Newsletter,
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First NNFF International Summer Camp Held In Utah

"Meeting so many people with NF was one of the best experiences I have ever had," wrote a young camper from California.

A Texan wrote : "I did things I always said I cannot do. On a scale of 1 – 5, I give the camp a 10 ! "

A New Yorker added : "The camp was an experience which has changed my life and made me see the world in a different way. The friends I have made in camp will be forever a great part of me."

From a Belgian camper who had been to all the other, previous camps elsewhere came : "This has been the most exciting camp so far. The rafting was a marvelous experience, something I shall never forget."

Raves indeed for the first NNFF International Summer Camp, which was held this August in hot, but beautiful Utah.

Campers ranging in age from 12 – 17 and junior counselors 18-30 years old had come from all parts of the United States, Canada, Belgium and Germany, -- from Alaska to Antwerp, from Texas to Toronto, from Berlin to Brooklyn. All had either NF1 or NF2, with varying manifestations and varying degrees of severity.

The were drawn to the camp because its stated purpose was :"…to give the children a wonderful summer experience, while at the same time also giving them the opportunity to be with others who have NF and share with them their life's experiences, their hopes and their fears."

The program was in three parts. During the initial days, the participants stayed with host families in and around Salt Lake City. The families had been recruited by the indefatigable NNFF Utah Chapter Jennifer Newman ("She is something else, this lady," was the way one grateful camper summed her up). There were individual activities organized by the families and group activities for all, such as an afternoon visit to a big amusement park, a night at a AAA baseball game featuring the local Utah Buzz, a cable car trip up the 11,000 foot Snowbird Mountain in the impressive Wasatch Range and attendance at a live television and radio broadcast by the famed Mormon Tabernacle Choir that was beamed to hundreds of stations around the world.

The mid-section and longest part of the program took place at the magnificently situated Camp Kostopulos in Emigration Canyon, near Salt Lake City. Completely surrounded by mountains, the camp specializes in programs for children with special needs and offered riding, fishing, arts and crafts, sleep-outs under the stars, swimming, hiking, games, rope courses and cook-outs. A special feature was a trip to the laboratory of Dr. David Viskochil a world class scientist who had been on the Dr. White's team that found the NF1 gene in Utah in 1990. The campers had a chance to see strands of DNA and inspect other lab specimens. The tour was followed by a lively question and answer session, which proved to be so popular that the campers asked Dr. Viskochil to come to Camp Kostopulos the following evening for a second session.

The stay in Emigration Canyon were followed by a long bus ride through mostly desert country to Moab in southern Utah, where SPLORE, a non-profit group specializing in children with special needs took everyone on a multi-day rafting trip down a particularly scenic stretch of the river.

"The best part of the camp, though, was making new friends and meeting so many other kids with NF," said one of the participants.

For information about the NNFF 1998 Summer Camp, please call 1-800-323-7938 x 32.

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U.S. Congress Increases US Army Neurofibromatosis Research Program To $ 9.8 Million for Fiscal 1998

The United States Congress has renewed funding for the US Army's Neurofibromatosis Research Program at an increased level of $ 9.8 million for Fiscal 1998.

This program began as the result of an initiative by the National Neurofibromatosis Foundation in 1992 and continues to be an annual priority for the Foundation's staff and volunteers. Foundation members in 19 States worked this year with their US Representatives and Senators to support the legislation whose chief sponsor is Rep. Jack Murtha (PA).

"We are absolutely thrilled by this development," said Foundation President Peter Bellermann. "This funding is enormously important to our efforts to find effective treatments for NF1 and NF2. The US Army NF Research Program has moved us from the test tube to the point where clinical applications and treatments are being designed. On behalf of all patients and their families in the world, our thanks go to our Board member Dr. Sally Wallner, her husband Dr. Nicholas Wallner and their friend Jack Sheehan who started all this years ago. We are all deeply indebted to Representative Jack Murtha from Pennsylvania, who introduced the legislation in Congress. People with NF have never had a more powerful or loyal champion than Mr. Murtha. I urge everyone to express their gratitude with a brief note to Mr. Murtha:

Congressman John P. Murtha
2423 Rayburn House Office Building
Washington, DC 20515

"Mr. Murtha," Bellermann continued, "was joined by the following Representatives and Senators who worked with him in support of the legislation and members may wish to send them notes of thanks as well":

Congressman C.W. Bill Young (FL)
2407 Rayburn House Building
Washington, DC 20515

Congressman E. Clay Shaw, Jr. (FL)
2408 Rayburn House Building
Washington, DC 20515

Congresswoman Marge Roukema (NJ)
2469 Rayburn House Building
Washington, DC 20515

Congressman David R. Obey (WI)
2462 Rayburn House Building
Washington, DC 20515

Senator Ted Stevens (AK)
SH-522 Hart Senate Office Building
Washington, DC 20510

Senator Daniel K. Inouye (HI)
SH-722 Hart Senate Office Building
Washington, DC 20510

Senator Trent Lott (MS)
SR-487 Russell Senate Office Building
Washington, DC 20510

Senator Tom Harkin (IA)
SH-731 Hart Senate Office Building
Washington, DC 20510-1502

Senator Richard C. Shelby (AL)
SH-110 Hart Senate Office Building
Washington, DC 20510

The House Appropriations Committee complimented "the Army Medical Research and Material Command for structuring a highly regarded, peer-reviewed program that is well co-ordinated with other research conducted by the National Institutes of Health. The Committee (also urged) the Army to focus on research leading to clinical trials of promising treatments and therapies for NF."

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The Pathogenesis of NFl and NF2: Therapeutic Strategies

By: Bruce Korf, MD, PhD
Harvard Medical School/Boston Children's Hospital
(Ed. Note: The following is a report on an annual meeting of the "NNFF International Consortium for the Molecular Biology of NF1 and NF2" in modified format. In 1996 the Consortium members decided to hold annual meetings in alternate formats. They will meet every two years in the familiar, full membership gathering. During the off-years smaller, by invitation only, meetings will be held. The latter will focus on the development of long-term directions for research in NF1 and NF2. This year's meeting at the Banbury Center was such a meeting.)

An international meeting on the pathogenesis of NFl and NF2 was held from July 14-17, 1997 at the Banbury Center, Cold Spring Harbor Laboratory, New York. The meeting was sponsored jointly by the National Neurofibromatosis Foundation and by the Wilson Foundation and included 36 participants from the United States, Europe and Australia. The major focus was the consideration of possible therapeutic strategies for NFl and NF2.

Research on NF1 and NF2 has made major progress since the identification of the two genes. It is remarkable that, despite having learned a great deal about the structure and function of these genes, much remains to be discovered before we understand exactly how changes in these genes cause the various features of neurofibromatosis. This is dramatically illustrated by the finding of a role for cyclic AMP in the NF1 pathway – a new and important finding after seven years of research with the NF1 gene. Undoubtedly other new discoveries remain to be made. As this research proceeds, however, there is now renewed commitment to rapidly translating research progress to clinical application. There is also a realization that clinical trials of the first newly developed drugs that may be helpful in

neurofibromatosis may not be that far off. Developing a plan for organization of clinical trials is now clinical research priority that will require close integration of basic research and clinical care.

The first session was devoted to cognitive function in NFl, and was chaired Dr. Kathryn North (Royal Alexandria Hospital, Sydney). Dr. North first reviewed current knowledge about cognitive function in NFl. The pathological basis for learning problems in NFl remains unknown. Further research, including work with MRI and functional imaging is needed. Dr. Paul Frankland (Cold Spring Harbor Laboratory) provided an update on work with NFl deficient mice. These animals display problems with spatial learning. Dr. Andre Bernards (MGH Cancer Center) and Dr. Yi Zhong (Cold Spring Harbor Laboratory) spoke about the NFl gene homolog in Drosophila. Flies with NFl gene mutations display a phenotype of small size. The phenotype is rescued by increasing levels of cyclic AMP (cAMP). This establishes a possible new physiological role for the NFl gene product that will require further study in higher organisms.

The second session, chaired by Dr. David Gutmann (Washington University) was devoted to optic glioma. Dr. Robert Listernick (Northwestern University) reviewed his experience with optic glioma in children with NFl. Although approximately 15% of his patients had MRI findings of optic glioma, only half of these children displayed symptoms, and only 3/31 showed evidence of progressive disease. Dr. Roger Packer (Children's National Medical Center) described his experience with chemotherapy for progressive optic glioma. Of 78 patients (14 with NFl) treated with Carboplatinum/vincristine, 60% displayed shrinkage of tumor. Response rate was the same in patients with or without NFl. Dr. C. David James (Mayo Foundation) summarized work on tumor suppressor genes in astrocytomas and Albert Wong (Kimmel Cancer Institute) reviewed work on signal transduction in astrocytomas. Dr. Gutmann presented evidence that the NFl gene is expressed in astrocytes subjected to ischemia. There is first a phase of cell proliferation following ischemia, and then cell differentiation. NFl expression correlates best with the differentiation phase.

The third session, on neurofibroma, was chaired by Dr. Bruce Korf (Harvard Medical Center). Dr. Korf presented a clinical classification scheme for neurofibroma and stressed the need for studies of natural history. Dr. David Viskochil (University of Utah) summarized evidence for loss of activity of the NFl gene in neurofibromas. Dr. Nancy Ratner (University of Cincinnati) described her work on the pathogenesis neurofibromas in NFl knockout mice. She has shown that neurofibroma-like tumors form in heterozygous animals after cutting of nerves. Dr. Tyler Jacks (MIT Cancer Center) reviewed his studies with homozygous and heterozygous knockout mice. Animals with chimerism for NFl -/- cells develop neurofibroma-like tumors. Animals with double knockouts of NFl and p53 develop particularly aggressive sarcomas in a fairly short time. Dr. Jonathan Epstein (University of Pennsylvania) reviewed his studies of heart defects in homozygous knockout mice. Dr. Louis Parada (UT Southwestern Medical Center) has shown that NFl -/- neurons survive in the absence of neurotrophins. Jackson Gibbs (Merck Research Laboratories) reviewed progress in development of farnesyl transferase inhibitors and Dr. Frank Lieberman (Mt. Sinai Medical Center) discussed the possible use of differentiating agents in tumor treatment.

Dr. Ephraim Casper (Memorial Sloan-Kettering Cancer Center) chaired the session on malignancy in NFl. He reviewed current data on natural history and management of malignant peripheral nerve sheath tumors (MPNST's). Dr. James Woodruff (Memorial

Sloan-Kettering Cancer Center) discussed the pathology of MPNST's and Dr. Alfred Neugat (Columbia University) made comments on epidemiology. Lawrence Baker (University of Michigan) discussed his experience with sarcomas and noted seeing cafe-au-lait spots on some of his sarcoma patients. Dr. Kevin Shannon (University of California, San Francisco) described his studies of leukemia in NFl knockout mice. White blood cell counts were not altered in leukemic animals treated with a farnesyl transferase inhibitor. He also reported an increased frequency of leukemia in heterozygous mice treated with cyclophosphamide.

The final session, chaired by Dr. James Gusella (Massachusetts General Hospital) was devoted to NF2. Dr. Gusella reviewed knowledge of the structure of the NF2 gene and the types of mutations seen in patients with NF2. Dr. Vijaya Ramesh (Massachusetts General Hospital) discussed studies of localization of the NF2 protein. Dr. Richard Fehon (Duke University) showed his results with a Drosophila merlin knockout. Disruption of this gene in the fly leads to localized overgrowth. Dr. Gilles Thomas (Foundation Jean Dausset/CEPH) has created an inducible mouse NF2 knockout. These animals develop schwannomas and will be of great value in further studies of the pathogenesis of NF2. Dr. David Gutmann reviewed his findings on the structure of merlin. Dr. Mia MacCollin (Massachusetts General Hospital) discussed the possibilities of using aminoglycoside antibiotics to overcome stop mutations in NFl and NF2.

The meeting ended with a discussion of protocols for tissue collection in NFl and NF2. The next meeting of the NNFF International Research Consortium will take place in Aspen, Colorado in June, 1998.

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NF2 News In Brief
by: John Petito
Editor, The NF2 Review

Looking for some extra support for neurofibromatosis type 2 (NF2)? There are many resources available that you may not be aware of, as new technologies are providing us with ever increasing options for dealing with NF2. The following is an overview of some of the options now available to us "NF2ers":

The NF2 Review Newsletter

The NF2 Review is a newsletter serving the NF2 community by providing a review of the resources available for living with NF2. The newsletter is printed three times a year (spring, summer and fall) and regularly features NF2 treatment/research news updates and an overview of recently published research articles about NF2. In each issue there are two regular pen-pal columns, "CONNEXXIONS" for postal addresses, and "NF2 Bytes" for those wishing to share their online address. There is also a Q&A feature, where reader's questions are answered by professionals working in the field of research or treatment of NF2. Because of our common experience with hearing loss, the recent summer issue features an overview of new and current related technology now available to us including the ABI, tactile aids, and even voice recognition software for communicating one-on-one. If you would like to receive The NF2 Review newsletter, contact John Petito, Editor at: The NF2 Review, c/o The House Ear Institute, 2100 West Third Street, Los Angeles, CA 90057, or E-mail: bgxg89a@prodigy.com.

New ABI Candidacy Update

Due to success of the multichannel auditory brainstem implant (ABI) program, the FDA recently approved expansion of criteria that will increase the availability of the device. The ABI has been increasingly used to treat deafness after removal of bilateral auditory nerve tumors in patients with NF2. Previously, the ABI could be implanted only during surgery to remove such tumors. Under the new criteria, patients who already have had both tumors removed can be considered for implantation. This means more patients with NF2 may receive the benefits of partially restored hearing with the device. Individuals with NF2 who wish to be evaluated as candidates under this new expanded criteria may contact Steve Otto, House Ear Institute, 2100 West Third Street, Los Angeles, CA 90057 (213) 353-7039 V, (213) 484-2642 TDD or visit the House Ear Institute's website at: http://www.hei.org/welcom.htm.

The NF2 Crew

Within the last 19 months a private computer online discussion group, The NF2 Crew, has been established where NF2 topics can be addressed freely. Issues discussed in the Crew can range from general chitchat to exploring the latest microsurgery/radiosurgery methods available. To join The NF2 Crew you must have access to the Internet. For more information, contact Jordan Harlow at: JDHarlow@aol.com. The NF2 Crew now has a website with online NF2 resources, appropriately titled the NF2Crew Website: http://www.webcrossings.com/nf2crew/.

Online Support For Young People

A new online support group just for young people living with NF2 is currently being organized. Donna Getz - whose husband and two of their 3 children have NF2 - has begun an informal online pen-pal group for children, and children of parents, who have NF2. Donna will supervise the newly formed NF2 Jr. Crew. If you would like to learn more about it you can send her a personal E-mail at: HmSchoolMa@aol.com.

NF2 IRC - Live Chat

Are you looking for a place to meet and chat with other NF2ers...without leaving home? If you have a computer with access to the World Wide Web, this may be the answer for you. Each Sunday at 3:00 P.M., and again at 8:30 P.M., Eastern Standard Time, a friendly group of NF2ers and supporters log on to their computers and the live chat begins! General questions about these weekly chats can be sent to Marianne Schneider at: mariann2@erols.com.

(Ed. Note: This column is a new feature which will continue in future issues.)

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Support Group Firmly Roots NNFF Colorado Chapter

(Ed. Note: The NNFF Colorado Chapter has had a particularly long and sustained record of success with running a Support Group for its members. The following is a brief account of the Support Group's activities written by Jane Cahn, the Group's leader.)

From the very beginning our group has defined its purpose as threefold: to educate ourselves, to support each other and to share resources within our community. Meetings are held monthly to allow for time for relationships to form and be cultivated. Childcare was recognized as an important element if families were to be involved and therefore childcare is provided at every meeting. We have recognized the importance of confidentiality when coming together. We trust each other not to tell our personal stories to other friends and families. In exchange, we have developed the bond of understanding that people facing a common life challenge share.

Our meetings are both structural and fluid. Announcements and information are shared prior to each program/speaker. Some meetings offer space for personal experiences to be shared in small groups and all gatherings incorporate a social opportunity at the end to visit over refreshments.

Out of the group has developed a small committee structure where individuals share in the work of the group. Members serve on the phone tree, educational planning, social, newsletter, outreach or childcare committees; through the work of these committees we have developed a way of networking with each other and of doing outreach through NF clinic to invite other families and individuals to participate.

The topics at our gatherings vary. We have had speakers address medical aspects of NF, coping with insurance, genetics research, neuro-psychological testing, self-esteem and more. Fears that we could rapidly exhaust our NF medical contacts have proven unwarranted. Together we have pooled our knowledge and found a wealth of resources and contacts of generous people willing to share their personal time with only our thanks as a gratuity.

The bridge the group has provided has been very meaningful to our Chapter. Through the group, new Chapter leadership has come forward. Through the outreach of the group, new Chapter members have stepped up with skills in fund raising. With the group as its anchor, the Chapter Board is looking at ways to expand. When people find a place where their needs can be met, they want to give something in return.

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Drs. Shannon and Packer Join NNFF Medical Boards
NNFF Medical Director Dr. Allan Rubenstein has announced that Dr. Kevin Shannon from the University of California/San Francisco has joined the Foundation's peer review panel, the Research Advisory Board and that Dr. Roger Packer from Georgetown University and the University of Virginia has joined the Clinical Care Advisory Board.

Dr. Shannon is an Associate Professor of Pediatrics at UCSF. He received his M.D. from Cornell University, served as a resident at the University of Texas Southwestern and as a post-doctoral fellow at UCSF.

Dr. Shannon is also a former Young Investigator of the National Neurofibromatosis Foundation. Among his many scientific achievements are his work that linked myeloid leukemia to the NF1 gene.

Dr. Roger Packer serves as Professor of Neurology and Pediatrics at Georgetown University. He is also Professor of Neurosurgery at the University of Virginia. He received his M.D. from Northwestern University, was a resident at Cincinnati's Children's Medical Center and a fellow at the Children's Hospital of Philadelphia, a fellow at Memorial Sloan-Kettering Cancer Center and a fellow of the American Cancer Society.

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New NF Groups In Austria & Bulgaria

The worldwide NF movement keeps growing, as evidenced by the formation of two new European organizations in Austria and Bulgaria. Both groups applied and were accepted as International Affiliates of the Foundation. Both have also sent information in their native languages which will be posted shortly on the NF Web Site. The Bulgarian organization, named The Bulgarian Workgroup (NFW) is headquartered at the Queen Giovanna University Hospital in Sofia and led by Dr. George Poptodorov, a neurosurgeon. All the participants are volunteers with a clinical or scientific interest in the neurofibromatoses.

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"I did it. But I am not good at it."

Dr. David Roemer: The 100 Mile Runner

Many who have NF understand when David Roemer says that during early childhood "I was not a good student. I tried hard, but I could not pay attention.". He was learning disabled and additionally slowed down by an attention deficit disorder.

Not that he dwelled on it. His brother was the one who needed help, being born 50% deaf and with multiple neurological disabilities. "Since his speech was garbled, our mother and I became his interpreters, and since he was odd looking, clumsy and emotionally naïve, I made it my responsibility to protect and to help teach and encourage him."

There was something else he could miraculously focus on: classical music. During his early teens he was able to learn how to play the classical guitar. He had to work at it and practiced endlessly, "up to eight hours a day." The work paid off. He embarked on a rapidly growing career as a concert guitarist.

It all came to a crashing halt at age nineteen when while on tour, a seemingly inncocent but persistent cold led to the discovery of a large tumor in his chest. "It was removed by thoracotomy and diagnosed as a neurofibroma." For a then unknown reason he bled post-operatively "coding once, and returning twice to the operating room."

"But the months I spent in the hospital started me on my path toward becoming a physician. For six years, music had enveloped me, defining my life and my self. Now I no longer found my life as a musician fulfilling. I needed to be more engaged with

others and to be of greater use. "I dreamed of becoming a physician, but the last 'hard' science course I'd taken had been high school biology, and I'd gotten a D !"

Not to be deterred, though, Roemer left the conservatory and his concert career and enrolled at Columbia University in pre-med studies. "It was difficult and discouraging at first. I got a couple of C's. My dream of becoming a physician was turning nightmarish."

During the day he worked in a lab as a research assistant to support himself. At night he went to school. Finally gaining admission to Brown School of Medicine (and much later "graduating as a physician) were two of the happiest moments of my life."

After his thoracotomy he had to work hard to re-gain his physical strength. He did it by "taking up my childhood passions: running and back-packing. I finished my first marathon - dead last, but I finished --, and later trekked 850 miles through the Sierras".

He was just about to start at Brown, when a new, large tumor was discovered in his lung. It was removed with a partial lung re-section, "and again I bled out. This time, there was an explanation: von Willebrandt's Disease". He was also diagnosed with neurofibromatosis.

Given his weakened condition, Roemer could not take a full course load and persuaded the dean of the medical school to let him spread out his studies over a longer than usual period. "I did alright with the course work, but what caught my interest were the contacts with patients and the stories they told. Most of them had a strong need to tell the stories of their lives to their doctors and I, for my part, found that hearing them was more rewarding than putting my stethoscope to their chests."

This led to the decision to specialize in psychiatry and eventual work with adolescents. Currently, "I am working on a project looking at Impulsivity and Low Frustration Tolerance as possible risk factors in a data set of 180 completed adolescent suicides. Working with this group has once again whetted my appetite for research. I'd almost forgotten how exciting it is."

Looking back, Dr. Roemer says: "It is obvious to me that my own experiences with illness, on an acute level, has everything to do with my career choice. Dealing with life-long genetic-chronic illnesses, has led to a special kind of understanding and insight" of others with medical problems. "My striving for ever greater physical challenges in Ultra-Running, Back-Packing and Mountain Climbing represent an over-compensation for my very real physical limitations. I have lost lung capacity, and I have some restrictive lung disease."

"My listening skills and attention to subtlety, originally developed as a musician, have developed even more thoroughly as a psychiatrist. Music tells a story just as the patients do. And stories are what I am interested in."

This summer Dr. Roemer completed a 100-mile Ultra Marathon in Vermont. Asked how he could accomplish such a feat he said : "Yeah, I did it. But I am not very good at it. I came in dead last. That's the important thing to me, that I set myself a goal and that I stick to it. My ambition is not to be the best at something like that. I can't be. My ambition is to do it and to complete it."

"My experiences have made me very determined, stubborn if you will. One thng I am very determined is that the illnesses I have had be turned into something positive. I don't want NF or anything else to run my life. One way for me to make sure that that doesn't happen is to find ways to turn these experiences into something positive. I don't want to be inward looking. That's what my work in music was all about."

"I want to give back to others with all the gifts that were give me."

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1997 U.S. Army NF Research Awards

The U.S. Army Research and Material Command has announced the 1997 NF Research Awards. In addition to the awards listed below, the Command has also issued for scientists to submit proposals for multi-year funding of natural history studies of plexiform neurofibromas in NF1 and vestibular schwannomas in NF2. The announcement of the latter are expected by early 1998.

Dr. Camilynn Brannan
University of Florida
"Dissection of the Pathogenesis of NF1 – Associated Myeloid Leukemia"

Dr. Channing Der
University of North Carolina at Chapel Hill
"Role of NF1 and NF2 Signaling and Transformation"

Dr. Richard Fehon
Duke University
"The Relationship between Genotype and Phenotype in Drosophila Merlin, and Human NF2 Genes"

Dr. Jan Friedman
University of British Columbia
"Analysis of Phenotypic Variability in NF1"

Dr. Tyler Jacks
Massachusetts Institute of Technology
"The Use of NF1 and NF2 Mutant Mouse Strains in the Investigation of Gene Function and Disease Development"

Dr. Mia MacCollin
Massachusetts General Hospital
"Genotype Phenotype Relationships in NF2"

Dr. Luis Parada
University of Texas, Southwestern Medical Center
"In Vivo Models of NF1: The Nervous System and Tumerogenesis"

Dr. Nancy Ratner
University of Cincinnati
"Wounding-Induced Manifestations of Type 1 NF"

Dr. Michael Rosenfeld
Regents of the University of California
"Molecular Mechanisms of Glial Abnormalities in NF"

Dr. Karen Stephens
University of Washington
"Pathogenesis of Germline and Somatic NF1 Gene Rearrangements"

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Thomas Gallagher & Harold Ramis Join NNFF Board of Directors
Foundation Chairman William Tarbart has announced the election of two new members to the national Board of Directors: Thomas Gallagher and Harold Ramis.

Thomas Gallagher is Vice Chairman of Oppenheimer & Co., Inc. the influential New York-based investment banking, securities brokerage and management asset firm. He joined Oppenheimer as a securities trader, became Managing Partner in 1985 and Executive Vice President in 1995 in charge of all Oppenheimer equity and fixed income operations. Oppenheimer & Co., Ltd. the firm's UK affiliate also reports to him.

Prior to joining Oppenheimer, Mr. Gallagher was a Senior Vice President and head of equity trading at Shearson American Express, a securities trader at Dean Witter, and a partner at Howard Associates.

Born in Brooklyn, Mr. Gallagher lives in Manhattan with his wife and two children. He is actively involved in fundraising for the Student Sponsorship Program, the Salvation Army and Neurofibromatosis.

Celebrated for his unique talents in writing, directing, producing and acting, Harold Ramis has been involved in many of the most successful screen comedies ever made.

Born in Chicago, Mr. Ramis received his B.A. from Washington University in St. Louis, MO. He returned to the University in 1993 to receive an Honorary Doctorate in Arts and in 1997 he was elected to serve on the Board of Trustees.

Harold Ramis made his start in comedy in 1969 with Chicago's famed Second City improvisational theatre while still employed as an associate editor at Playboy Magazine. In 1974 he moved to New York to help write and perform in the National Lampoon Show with such luminaries as John Belushi, Gilda Ratner and Bill Murray.

His Hollywood breakthrough came in 1978 with the blockbuster Animal House. He then teamed up with Ivan Reitman as writer and producer/director for such box-office hits as Meatballs, Stripes and Ghostbusters I & II. He also starred in the latter two.

He directed and co-wrote Caddyshack, which starred Bill Murray, Chevy Chase and Rodney Dangerfield. This was followed by the popular National Lampoon's Vacation, a film in which he directed Chevy Chase and Beverly D'Angeles. He then directed Robin Williams and Peter O'Toole in Club Paradise, which he also co-wrote.

Mr. Ramis then co-produced and co-wrote the comedy hit Groundhog Day, starring Bill Murray again and Andie MacDowell. Most recently he directed Al Franken and Laura SanGiacomo in Stuart Saves His Family. Mr. Ramis' appearance in Baby Boom, opposite Diane Keaton, marked his debut as an actor in a film he had not written, produced or directed. He also appeared in Stealing Home with Jodie Foster and Mark Harmon and with Warren Beatty in Love Affair. He was executive producer/co-writer for Back To School, the Rodney Dangerfield comedy.

Mr. Ramis lives with his wife and two children in suburban Chicago.

"We welcome both Tom and Harold to the Foundation and to the Board of Directors and thank them for their commitment to our cause" said Chairman Bill Tarbart. "They each bring important new strengths to our fight against NF. Tom's and Harold's diverse talents and experiences will be significant new resources for the Foundation."

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Kids' Council News
Megan Leaf and Jenny McElroy are happy to welcome two new vice-Chairpersons to the Kids' Council, Jessica Azwol from Washington State and Giuliana Pullaro from Connecticut.
There are now 44 members of the Kids'Council
Look for the FIRST NEWSLETTER this Fall to find others living near you.
ATTENTION ARTISTS! We are searching for a logo for the Kids' Council, but need your help. Please join our "First Art Contest". Send in your ideas for a logo (a dancing daisy?…a walking, talking daisy?..or maybe not a daisy at all…). Please submit entries to NNFF, Kids' Council, 95 Pine St., 16th Fl., NY, NY 10005.

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Seeking Pen Pals I am 34 years old, interested in photography and skiing and would like to correspond with others with NF in the U.S. – Robert Fleury, 10 Prendergast St., Dunedin, New Zealand

I am 40, live in the Chicago area and am interested in being a pen pal to anyone who needs to talk. – Jeff Hadley

I would like to hear from others, I am 25. – Christopher Morton, 401 Hill St., Moncks Corner, SC 29461

Teen would love to hear from others. – Mieke Clark, 337 N. Hollywood Way, Burbank, CA 91505

My name is Jeff, I'm 26 and would love to talk to others.

I'm 10 years old, have congenital bowing of the tibia, and have had 3 operations. I would love to write to others. – Nicole Potachniuk, 421 Rockaway Pkwy, Valley Stream, NY 11580

I'm 32 years old. I would like to talk to others who have decided not to pass the NF gene on to their offspring and have considered adoption. – Kim McLaughlin, PO Box 3087, Laredo, TX 78044

I have NF1 and am 34 years old. – Lisa Seldon, 6223 W. Beech St., Everett, WA 98203

Seeking email contact with families of children with NF1 spinal tumors. – Vanessa Croft & Beatrice Beladi

35 year old dad, has NF, so does 1 child. Would like to talk to others. - Stuart Clawson, 8408 10th Ave. So., Bloomington, MN 55420

I am 32, have NF1, and am thinking about having children.. I would like to talk to other women who have decided to have children and how it affected their NF during pregnancy. – Kristin Howell, 35 Ferrin Pl., Mt. Clemens, MI 48043

Please write. – Sharon Shepherd, PO Box 2, Metairie, LA 70004

I have NF1. I'm a 53 year old retired police officer. – William E. Holliday, Jr., 388 Dalnaida Rd., Montgomery, AL 36109-2834.