund” status.

To encourage the creation of or growth towards Leadership Funds, we have several attractive options unique to this type of fund: 1) planned gifts (i.e. bequests, charitable trusts, etc.) can be used to start or annually maintain a Leadership Fund; 2) the Foundation will produce and mail your annual appeal letter for you if you wish and; 3) Leadership Funds can (but are not required to) designate the use of its money to general programs or it can specify research projects related to either NF1 or NF2.

The potential of Family and Leadership Funds is very exciting. They can move us all closer to our common goal of finding a cure or treatments for NF. With your help we are doing just that. To find out more about establishing either a Family Fund or a Leadership Fund please call Andrew Phillips our Vice President for Development at 800-323-7938 ext. 31.

NF

BOOK REVIEW • Neurofibromatosis: Phenotype, Natural History, and Pathogenesis

Dr. Eric Legius of the Center for Human Genetics, University Hospital of Garthuisberg Leuven in Belgium reviews the new book, Neurofibromatosis: Phenotype, Natural History, and Pathogenesis. Third Edition. Edited by J.M. Friedman, D.H. Gutmann, M. MacCollin and V.M. Riccardi. The Johns Hopkins University Press, Baltimore and London, 1999.



This is the third edition of a comprehensive book on neurofibromatosis (NF). The first edition had two authors, Riccardi and Eichner and the second edition only one, Riccardi. This third edition is different from the two previous editions because this edition has four editors and eleven contributors. However, if you start reading in the book you will

find out that this is not the only difference.

The largest part (part 1) deals with NF type 1 and a smaller part 2 describes the difference aspects of NF type 2. It is a good idea that the previous system of numbering all possible different types of NF is not used anymore.

All contributors are involved in different aspects of NF research, and most authors have a large clinical experience with all aspects of NF. Extensive use is made of different large clinical databases showing data and associations that cannot be obtained by the clinical practice of one person. The combination of research experience, clinical database data and large personal experience of the different authors makes this book an important resource for everyone involved in NF. This book is unique in its category because of its

wealth of statistical data, numerous clinical pictures and latest research data put into perspective by experienced authors.

Every chapter contains a well-balanced and nicely illustrated overview of the topic with numerous up to date references. Current data are described and future research is discussed. The different chapters make you think of how you can integrate all aspects of NF in a scientific model, and several suggestions are provided. Reading several chapters in this book will give the reader new ideas for future research. It will be an important resource not only for facts but also for ideas.

To purchase a copy of Neurofibromatosis: Phenotype, Natural History, and Pathogenesis for \$99.95 (plus \$3.20 for shipping) please contact the Foundation at 800-323-7938.

