

Newsletter, Volume 19, No. 2; Winter, 1998

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World's First and Largest NF Organization Marks Milestone:

The Foundation Celebrates its 20th Anniversary
The history of neurofibromatosis changed dramatically in 1978. With it so did the prospects for a better life of all patients and families with NF around the world.

Twenty years ago, there was no NF organization in the world. Nor was there a national research program anywhere to combat the disorders NF1 and NF2.

Two individuals changed all that in 1978, Lynn Courtemanche, a woman with NF, and her physician, Dr. Allan Rubenstein.

After being diagnosed with NF Ms. Courtemanche asked Dr. Rubenstein if she could join a support group. "Unfortunately," he told her, "there isn't one."

"That's not right," was Ms. Courtemanche's reply. "If I had heart disease, I could go to the Heart Association. With muscular dystrophy I could go to the Muscular Dystrophy Association. Why isn't there a group for people like me with neurofibromatosis?"

"You are right," Dr. Rubenstein agreed. "So, why don't you start one?"

"Ok, I will, but only if you do it with me," was Ms Courtemanche's immediate rejoinder.

"Alright, you got yourself a deal."

With these simple words the revolution in neurofibromatosis began. Ms. Courtemanche and Dr. Rubenstein quickly recruited a young attorney, Joel Hirschtritt, Esq., and together they incorporated the first NF organization in the world.

The combination of a patient and a physician/scientist as founders proved to be the ideal partnership for a venture that focused primarily on research but always kept the health and well-being of patients as its overarching and ultimate priority.

The founders made a fundamental decision early on. Assessing the many and often overwhelming needs of patients and families, they reasoned that with modest resources, the only way they could have a decisive impact on the health and well-being of every patient and family was to start a research program. They knew, of course, of all the other needs, such as direct support for the clinical needs of patients and public awareness.

But research aimed at finding effective treatments for NF1 and NF2 would benefit everyone to the same degree, no matter what the particular manifestation of NF, no matter what the severity of the individual's case, no matter whether the problem was inherited or the result of a spontaneous mutation, no matter what a patient's social, economic, gender, racial or ethnic background were, and no matter where patients lived, here or abroad.

Convinced that research should be the highest priority, Dr. Rubenstein set about recruiting some of the world's foremost scientists in a number of fields relevant to neurofibromatosis. "The caliber of our Research Board was very important to us from the very beginning," said Dr. Rubenstein recently. "Lynn Courtemanche agreed that we should try to get the very best people we could. Not only would high level people jump-start our research program, their involvement with us would also make it possible for us to solicit financial support from small as well as large donors, corporations and foundations. So I started calling scientists, and Lynn began to build up the lay part of the organization."

This very basic decision about priorities at the outset led to a record of accomplishments over the past twenty years that has become a model for other health care organizations, including other NF organizations in the world.

The highlights over the past two decades have been:

Important Milestones of
The National Neurofibromatosis Foundation
1978

The National Neurofibromatosis Foundation was founded by Lynn Courtemanche, Dr. Allan Rubenstein and Joel Hirschtritt, Esq.
The Foundation instigated the first Neurofibromatosis Clinic in New York City
The Foundation created its first state chapter

1980

NIH Consensus Conference on NF
The Foundation formed its first Medical Advisory Board

1982

Comprehensive NF clinics open in several U.S. institutions

1983

The Foundation began the first national research program on neurofibromatosis in the world, this initially with very small grants.

1985

The Foundation convened a major international scientific conference on NF. The conference was held at the New York Academy of Sciences and included everyone active in NF research at the time. This landmark conference was the precursor of all Foundation sponsored subsequent international meetings and collaborations, the 1987 Runnymede meeting in England two years later, the creation of the "NNFF International Consortium on the Molecular Biology of NF1 and NF2", the "NNFF International Consortium on Point Mutations in NF1", the NIH Consensus Conference, the creation of the International Neurofibromatosis Association, etc.

1986

The Foundation hired its first full-time professional staff.

1987

The Foundation instigated the landmark Consensus Conference at the National Institutes of Health established the diagnostic criteria for NF1 and NF2 still in use today, the Conference established also the nomenclature for NF1 and NF2, and established the guidelines for the management of NF1 and NF2. The "NNFF International Consortium on the Biology of NF1 and NF2" was established. It represented then and still does today the most remarkable scientific collaboration by all of the world's leading scientists involved in NF1 and NF2 research -- 32 scientists in 1987 and about 290 in 1998. Scientists funded by the Foundation found genetic markers for both NF1 and NF2.

1988

Scientists funded by the Foundation developed diagnostic DNA, prenatal and presymptomatic testing for familial cases of NF1.

1989

The Foundation began the development of the first comprehensive, International Database on neurofibromatosis.

1990

Scientists funded by the Foundation found the gene for NF1 and "neurofibromin", the gene product it encodes.

The Foundation and Thieme Medical Publishers published the first "Handbook for Patients, Families, and Health-Care Professionals" edited by Dr. Allan E. Rubenstein and Dr. Bruce R. Korf.

1991

The Foundation created the Mutation Analysis Consortium for NF1, a worldwide collaborative effort to speed the detection of mutations in the NF1 gene.

1992

The Foundation instigated the formation of the International Neurofibromatosis Association (Luxembourg), together with 10 scientists, clinicians and lay leaders from 8 countries and 4 continents.

The Foundation worked to obtain from the United States Congress -- \$ 8 million for NF research via the US Army -- this research to be carried out over the next three years.

The Foundation obtained an additional \$ 2 million from the US Congress for NF research at the National Institutes of Health (NIH), thus increasing their NF research funding by 53%.

1993

Scientists funded by the Foundation discovered the NF2 gene and "Merlin Schwannomin", its gene product.

The Foundation established the "NFF International Clinic Network", a worldwide collaborative effort to improve the diagnosis and management of patients with NF1 and NF2.

The Foundation created the first website for neurofibromatosis, thereby creating easy and low cost access to information about NF to anyone in the world.

1994

The Foundation announced the first national, Multi-Center Clinical Trials in NF1.
The Foundation created the China Neurofibromatosis Research Institute.

1995

The Foundation announced direct gene testing for NF1 and NF2. The new technology was based on Foundation funded research.
The Foundation was instrumental in obtaining a second \$ 8 million from the United States Congress for NF research via the US Army.

1996

NNFF funded scientists began the first molecular approach to unraveling the connection between NF and learning disabilities.
The Foundation worked to obtain a third \$ 8 million from the United States Congress via the U.S. Army
NNFF formed the Working Group for Therapies in NF1, the first organized effort in the world focused solely on the development of treatments in NF. The Working Group completed its activities and issued a final report at the end of 1996. The Task Force report covered neurofibromas (including plexiform neurofibromas), malignancies, optic gliomas and cognitive development in NF1.

1997

The Foundation's Clinical Care Advisory Board, in collaboration with clinical experts and scientists worldwide, reviewed and expanded Diagnostic and Management criteria for NF1 and NF2.
The Foundation worked to obtain \$ 9.8 million from the United States Congress for NF research via the U.S. Army.
The Foundation created the Kids' Council, an organization led and managed by young people 6-17, with programs for children.
The Foundation created the first NNFF International Summer Camp for Children with neurofibromatosis
This has been a strong history of growth for the benefit of patients and families with NF1 and NF2. The various milestones have brought us to the "translational research" phase where scientists and clinical researchers are beginning to use the knowledge gained on the molecular level for the development of clinical applications. Clinical trials have begun and will grow in number in both NF1 and NF2 over the next few years. Rational treatments are no longer only a hope and a prayer. They are a goal which scientists believe can be reached over the next several years.

1998 - The Foundation Today

Associates and Contributing Members: 40,000 in all 50 States and 52 other countries.

International Affiliates: 45 in 33 countries

Chapters: in 29 States

Head Office: New York City

Field Offices:

Los Angeles, CA

Dedham, MA

St. Louis, MO

Seattle, WA

Number of Salaried Staff: 19

Annual Budget: \$ 2.9 million

Scientific Meeting Held in Maryland: NF2 -- Present and Future

By: Janet Stoeckert

Director, Research Administration and Services

The House Ear Institute, Los Angeles, CA

The House Ear Institute (HEI) and the National Neurofibromatosis Foundation (NNFF) co-sponsored a Workshop on "NF2: Present and Future" in Rockville, Maryland this fall. The purpose of this meeting was to invite NF2 researchers to review the significant scientific progress made in NF2 and to discuss research directions toward developing novel approaches to its prognosis, prevention, and treatment. Novel approaches for treatment included gene therapy and gene-based therapy. It was hoped that this critical analyses of recent progress and focus on future needs will mobilize researchers to make rapid progress in the treatment and prevention of NF2.

Approximately 50 individuals were invited to attend. They included (1) researchers with expertise in NF2, (2) representatives from the National Institutes of Health, particularly NIDCD, NEI, NCI, NINDS, and US Army Medical Command, (3) members of the NF2 community (Barbara Franklin, whose son has NF2, Cornelia Biddle, who has NF2, and (4) representatives from HEI and NNFF.

Prior to the workshop, the organizers identified four topic areas of particular relevance to the current and future study of NF2. These topic areas were: Natural History, Molecular Biology: Genotype and Phenotype, Cell Lines/Animal Models and Innovative Treatments such as Gene Therapy and Gene-Based Therapy.

In order to facilitate both a current review of each topic area and the development of a report of future recommendations, invited attendees were assigned to the four topic areas (panels) based on their area of expertise. To further facilitate this process, panel chairs were also assigned.

The following served as panel chairs:

Gareth Evans, M.D., University of Manchester, UK (Natural History)

Mia MacCollin, M.D. and James Gusella, Ph.D., Harvard Medical School/MGH
(Molecular Biology: Phenotype/Genotype)

Tyler Jacks, Ph.D., MIT (Cell Lines/Animal Models)

Bernd Seizinger, M.D., Ph.D. , Genome Therapeutics, Princeton University
(Innovative Treatments such as Gene Therapy and Gene Based Therapy)

The panel chairs were asked to contact their panel members and prepare a preliminary report before the meeting which included: (1) A review of what they consider to be the most important advances made in NF2 research in the last five years in their panel topic area and (2) Research data needed to develop innovative approaches to the treatment of NF2 including gene therapy and gene-based therapy. Dr. Francis Collins, Director, National Center for Human Genome Research, NIH and co-discoverer of the NF1 gene challenged the participants with a keynote speech on the topic "Bold Thinking in Genetic Disease Research". He was followed by Col. Irene Rich of the US Army Materials and Medical Command on the topic of Army funding for NF2 research.

Summary reviews of significant contributions made in NF2 and relevant advances in each panel topic area were given by panel chairs or designated panel members. These highlighted what is now known and what is not known at this point in NF2 research.

After these sessions, the four Panels broke into groups for the afternoon to discuss where future research on their panel topic area and to make recommendations for short term (3-5 years) and long term research goals (5-10 years).

The following morning, the Panel Chairs and/or their designees presented their panels' recommendations for future directions to all attendees and lively discussions ensued.

Panel Chairs are now in the processes of preparing draft summary reports including a brief introduction to the topic area, a summary of recent advances/contributions, a discussion of methodological limitations (if any) and recommended future research goals by the panel including future collaborations. They will submit their reports to each of their panel members for review and feedback. The final reports will be submitted to the meeting organizers who plan to publish them in a relevant scientific journal.

* * * * *

Research Newsletter in Cyperspace

The Foundation has ceased publishing its Research Newsletter in its traditional hardcopy format. The newsletter continues to be published now as part of the popular NNFF website <http://www.nf.org> . Both the 1996 and the 1997 Research Newsletter are already available on the website and can be downloaded from there into hard copies. The decision to publish in this format was based on the vastly greater medical and lay audiences using the website and the considerably lower

publishing costs of the new format.

Research Call: Tumor Tissue 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. 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

Annual Harvest Dinners Held In November Across the U.S.

The annual tradition of celebrating continued progress and accomplishments continued as the Foundation and its Chapters held Harvest Dinners across the United States with dinners, auctions and galas.

The SeaTac Marriot Hotel in Seattle, for example, was the site of this year's Washington Chapter's Harvest Dinner. Nearly 200 supporters attended the gala which was sponsored by Nintendo of America and J&H Marsh McLennan. Eleven year old Tara Turley-Dean of British Columbia, Canada was the featured speaker. Tara is a celebrity in her hometown of Vancouver where she is prominently featured on milk cartons and can be seen on bus posters throughout the city.

"The guests enjoy the fun and even more knowing that they are supporting an important cause", said Tyler Jenner, the Chairperson of the 1997 Harvest Dinner in New York City. And have fun they did! This year's gala was held at the festive Churrascaria Plataforma in New York City to the sounds of a Brazilian samba band. Honorary Chairpersons of the Dinner were Dr. Mauro and Mrs. Janete Geller of Rio de Janeiro. Dr. Geller is a longtime supporter of the NNFF and a Board member of the International NF Association. He developed and chaired the first NF medical meeting in the Southern Hemisphere, creating substantial awareness for NF in South America, among physicians, as well as patients and families.

Joseph S. Byrka of South Windsor, CT received the 1997 Lynn Courtemanche Award for his outstanding contributions to the Foundation's fundraising efforts. Mr. Byrka is responsible for the Foundation's recent Public Service Announcements which have aired on TV stations across the country. The PSAs feature Joe's son, Chris and Mark Chmura, a member of the Super Bowl XXXI Champion Green Bay Packers.

The Idaho Chapter of the NNFF celebrated the progress in the fight against NF with their annual dinner hosted by Chapter President, Suzie Crisci. A record number of

participants turned out to raise record new funds for NF and enjoy the festivities held in November.

More than 250 supporters gathered at the California Chapter's 9th Annual Chapter's "Night of Chance". On hand were a host of celebrities including, Elaine Ballace, Beth Broderick, Christopher Cass, Patrika Darbo, David Dukes, Mark Feuerstein, John Glover, Dennis Haskins, Steve Hyner, Leila Kenzle, Kate Linder, Jason Marsden, Katie Mitchell, Arden Myrin, Stuart Pankin, Peggy Rea, Zelda Rubenstein, Will Shriner, Michael Silver, Arlene Sorkin, John Volstad, Mark Walberg and Steve Wilder. The highlight of the evening was a silent auction at which time exciting trips to the South of France, Bali and Puerto Vallarta went to the highest bidders.

The mood was festive everywhere else, too. Spirits ran high in the belief that the year's progress positions us well for new achievements in 1998, especially in the area of "translational research" which should produce clinical trials soon.

* * *

THANK YOU TO ALL OUR SUPPORTERS

To all of the corporations, foundations, members, families and individuals who have invested in our work, we extend a heartfelt "thank you!" Your gifts to the Foundation have not only allowed us to achieve great strides over the past twenty years, but more importantly provide all of us in the NF community with hope and dreams for future progress. Once again, 1997 was a very productive year for NNFF. The support we receive from you enables us to continue to devote over 83% of our income to research, programs and services for those living with NF.

We regularly receive notes and letters from those we serve. Their words of gratitude are really directed to you, our loyal contributors and friends. We would like to share a recent message.

"Thank you so much for letting me know I am not alone and that I don't have to suffer in silence. Your newsletters mean so much to me. I'm 25 years old and found out I had NF when I was 10. After three operations and the possibility of more in the near future, I know I can turn to you for support."

Love,
Scott A. Robertson
New Jersey

With your continued support we will work together to find treatments and a cure for NF, and enhance the lives of friends like Scott. On behalf of all of us at the Foundation, thank you for your partnership!

* * * *

European NF Groups Meet in Paris

By: Arvid Heiberg, M.D.
Oslo, Norway

Organized by Professors Jean Claude Stalder and Pierre Wolkenstein, the 7th annual meeting of the European NF Group was held in Paris, France, during early December 1997. As usual, the respective European lay groups held their own meeting simultaneously; and a joint session of scientists, clinical experts and lay leaders concluded the event.

More efforts for such joint meetings would probably be useful for the effective exchanges of the different experiences with NF between patients and families on the one hand and medical professionals on the other. Different countries also have different cultures and traditions. As a result the attitudes of the lay societies towards NF vary as much as those of the medical experts.

The meeting was held as an adjunct event to the annual meeting of the European Dermatology Association. This meant special attention for NF among dermatologists and allowed the NF groups to participate in a special tour of the magnificent Quay d'Orsay museum.

The meeting had good attendance with about 150 participants, reinforced by some of the representatives of the International NF Association (INFA) from the USA, who gave overview plenary lectures.

Among the new items of interest to this reporter were studies on heart tumors found in 2 of 160 patients with NF. Another report was on lesions in corpus callosum in 10 out of 275 NF1 patients, nine of whom also had learning problems. Venous angiomatous malformations were reported in the posterior cranial fossa in another patient, with NF possibly related.

The Leuven (Belgium) group reported a large series of 120 children thoroughly investigated for learning disorders and their behavioral profile on the Child Behavior Check List (CBCL). Learning disabilities were found in about half of the children, and the verbal IQ was higher than the performance IQ by 12 points. Gross motor abilities were lower than fine motor skills, with balance and running skills being the worst. The longitudinal IQ values showed a sinking curve, that is the gap increased with age. The maturation process in children with NF was slower than in the controls. The behavior profile showed that one-third of the children were in need of some kind of professional intervention. A similar fraction had problems with attention, with about 10% meeting the criteria for attention deficit hyperactivity disorders. 40% had social deficit problems -- all unrelated to IQ scores and to particular NF somatic disease manifestations.

Dr. Bruce Korf (Harvard/Boston Children's) and Dr. Eric Legius gave overviews of the present state of NF mutations. The types of mutations vary as do the sites of mutations. Several tests have to be used in mutation screening, which is still not appropriate for routine use. The best genotype:phenotype correlation found so far is between very large deletions and dysmorphic features and lowered IQ. Another family showed simultaneous segregation of the Noonan-NF phenotype through four generations with the Noonan phenotype caused by a 17q mutation and not the normal Noonan locus at 12q. A German group presented on 160 patients, identifying

mutations in 70% by the TGGE or the protein truncation test. The most frequent mutation sites were exons 37 and 31 with 4% and 2% of the mutations respectively.

Ferner et al. from the UK presented speech analysis data on 40 patients from England. They found somewhat surprisingly that speech was abnormal in some respects in every one of their subjects. The pitch was wrong in more than half. Speech was too fast in many. There were additional mistakes in over 70% and spelling problems in half. Verbal fluency was lower than expected and there was a correlation between the IQ, speech and socio-economic status pointing to a concomitant language and cognitive deficit.

A European multicenter study of 76 patients with congenital bowing and pseudarthrosis of the long bones was reported. By far the most frequent location was the tibia, then the fibula. The first signs usually appeared before four years of age, and the results were poor even when the patients were in expert hands. More than one procedure was the rule. The average was four, although the treatment was not completed in most patients.

Interesting new data were presented by a French group on a transgenic mouse model which promises a better understanding of tumor development and regulation. Tumor regulation of the p53 gene is probably also involved, adding to the complexity. All in all, it was a good meeting from the scientific and social points of view -- even for Paris in winter!

Annual Clinical Symposium Held

The 1997 Neurofibromatosis Symposium, took place in Baltimore, MD this fall. It was held in conjunction with the annual meetings of the American Society of Human Genetics and its purpose was several-fold. These annual symposia are forums to bring clinicians up-to-date on the latest developments in NF1 and NF2. They are also a platform for scientists and clinical researchers to present their newest findings. Finally, they are forum where clinical experts from around the world share diagnostic and management issues presented by their patients.

The Baltimore symposium was chaired by Dr. David Viskochil (University of Utah), Co-Chairman of the Foundation's Clinical Care Advisory Board. Despite the late hours (7:00 pm to 10:00pm) an audience of about 200 scientists and clinical experts heard the following presentations:

Dr. Michael Baser (UCLA) discussed "Malignant Nervous System Tumors in NF2". Dr. Lan Kluwe (University of Hamburg, Germany) reported on "Skin Tumors in NF2". His studies showed that in 52 patients with NF2 458 skin tumors were found. His results "suggest that loss of the second NF2 allele is a frequent event in skin tumors and this second genetic alteration occurs independently in each tumor.

Jacek Szudek, a graduate student working in the lab of Dr. Jan Friedman in British Columbia, Canada, gave a talk on "Associations of Clinical Features in Children With NF1". His mentor Dr. Friedman presented "Cardiovascular Malformations in NF1". Based on information gleaned from 2500 patient profiles in the NNF International Data Base which he manages, Dr. Friedman concluded that "pulmonic stenosis is more common than expected in individuals with NF1. Other cardiovascular malformations may also be unusually frequent among NF1 patients".

Dr. Eniko Pivnick from the University of Tennessee spoke about a "Delineation of a Common Facial Appearance in NF1". In a talk titled "A Sex Bias in the Origin of New Mutations in the NF1 Gene: The Nature of Mutations and Their Possible Mechanism" Dr. Meena Upadyaha from the Institute of Medical Genetics in Cardiff, UK, stated that "there may be a sex bias in the origin of new mutations in the NF1 gene, with microlesions more likely to be paternally derived and gene deletions tending to arise on the maternal chromosome. The precise mechanisms underlying these biases are as yet unknown."

This was followed by Dr. Messiaen from the University of Ghent in Belgium who reported on the "Identification of 9 Different NF1 Mutations in 13 Unrelated Belgian Patients Using the Combined Approach of the Protein Truncation Assay and Heteroduplex Analysis". Dr. Sonja Rasmussen from the University of Florida, one of the 1997 NNF Young Investigators, discussed "Somatic Loss of the NF1 Gene in Plexiform Neurofibromas in NF1".

Dr. Sylvie Langlois, from the University of British Columbia, Canada, raised a possible issue with "NF1 in Cousins With Unaffected Parents: Non-Penetrance or Coincidental New Mutations?", but concluded that the phenomenon probably represented co-incident new mutations. Dr. Gareth Evans from the University of Manchester, UK presented on "Somatic Mosaicism in Classical Type 2 NF Lesions For Other Cancer Prone Syndrome". He stated that "the mosaicism that we have found in NF2 could be applicable to other tumor syndromes, such as retinoblastoma, neurofibromatosis type 1 and von Hippel-Lindau Syndrome.

The symposium chairman concluded the session with a brief up-date on the search for Modifier Loci in NF1, and especially the ambitious efforts of a European led group under the direction of Dr. Gilles Thomas in France.

NF Profile

"Silence and Peacefulness a Relief":

Michie Stovall O'Day: An Artist Living With NF2

"When I paint, I am in a different world, one in which my deafness is immaterial; and the silence sharpens my vision. I embrace the scene before me and welcome the solitude and focus that my deafness makes possible."

Michie Stovall O'Day has been painting for 10 years, following in the tradition of her grandmother Virginia folk artist Queena Stovall (1888-1980). It was, however, only when Michie became deaf in 1996, that she began to fully appreciate the abundance of her visual world.

Her mother died of NF2 in 1976 when she was 46 years old. Her brother died of NF2 when he was 32. Michie was told that she, too, probably had NF when she was 19, although the first tumor didn't appear until age 26. She says that she had done some reading on it, but could find very little information back in 1976.

Michie had microsurgery to remove acoustic neuromas when she was 26 and 27. She thinks her youth and excellent medical care worked in her favor, "although each operation was 8 hours long and involved full removal of the tumors, I had no facial paralysis and I was back to work in 3 weeks after each surgery".

The first surgery resulted in deafness in the left ear and the second in moderate hearing loss in the right ear. What amazed Michie, however, was that she retained 100% word discrimination. During the course of the operation, the evoked potential response test showed no response and the doctors thought she would be completely deaf. But when she awoke, she could hear.

"This seemed like a miracle to me, and perhaps that has something to do with the strong sense of mission I've had ever since", says Michie.

Everything was fine for several years. Then in 1990, her hearing started to decline, and she learned that the acoustic neuromas had returned. She had stereotactic radiosurgery on one side in 1991 and fractured radiosurgery on her "good side" in 1996. The latter was her last chance to save what hearing she had left or it could destroy it altogether. Within 48 hours of surgery, it was gone.

Says Michie of her loss, "I believe that my tired, abused acoustic nerve gave up the ghost when we zapped it. Do I have any regrets? Not at all. I had done my homework and was prepared to risk hearing (which would soon be gone anyway) in order to keep some".

Ms. O'Day sums up her experience: "Strange as it may sound, after years of struggling to hear, to understand, to interact, the silence and peacefulness that comes with deafness was and remains a relief. I'm now much more cognizant of intuitive communication strategies -- body language, vibes and all that. It's fascinating, and if deafness is the program, then I welcome the new perspective. It's not always easy. There are times when it is very hard, but I believe this is a valuable experience and I want to take advantage of it."

"I paint because I am joyful that I have survived these tumors, that I am still here and functioning. If my paintings can impart some of the strength and peace I have found through these experiences, then I've gotten the message across. And if I can see someone respond as they look at my paintings, then I have heard their reply".

"Having NF2 and painting are like two sides of the coin for me", says O'Day. "Each compliments the other. In fact, I've often believed that there is some little artistic bud attached to the NF2 gene as I know several other artists with NF2. But rather than thinking of my art as an outlet for pain or sorrow, I see it as a celebration of the spirit."

A folk artist, Ms. O'Day was born in Lynchburg, Virginia. Her works are in private collections throughout the United States. In February, 1998, her work will be exhibited in the Atrium Gallery of the Lombardi Cancer Center at Georgetown University Medical Center in Washington D.C.

Your Turn

Perspectives, Questions, and Comments from Patients and Families

(Ed. Note: This feature of the Foundation's Newsletter was developed to encourage patients and families to share their perspectives, concerns and questions with others. When appropriate, medical specialists answer questions raised by readers. The answers can only cover generally applicable situations, and cannot take the place of consultations and specific medical care. If you would like to share your views or raise any questions, please submit them in writing to Fran Morris, Editor, NNFF, 95 Pine St., 16th Fl., NY, NY 10005 or send your message via Fax: 212-747-0004 or e-mail: nnff@aol.com.)

Tumors In The Mouth

Have you ever heard of tumors under teeth? -- K.G., Baltimore, MD

Dental problems, e.g., oral neurofibromas and jaw cysts or neurofibromas can occur, however, infrequently. They could cause problems requiring oral surgery, orthodonture or even speech therapy.

Depression

Is depression a common symptom? -- Anon.

Neurofibromatosis can cause depression. Anxiety about the need for medical treatment, a sense of losing control and the feeling of being different from others are often experienced. Individual or family counseling by a social worker or psychotherapist is often helpful.

Segmental NF

I have been told I may have the signs of NF, but only on one side of my body. Can you tell me more about this? -- N.P., Belgium

The term "segmental neurofibromatosis" is used to describe patients with features of NF1 confined to one or more areas of the body. The affected segment may have only a limb or a portion of the trunk affected. The most likely explanation for segmental NF1 is mosaicism of the NF1 gene. Mosaicism describes a person with a mixture of the affected and unaffected genes.

Pen Pals

I'm 38 and need to share with others like myself with NF1. -- Kathleen Alexander, 257 W. Main #E, Ravenna, OH 44266.

I'm 24 and would like pen pals. I enjoy music and writing. -- Nathan Dickenson, 18 Kensington Ave., 5B, Jersey City, NJ 07304; email: NKD452@aol.com

Will answer all who write. I'm 38 and would like to be a pen pal. -- Debbie Hammonds, 82 Magnolia, Martinsville, IN 46151

Enthusiastic, 30-something woman would love to hear from others with NF. -- Jeanne Ahrens, PO Box 962, So. Orange, NJ 07079

Teen age brothers with NF would like to hear from you. Jason (16) and Jacob (14) Stafford, 419A Longmeadow Rd., Eggertsville, NY 14226-2918

A 30 year old woman would like a pen pal in Spanish or English. -- Ana Laura Dominguez Orozco, Apartado Postal #583, CP 81001; Guasave, Sinaloa, Mexico.

I'd like to penpal, I'm 28. -- Todd Wadas; 119 Alpine Dr., #4, Dewitt, NJ 13214
Please write. I'm 32 with NF1. -- Suzanne Benitez; 8135 Zona, Indianapolis, IN 46227

* * * *

2nd NNFF International Summer Camp For Teens

The National Neurofibromatosis Foundation will be holding its 2nd International Summer Camp for teens (12-18 years) from August 1-11, 1998 in Utah. The purpose of the Camp is to provide teens with Neurofibromatosis 1 and 2 from around the world with the opportunity to share their experiences, hopes and fears about living with NF while enjoying a wide variety of exciting outdoor activities.

The program for the Camp this year will encompass a 2-day stay at the University of Utah dormitories during which time the campers will visit a variety of attractions in the Salt Lake City area. This will be followed by a 5-day stay at Camp Kostopulos in beautiful Emigration Canyon, Utah. Camp K is certified by the American Camping Association and is specially equipped for people with special needs. While at Camp K, campers will participate in horseback riding, swimming, arts & crafts, hiking, fishing and many other outdoor activities. Next the campers will travel by bus to Moab, Utah where they will embark upon a 3-day rafting trip down the mighty Colorado River. This was certainly the highlight of last year's camping program.

The cost is \$525 per camper, transportation not included, and the number of participants is limited 40. To obtain an application please contact: Fran Morris; NNFF; 95 Pine St; 16th Fl.; NY, NY 10005; Tel: 1-800-323-7938; email: nnff@aol.com

Sponsor a Camper

While the 1997 NF Camp was enormously successful and over 40 individuals were able to participate, for cost reasons several families who expressed an interest could not afford the fee. You could help send one of these children to the 1998 Camp with a gift of \$900 to underwrite the tuition and airfare of one camper who otherwise could not participate. Your contribution is tax deductible, but more importantly, you will be providing a teenager with NF an experience they will remember always. For more information on ways you can support the 1998 NF Camp, please contact Robert Laconi, Director of Development, at 800-323-7938, Ext. 31.