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Hello, and welcome to The NF2 Review!”...

With those unassumming words, in April of 1994, a newsletter was born, and a vision was realized. At that time, John Petito, the late Founder of The NF2 Review, recognized the need for better access to information about neurofibromatosis type 2 (NF2) for both patients and health care professionals.

He also knew, all too well, the need for better access to other “NF2ers.” The rarity of NF2, and the subsequent hearing loss it causes, can result in a certain degree of isolation. John had hoped that this newsletter would become a place where folks could express themselves – not everyone’s experiences with life’s joys or struggles is the same – and where individuals with NF2, their families and friends, could meet others who deal with NF2 every day.

The goal of this publication will always be to remain true to that vision. Please continue to share your opinions, thoughts and desires with us, so we can better serve you, the reader. This is your newsletter!

Gail Petito
(still reluctant) Editor

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Needles in the Brain(STEM) / Bob Shannon, Ph.D.

You want to stick those needles … where?! In my brainstem?! Won’t that hurt?!”...

I’m imagining the dialog with the first NF2 patient to receive the new Auditory Brainstem Implant (ABI) with penetrating electrodes. It sounds like science fiction or masochism or both (actually there are no pain receptors in your brain, so it doesn’t hurt at all). After years of design and safety testing, the new model ABI is entering a new phase, which will end up in the first patient in the next year or so. We’re hopeful that the new design will result in improved speech recognition, but we won’t know for sure until we try it.

The present ABI is an implanted device much like a cochlear implant, except that the electrodes are placed not in the cochlea, but in the brainstem following the removal of a vestibular schwannoma (VS). The ABI was first developed at the House Ear Institute (HEI) in the late 70s. Later, in the early 90s, HEI teamed up with Cochlear Corporation to manufacture a multi-channel version. There are now more than 120 people with the multi-channel ABI worldwide. Although it doesn’t work as well as the more common cochlear implant, it does provide people deafened by the bilateral VSSs of NF2 with some auditory sensation and lots of help with lip-reading.

Please see Needles on page 2
A few ABI patients can even understand enough words through the device to enable them to have limited conversations on the telephone. We’ve been doing research for years to understand how ABIs work and how to make them better.

In 1989 HEI researchers teamed up with Dr. Douglas McCreery at the Huntington Medical Research Institutes (HMRI) in Pasadena to begin the development of the next generation of ABI devices. We think that the reason that present ABIs don’t work as well as cochlear implants is that the electrodes are not making good connection to the pitch dimension of hearing. All of the electrodes sound similar in pitch to many ABI patients.

In contrast, each electrode elicits a clearly different pitch sensation in cochlear implants. So we started working on an electrode design that would contact the pitch dimension of the cochlear nucleus – the first auditory nerve relay center in the brainstem.

We were able to obtain a contract from the Neural Prosthesis Program at the National Institutes of Health to develop a new ABI system with electrodes that would actually penetrate into the brainstem. Our hope was that penetrating microelectrodes (they’re actually smaller than a hair – not exactly needles) could connect better to the pitch dimension of the auditory brainstem and would produce better speech understanding.

In the last 11 years we’ve conducted many experiments to design the new electrodes and to test the safety of the new electrodes. HEI Neuroanatomist, Dr. Jean Moore, has worked closely with Neurosurgeon, Dr. William Hitselberger, to figure out how to find the right place to put the penetrating electrodes (we certainly don’t want to stick them in the wrong place). Doug McCreery has tried dozens of electrode designs in cats to make sure the electrodes and the insertion process is safe.

Some of the electrode designs required Leo Bullara, the electrode designer at HMRI, to machine grind a beveled edge on the electrode tips. These electrodes are so small that you can hardly see them without a microscope. And Leo had to design a system to grasp these tiny wires and make a precision beveled edge on the tips. For other designs the tips of the electrodes were etched to give them sharp pointed tips or slightly rounded tips. I should note here that sharp is a relative term – the tip of a normal sewing needle would look as blunt as a baseball bat.

We poked the new electrode designs into little pieces of brain tissue (and even into a couple of T-bone steaks that were sacrificed for research) to make sure they wouldn’t bend or break. We measured the responses of neurons in the brain when we stimulated the new electrodes to make sure we were activating the different pitch areas of hearing. Doug McCreery has developed a small “gun” to shoot the electrodes into the brain at just the right speed and at the right angle. He’s worked with Dr. Hitselberger and Dr. Moore to make sure that the tool is easy for the surgeon to hold and use properly, and to ensure that the electrodes end up in the right place.

And now, after more than 11 years of research and design, we are ready to try the first ABI with penetrating microelectrodes. Doug McCreery has gone to Sydney, Australia to teach the people at Cochlear Ltd. how to build the electrode assemblies. A proposal is being assembled that will have to be approved by the FDA.

And then we will look for someone with NF2 who is about to have a VS removed, who will probably say, “You want to stick those needles ... where?!”
Scientists agree that the Auditory Brainstem Implant (ABI)* used by patients with neurofibromatosis type 2 (NF2)** doesn’t work as well as the cochlear implant.*** It is believed that this lower level of performance is caused by the very restricted range of pitch perception allowed by the surface electrode used in the device. “Our goal is to make the ABI work better by developing an electrode that penetrates the surface of the brainstem,” states Dr. Jean Moore, head of the House Ear Institute’s Neuroanatomy Department. “We believe that micro stimulation will activate the neurons more individually, and so provide more specific pitch information and speech perception for ABI users.”

Dr. Moore’s first step was to learn the topography of the cochlear nucleus region of the brainstem. To accomplish this, Bryan Wu and Jay Huang created a computer-assisted 3D model of the head and brainstem of tumor patients. Interactive modeling of the various device designs with the human anatomy followed this. The modeling was an exacting process because acoustic tumors compress the auditory structures and cell death caused by the onset of deafness makes the cochlear nucleus shrink. With these AutoCAD computer models as her guide, Dr. Moore took on the role of a designer, using her neuroanatomical information to determine the appropriate size and shape of the microelectrode array.

After a series of biological tests, Dr. Douglas McCreery, at Huntington Medical Research Institutes (HMRI) in Pasadena, fabricated the microelectrode array. The array, which penetrates the human brainstem (only) at speeds greater than 50mm/sec, consists of several single iridium wire electrodes set in an epoxy base. Because the point of entry will determine the orientation of the “thumbtack” shaped array, this placement requires more finesse and accuracy than that of the existing surface electrode. The difficulty is compounded by the fact that placement occurs ‘blind’ because the cochlear nucleus is not visible on the brainstem

*Abbreviation: ABI, Auditory Brainstem Implant
**Abbreviation: NF2, Neurofibromatosis Type 2
***Abbreviation: Cochlear Implant
ABI News

ABI Receives “Thumbs Up” from FDA

Endorsement represents the culmination of more than 20 years of research

by Bob Shannon

Gaithersburg, Maryland – On July 21, Cochlear Corporation presented the Auditory Brainstem Implant (ABI) to an expert panel of the Food and Drug Administration (FDA) for approval. The panel approved the ABI unanimously and enthusiastically. This outcome represented the culmination of more than 20 years work by the researchers at the House Ear Institute.

The first ABI was done in 1979, when an NF2 patient (Marilyn Davidson) was presented with the possibility of some hearing by implanting an electrode in her auditory brainstem following removal of a vestibular schwannoma. Although the physicians, Dr. William House and Dr. William Hitselberger, were not confident that such a procedure would work, Marilyn insisted on trying it. She was able to hear some sounds and gradually learned to use the limited sounds to help with lip-reading and sound identification. Following a revision surgery in 1981, Marilyn has used the ABI daily for almost 20 years.

Between 1979 and 1992 the House Ear Institute (HEI) implanted 25 NF2 patients with a single-channel version of the ABI. In 1992 HEI teamed up with Cochlear Corp. and Huntington Medical Research Institute in Pasadena to develop a multi-channel ABI. Since 1992 the multi-channel ABI has been implanted in over 100 NF2 patients in the US (75 of them at HEI) and an additional 40 patients in Europe.

As I sat in the room watching the FDA panel deliberating the ABI, the importance of the occasion didn’t quite sink in. But as the panel started to vote, suddenly a wave of realization came over me – they’re about to approve the ABI! After more than 20 years of research and development, it has finally been approved by the FDA as a safe and effective device! Yahoo!

After the initial wave of euphoria, my next thought was that I wished John Petito could have been here to see this day. John was ABI patient number 12 and was a critical factor in the research that made the ABI possible. He was the workhorse behind much of our research. As one of the early ABI patients, John understood that lots of hard work was necessary to understand how the ABI worked and how to improve it. He volunteered for hundreds of hours of tedious testing in the lab. Much of what we know about how the ABI works comes from John’s hard work and long hours in the lab. Certainly, a portion of this milestone is due to John’s dedication to the project.

The approval became official in early August, when Cochlear Corporation received the letter of notification from the FDA. FDA approval usually means that insurance companies will more likely cover the cost of the ABI, and that the ABI may now be available at more centers around the country.

Testing, Testing ...

John Petito, ABI implant #12, is hooked up and ready for testing at the House Ear Institute.
Q: As someone who is about to undergo my fourth debulking in my only hearing ear, and who is contemplating radiotherapy, I am wondering if your views have changed?*

A: Here are my views:

There are three options for treatment of VS, watchful waiting, surgery and RT. When an only hearing ear is involved, I go for watchful waiting for as long as absolutely possible. I think that overall, surgical outcomes in experienced hands are better then RT outcomes in the short and medium run. I think there comes a point when the surgery becomes too difficult because of repeated procedures and/or the patient can no longer tolerate surgery. At that point RT rises to the top. Currently, I think that fractionated offers a better chance at hearing retention then single dose (gamma knife).

I also think the risks to other cranial nerves, especially facial, are better with fractionated then with single dose. My RT people are trying to convince me that proton beam fractionated has even less risk then standard RT. I’m a hard one to convince however, plus its only available in two centers in the US.

I think that Gareth Evans’** points about the risk of malignancy are excellent ones. I think that each patient needs to look at the risk of short-term hearing loss versus long-term malignancy (which would certainly be fatal), and then make up their own minds.

So having said all that, I encourage everyone with one hearing ear to learn sign language and become fluent; then when the time comes, sit down with an experienced surgeon and an experienced radiation oncologist and weigh the choices carefully. Everyone comes to their own conclusion.

*Marie Drew underwent the debulking procedure prior to planned radiotherapy. However, when she became deaf during the debulking, she chose additional microsurgery to remove the rest of the tumor and did not have the radiotherapy. Her resulting facial paralysis has left Marie with mixed feelings about the decision to proceed with further microsurgery. “I had been told that the chances were very good at preserving the facial nerve. If I had to do it again, I would have taken the debulked tumor, even with deafness, and I would have gone for Peacock radiosurgery or Proton beam, fractionated. But of course, that is all Monday morning quarterbacking! I just see a need for more balance. There is far too much emphasis placed on saving the hearing, and far too little placed on saving the facial nerve.”

**Gareth Evans is a Clinical Geneticist in Manchester, England.
$17 Million Approved For Neurofibromatosis Research

Increase in funding reflects continued support of neurofibromatosis research

NEW YORK – On September 6, the U.S. Congress approved the appropriation of $17 million for neurofibromatosis (NF) research during the next fiscal year. The bill was then signed into law by President Clinton. Research funding for NF was thus increased from last year’s $15 million appropriation.

The US Army’s NF Research program began as an initiative of the National Neurofibromatosis Foundation and continues to be a high priority of the Foundation. This year more than 13,000 of the Foundation’s members were involved in the legislative process leading to the appropriation. To each and everyone who was involved, many thanks.

NNFF President Peter Bellermann expressed gratitude to Representative James Moran (D-VA) and also to Representative Jack Murtha who was the original sponsor of the NF research program at the US army nine years ago and remains one of its greatest champions. Special thanks also goes to Rep. Jerry Lewis (R-CA), Chairman of the House Appropriations Subcommittee for Defense and to Senators Ted Stevens (R-AK) and Daniel Inouye (D-HI) who lead the Senate Appropriations Subcommittee for Defense.

News Source – The NNFF Website at www.nf.org

NNFF Research

The National Neurofibromatosis Foundation has announced the recipients of its research awards for the academic year 2000 – 2001. Some of the awards are as follows:

The Adam Goodkind Family Fund
Dr. Sushmita Maitra, Duke University
(Two-Year Young Investigator Award)

“The Role of Merlin in Proliferation and Cellular Differentiation in Drosophila”

With her experiments in the fruit fly/drosophila model, Dr. Maitra will work on the question: why do specific (Schwann) cells over proliferate and cause tumor formation when the NF2 gene mutates? Her experiments are also designed to further elaborate on the normal function of the NF2 protein, Merlin, in cells. She will study especially the interaction of the Merlin protein in another tumor-suppressor gene to determine how this interaction causes defects in cell growth differentiation. Finally, Dr. Miatra will investigate whether NF2 tumors occur because Merlin interacts with still other genes.

The Marcy and Richard Horvitz Family Fund
Dr. Dominique Lallemond, Harvard Medical School/MGH Cancer Center
(Two-Year Young Investigator Award)

“Investigation of the Role of NF2 Gene Product, Merlin, in Cell Adhesion, in Vitro and in Vivo”

Dr. Lallemond proposes to study two things, namely what role the NF2 protein, Merlin, normally plays in cell movements and adhesions, and secondly why the NF2 gene, in its mutated form, causes abnormalities in cell movement and cell mutations. These studies are of considerable importance to all NF2 research, but they also hold great potential for studies in cancer that seek to determine how cancer cells spread in the body and give rise to metastasis. Dr. Lallemond will carry out her experiments both in vitro (the petrie dish and in vivo, i.e. in the mammalian NF2 mouse model.

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Young Investigators Awards Announced

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The Adam Goodkind Family Fund
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NF Symposium and the American Society for Human Genetics Meeting

by Michael Baser, Ph.D.

The host city chosen for this year’s American Society of Human Genetics meeting, held in October, was Philadelphia, Pennsylvania. The ASHG, which meets every year, is one of the largest genetics meetings in the world; typically about 5,000 people attend. Roughly 10% of the studies that are submitted are chosen to be presented in the slide sessions, and the rest are presented as posters.

The NNFF sponsors an NF Symposium, held the night before the regular ASHG scientific presentations begin, so that NF investigators whose studies are not being given as talks at ASHG have an opportunity to present their studies as talks for an audience that is specifically interested in NF. Approximately 150 people attended this year’s NF Symposium.

Please see ASHG on page 14

Workshop on NF2 and Vestibular Schwannoma

by Michael Baser, Ph.D.

CHESTER, WALES – The Chester workshop was attended by about 30 people, almost all from the UK and Europe. The July meeting was organized and sponsored by Drs. Richard Ramsden and Gareth Evans from Manchester. The workshop was being held for the first time this year, and plans are to hold future gatherings every two years. Chester is at the northeast corner of North Wales, a remarkably beautiful area of England, very hilly and green. The city of Chester itself is historic; it began as a Roman garrison and today has the best-preserved Roman wall in England. The wall surrounds the city and has been converted to a promenade, so that you can walk along the top of the wall and look down on the city.

The purpose of the Chester workshop was to plan the future of vestibular schwannoma and NF2 research in the United Kingdom. The format of this meeting was different than the ASHG or NNFF meetings. There were scientific presentations on the first day on:

- Genetics of vestibular schwannoma and NF2 (Gareth Evans)
- How big is the problem – regional workload (Susan Huson)
- Surgical management of non-VS lesions (Susan Huson)
- Does it matter where you are treated? (Michael Baser)
- Imaging in NF2 (James Gillespie)
- Surgical management of VS (Jens Thomsen)
- Radiation treatment of VS (David Forster)
- The Auditory Brainstem Implant (ABI) (William Slattery)

On the second day people broke into working groups of 6 people with reporters. These groups each prepared statements on different topics that were then presented to the entire group as research priorities, or where we would like to be in 5 years. The working group topics were:

- ABI and Cochlear Implants
- Quality of life issues
- Non-surgical treatment of vestibular schwannoma
- Surgical management of NF2
- Genetics
NNFF International Consortium for the Molecular Biology of NF1 and NF2

by Michael Baser, Ph.D.

ASPEN, COLORADO – The NNFF meeting is held every two years in Aspen, which is a wonderful place for NF researchers from around the world to get together and present their findings. The meeting is held in the Hotel Jerome, a great old hotel that has been restored to its original splendor from the days when Aspen was a mining town. The surrounding mountains provide lots of opportunities for scenic walking, biking, and hiking. About 200 NF researchers attended this year’s conference, held in June. There were many presentations and posters on NF2 at the meeting, so I will only list their titles: further information can be obtained from the NNFF*. Some of these studies have already been published and can be found in the literature review in this issue of the NF2 Review.

Presentations

- Wiederhold et al. - The NF2 tumor suppressor merlin and its interactions.
- Ricard et al. - Evidence that the focal adhesion protein paxillin closely interacts with merlin in primary rat Schwann cells.
- Scoles et al. - Neurofibromatosis 2 (NF2) tumor suppressor schwannomin interaction with HRS regulates STAT signaling and Schwann cell proliferation.
- James et al. - Merlin selectively binds F- but not G-actin, and stabilizes the filaments through a lateral association.
- Brault et al. - N-terminal folding of the NF2 tumor suppressor protein regulates subcellular localization and protein interactions.

Posters

- Baser et al. - Predictors of survival in neurofibromatosis 2: preliminary results.
- Baser et al. - Evaluation of different clinical diagnostic criteria for neurofibromatosis 2 in patients without bilateral vestibular schwannomas.
- Shamisa et al. - Glioblastoma multiforme (GBM) arising in the field of gamma knife radiosurgery for vestibular schwannoma: case report and review of the literature.
- Gutmann et al. - Functional analysis of NF2 missense mutations.
- Rosenbaum et al. - Enhanced proliferation and potassium conductance of Schwann cells isolated from NF2 schwannomas can be reduced by quinidine.
- Heinrich et al. - Mutations and allelic loss of the NF2 gene in neurofibromatosis 2-associated skin tumors.
- Hung et al. - Axonal growth stimulation in human vestibular nerve schwannoma.
- Fauoda et al. - Induce of expression of neuregulins and their putative receptors Her-2, Her-3 and Her-4 in human vestibular schwannoma.
- Colton et al. - Gene expression in NF2’s bilateral and sporadic human vestibular schwannomas.
- Antinheimo et al. - Population-based analysis of sporadic and type 2 neurofibromatosis-associated meningiomas and schwannomas.
- Johnson et al. - The role of the NF2 tumor suppressor, merlin, in epithelial cell morphology and motility.
- Kaufmann et al. - Aberrant splicing in NF1 and NF2 in several human tumours.
- Li et al. - Urokinase-type plasminogen activator is highly expressed in human NF2 schwannomas.
- MacCollin et al. - Molecular determination of somatic mosaicism in typical NF2 patients.
- Morrison et al. - The NF2 tumor suppressor gene product, merlin, mediates contact inhibition and cell cycle progression through interactions with CD44.
- Zhao et al. - Morphogenic and actin-binding characteristics of the NF2 tumor suppressor protein merlin.
- Krosl et al. - The NF-2 status of meningiomas is associated with tumor localization and histology.

*The National Neurofibromatosis Foundation, Inc., 95 Pine Street, 16th Floor, New York, New York 10005. Or you can visit their website at: www.nf.org
The Lighter Side of Research

An Irreverent Look at the U.S.-European NNFF Aspen 2000 Soccer Match

Or, how it feels to get beat like the family mule: a personal perspective

by Michael Baser, Ph.D.

Some in the NF2 community may wonder what NF2 researchers do when we’re not doing research. We pretty much do what others do for fun, except that we have made this odd career choice to spend a lot of time in the dank dungeons of science, to use John Petito’s phrase. The NNFF International Symposium on the Molecular Genetics of NF1 and NF2 in Aspen Colorado in June was taken up almost entirely with scientific presentations and related meetings (see accompanying article), but there was a raft trip down the Upper Roaring Fork, a soccer match between U.S. and Europe NF2ers, and a beer tasting extravaganza.

In the soccer match, there were 5 people on the European side and 6 people on the U.S. side, a noble but (as it turned out) unnecessary concession by the Europeans to Stateside soccer inferiority in centuries past. We immediately realized two closely-related things: (1) we were not as young as we used to be, and (2) we were playing at 8,000’ altitude. This became apparent after we jogged a few steps and had to pause 10 minutes to catch our breath.

The first half was brutal, with the Europeans scoring at least 15 unanswered goals. I have mercifully forgotten the name of the amazing Portuguese fellow who dribbled around everyone as if they were standing still. For my part, I can attest that I was, in fact, standing still. It seemed to me that the Europeans enjoyed an average height advantage of about a foot, which I used as a flimsy rationale to throw myself with wild abandon at their kneecaps in a vain attempt to deflect the ball.

An elegant moment (or acutely embarrassing one, depending on your team) came when Romano was in front of, but facing AWAY from, the U.S. goal, and scored by faking out everyone and very gently kicking the ball BACKWARDS into the goal! Gareth Evans from Manchester was the liaison from Manchester United, the World Soccer Club 1999 champions. The relation of Gareth’s individual athleticism to his home team’s international domination may be tangential, but those of us from the U.S. who knew of this connection had (very brief) feelings of trepidation nonetheless. Gareth is more famous for directing and acting in Shakespeare plays, although someone was circulating an obvious canard about the full monty.

The first possession of the second half was inspirational: the U.S. goalie kicked the ball all the way into the European goal! He did this while wearing open-toed sandals, thereby enriching his podiatrist. U.S. pride was solidified by Dave “El Jefe” Vischochil, who scored two more goals, ably assisted by an Australian striker. The Australian was designated as a de facto American before the game, which was fortunate since it seems unlikely that any of our mates Down Under would wish to become de jour Americans on the basis of the European-U.S. goal ratio.

The U.S., through appropriate diplomatic channels, has already demanded a rematch for the Aspen 2002 meeting. We are mounting an intensive recruiting search in the Pacific Northwest for Bigfoot, with the hopes that the Europeans don’t counter with the Abominable Snowman. Both sides will bring oxygen tanks.

Strangely enough, the beer tasting extravaganza was not related to the soccer match. To non-cognoscenti (such as myself), beer tasting does not simply involve guzzling weird diuretic ales. About a half-dozen researchers each made impassioned pleas for the virtues of one of their country’s emblematic brews to a large crowd, and many glasses of each beer or ale were set out on the bar for potential imbiberers. My dedication to scientific objectivity was so intense that I had no choice but to extensively sample each one. If I remember correctly, an extremely dubious assumption, the beers and ales came from England, the U.S., Belgium, and… well, a few other countries. Eric Legius provided extensive audiovisual documentation of some unusual and anatomically correct aspects of his beer’s label, which would be of keen interest to medieval art historians, and probably no one else (sorry Eric).

To John: this Bud’s for you!

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Jordan’s Journey

“I’ve got great plans. I’ve been thinking about seeing. There are lots of things to see; unwrapped gifts and free surprises. The world is fairly studded and strewn with pennies cast broadside from a generous hand. But ... who gets excited by a mere penny? If you cultivate a healthy poverty and simplicity, so that finding a penny will literally make your day, then, since the world is in fact planted in pennies, you have with your poverty bought a lifetime of days. It is that simple.”

“Pilgrim at Tinker Creek” – Annie Dillard

Braille books, communication equipment, photographs of friends, family and of Winston, her cocker spaniel and inspiration for her online moniker, “JDMcVootie”... These are just some of the things that filled Jordan Anne Harlow’s upstairs “home area.” Jordan’s lofty niche was carved out of the Harlow home just for her; a place made safe and secure; a place much-loved, where cozy visits with friends and shared laughter was treasured. This part of the Harlow household was imprinted with Jordan’s exuberance for life. Even Shannon, the family dog, would get caught up in it, waiting every morning for Jordan at the bottom of the stairs before the start of her own day. Yes, a much-loved haven perhaps ... but one that Jordan knew would soon bring added limitations to her already impaired independence.

Jordan understood the increasing frailty of her own life and had made it known how important it was for her to be in her own bed, in her own home, when her time came. Jordan’s mother, Annette Harlow, said that Jordan’s sense of timing always seemed to work toward God’s “quality of time.” On October 4, that timing proved impeccable. Only six days after returning from a fragile, yet exquisite visit with a dear friend in Maine, Jordan Anne Harlow, tucked away in her much-loved niche and in her own bed, quietly passed away. For her, the “NF2 Monster” was no more. She was 34.

Neurofibromatosis type 2 (NF2), as formidable as it is, seems to find those it afflicts even more so. Jordan had a very aggressive manifestation of NF2, her own resourcefulness, tenacity and willingness to bend and not break with each new limitation or loss became her most compelling weapons in the NF2 war. When she knew she would lose her hearing, she learned sign language. Later, when she realized that she would also lose her vision, she learned Braille. For the unflappable Jordan, with each new limitation or loss came adjustment and learning new ways to do the same old things.

Jordan would acknowledge that NF2 was a part of her life – that was something she could embrace – but never allowed NF2 to define it. As a matter of fact, she believed NF2 had taught her many things – that were it not for NF2, she would be a different person. In an interview for the Spring NNFF Newsletter* she shared, “The biggest impact NF2 has had on my life is to make my faith stronger, my love and appreciation of my family and friends deeper, and my gratitude for the little blessings more heartfelt.”

Jordan packed many accomplishments into her 34 years. A resident of Lake Charles, Louisiana, most of her life, Jordan graduated from Barbe High School, where she was an officer in the Octagon Club and a member of the National Honor Society, later attending McNeese State University. While at MSU, Jordan earned a B.A. in sociology and an M.A. in psychology, was a member of Phi Mu Sorority and a Panhellenic

officer. She was a graduate assistant in the counseling center, where she worked with those with special needs. The Mayor’s Commission on Disabilities presented Jordan with their 1989 student achievement award. She was on the Board of Directors for the Southwest Louisiana Independence Center and served several years on the Mayor’s Commission on Disability. In 1990 she was selected as the Conference Chairperson for the first annual “We the People Conference,” which was sponsored by the city and provided information to people with special needs and their families. Jordan was also very active at St. Andrew Presbyterian Church, where she periodically taught Sunday school and Vacation Bible School.

Jordan was a gifted writer, contributing articles to several newsletters, including Life After Deafness, The NF2 Review and the Association of Late Deafened Adults. Jordan also worked as contributing editor on a children’s book, “Missy Morgan and the Poke-A-Dot Braille,” now in its third printing.

Jordan also played a substantial role in the establishment of the NF2 Crew, an online support group specifically for folks with NF2. The “Crew” was originally conceived by Jordan and a handful of other NF2ers – Marianne Schneider, Jennette Braaten and Steve Silverman, members of the SayWhatClub, an online support group for deaf and hard of hearing people. When the small group realized they shared the same vision, they began trying to figure out a way to make it happen. Shortly thereafter, in the spring of 1996, the NF2 Crew made its debut in cyberspace, and has quickly grown to well over 100 currently online. Jordan played “ace reporter” for the August ‘96 issue of the NF2 Review, covering this historical moment for online support. The original Crew members likened the name they’d chosen for the group to boating crews that work together for a common cause, supporting each other through the good and the bad. What began initially as an electronic bulletin board on the Internet has become a “place” where all NF2ers, their friends and families, can share experiences and information.

It is a place where Jordan loved to go, meeting old friends and making new ones. It was also a place where Jordan’s mom, Annette, went with heavy heart to notify those friends of Jordan’s passing. To Annette, these were her friends, too, for she had become the link between them and Jordan, working as Jordan’s eyes. In some of her e-mail postings to the NF2 Crew, Annette wrote of that special link, of her relationship with Jordan and of the family’s appreciation of the Crew’s support ...

“When I think about the relationship Jordan and I had, I marvel at how we managed our love, our space, our friendships, our faith. What mother do we know who would be privy to their daughter’s most personal and intimate feelings? As she became blind, she gave me a precious gift when she allowed me to act as the messenger between you and she in your letters and correspondence. I accepted that as the most precious of gifts – for she gave me your thoughts and fears and dreams. Hopefully, I was able to honor you and your love for Jordan each day, each week, each month.

“As Jordan’s death became a reality, your comfort and gentleness grew and kept growing until it became a formidable mountain of love. Your love came in the form of food and cards; journeys from across the country by car and plane; hugs and shoulders to cry on; music and words of praise; plants and flowers; and, finally, your presence on that warm, Sunday afternoon. You gave us a bountiful harvest and we are finding nourishment in its memory.”

“Jordan had such a bright intelligence, which she encircled with wit and tenderness. When she gave me the responsibility of performing her e-mail duties, printing incoming mail and sending her composed letters, she began calling me the “mouse lady.” We laughed at her cleverness! However, it is now time for me to relinquish that title and, as someone said, allow Jordan to now be reached at JDMcVootie@Heaven.com. For we certainly know that she is hearing and seeing and dancing and finding delight in the fact that she overcame that old NF2 “whammy jammy” (SMILE).”

Jordan had suggested that in lieu of flowers, donations might be made to either of the following:

The National Neurofibromatosis Foundation, Inc. (NNFF)
95 Pine Street, 16th Floor
New York, NY 10005

or

The Jordan Anne Harlow Memorial Fund
Endowment for the Assistance of McNeese Students with Disabilities
McNeese Foundation
P.O. Box 91989, MSU
Lake Charles, LA 70609
**NF2 Support ONLINE**

**NF2 Crew**

The NF2 Crew is an online information, support and sharing group for persons with NF2 and their family members and friends. Members discuss treatment options, share experiences and coping skills, jokes and friendships. To join the NF2 Crew, the address is: NF2_Crew-subscribe@yahoogroups.com

**NF2 Crew Website**

www.webcrossings.com/nf2crew

The NF2 Crew Website continues to grow as a resource for the NF2 community. The site is part of the NF Webring, a group of award-winning NF sites, to which you can easily link up with from the Crew site home page.

Currently the website is in sort of a freeze. Webmaster Pete has taken on a new job, as well as adding a personal life in there (is that allowed?), but there are big plans for it in the future. First, I’d like to thank Miller family and Webcrossings.com for continuing to host the site on their web server. We will be moving the site to another server and looking into the possibility of securing our own domain name for the Crew. For the Non-Geeks out there, this means that the website will be accessed by some cool name like: http://www.nf2crew.com. I also plan to update the biographies system to a much smoother system that uses a database to store the page instead of one huge file. This will allow members to edit their own bios directly. Watch the website for things to happen!

Remember – website additions, updates and compliments can be sent to nf2@openvoice.org. Complaints can be sent to billgates@microsoft.com (grin).

Until next time …

Pete, the NF2 Crew Webmaster

**WebSightings**

The Internet has become a storehouse of information for researchers, doctors and other health care professionals, as well as an invaluable resource of personal support for NF2ers, their families and friends. The aim of WebSightings is to offer readers a sample selection of NF2-related websites that offer just such support and information. If you have a favorite website that you would like to see mentioned here, please submit them.

**NF, Inc.**

“Serving NF Families Since 1988”

www.nfinc.org

We are a non-profit organization dedicated to individuals and families affected by neurofibromatosis and related disorders. We serve these needs through coordinated educational and personal support, as well as clinical and research programs. NF, Inc. also promotes national, state and local community involvement. We have a packet of NF2 materials that we distribute upon request, a physician’s referral listing, a video that is open-captioned and conduct meetings with the aid of “Real Time Captioning.” Some of the meeting presentations are also posted on the NF, Inc. Website.

**National Neurofibromatosis Foundation (NNFF)**

www.nf.org

Highlights of the NNFF Website continue to be the NF Chat room, open 24 hours a day, and the NNFF Bulletin Board, which each month features different NF2-related topics. The National Neurofibromatosis Foundation, Inc. (NNFF) is a non-profit medical foundation, dedicated to improving the health and well being of individuals and families affected by the neurofibromatoses (NF1 and NF2). Towards this end, the Foundation sponsors scientific research aimed at finding the cause and cure for both types of neurofibromatosis, NF1 and NF2: promotes the development of clinical activities; develops programs that will increase public awareness of neurofibromatosis and provides support services for patients and families with accurate and comprehensive information about neurofibromatosis, with support group activities and referrals to qualified physicians and healthcare professionals.
Nuestra misión es:

- Mejorar la calidad de vida de los afectados de la NF, ofreciendo:
  - Ayuda y asesoramiento tanto a los afectados como a sus familiares, orientándolos a la rehabilitación física, psicológica y a recuperar la autoestima perdida.
  - Información, por medio de seminarios, cursos conferencias, publicaciones y congresos, del conocimiento que se tenga de la NF y de los avances realizados para su reconocimiento, prevención y tratamiento.
- Y que el colectivo de afectados pueda beneficiarse de los tratamientos médicos más avanzados.

The Acoustic Neuroma Association of Canada (ANAC)

www.anac.ca

The purpose of this website is to increase and expand the accessibility of current and relevant information about acoustic neuroma for patients and their families and for health professionals. You may also E-mail Glyn Smith, National Coordinator, at: anac@compusmart.ab.ca

The Neurofibromatosis Association – U.K.

www.nfa-uk.org.uk

The Neurofibromatosis Association has four main aims:

- To provide information on NF to patients, medical practitioners and others, and to provide support to those affected by NF, and their families, which also includes helping to link them with the medical profession to their mutual benefit. In doing so, we are able to promote awareness and understanding of the problems encountered with the disorder.
- Raising funds to support research into NF.
- Organizing seminars or symposia to study, discuss and disseminate information and research findings on NF.
- Maintaining liaison with like-minded organizations and medical professionals both nationally and internationally.

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surface. Neurosurgeon Dr. William Hitselberger will address this problem by using specific surface landmarks to triangulate the approach for optimum insertion of the penetrating electrode.

The microelectrode array is so miniscule that forceps cannot hold it. This has necessitated the creation of a tool to manipulate the array. Recent tests conducted by Dr. Hitselberger have demonstrated that the tool, resembling a miniature harpoon gun, efficiently injects the electrode array into brain tissue. The first trial use of the new electrode in a patient is expected in the fall. These initial patients will be evaluated and tested by the Auditory Implant and Perception Research Laboratory, under the direction of Dr. Robert Shannon, to determine the benefit of using a penetrating microelectrode.

*Device stimulates the brainstem and benefits patients who would otherwise be totally deaf.

**NF2 causes tumors on both hearing nerves that are surgically severed with tumor removal.

***Electrode implanted in the inner ear artificially stimulates the hearing organ (cochlea) of patients with a profound hearing loss.

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mosaicism. Woods et al. presented a mathematical model for the age at onset of both vestibular schwannomas in NF2. This model includes the underlying mechanisms of NF2: the “two-hit” model and genotype phenotype correlations. The authors compared the predictions of the model with actual data, and the model fit the data very well. Parry et al. presented a longitudinal study on the growth rates of vestibular schwannomas in NF2. They found that younger patients had the highest growth rates. This finding is consistent with a German study by Mautner et al. Pitts et al. presented a poster at ASHG on the first known case of mesothelioma and NF2, which is of interest because NF2 mutations may also play a role in causing mesothelioma.

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TRIPOD Captioned Films

www.tripod.org

The Movie Audience is … Everywhere

TRIPOD Captioned Films (TFC) is a non-profit community outreach of the TRIPOD Model School Program in Burbank, CA. A program for Deaf and Hard-of-Hearing children and their families, TRIPOD has received support from the entertainment industry since its inception in 1982. As a result, TFC has proven to be a natural partner, bringing together the studios, movie theaters and the captioned-filmed audience. Open-captioned films make major motion pictures – top box office hits like TITANIC, MULAN, X-FILES and BATMAN – available quickly (usually within 4 weeks of national release) and on a wide scale. New captioning technology has made viewing open-captioned films more pleasurable, not only for deaf and hard-of-hearing audiences, but their hearing friends and family as well. Be sure to check the website for updates and current confirmations. Showtimes and theater locations can also be obtained from the website by clicking on “links to theaters.”

Bringing it Home ...

If you are interested in seeing open-captioned films in your neighborhood local theater, or if you are a theater owner wishing to bring the open-captioned experience to your community, call (818) 972-2080 for information or fax us at (818) 972-2090. We are available to assist everyone through the entire process, insuring your success.

Reprinted from The Funny Times, 2000
The groundwork is being laid for the 7th annual gathering of the faithful in Las Vegas, Nevada, and the dates are March 15th through the 18th. Group reservations this year are at Harrah’s Hotel and Casino. The Vegas NF2con is purely a social event, which provides opportunities for NF2ers and their companions to meet and share friendships and support. There are no seminars or symposiums scheduled ... you need only to plan on enjoying yourself.

Although Pat Dillon, a.k.a. Mr. Las Vegas, has moved from Vegas to parts unknown (actually we do know where he is... we just don't want him to know we know), he is still coordinating the event and can be reached for details by:

E-mail - pdillon438@aol.com
Snail Mail - Pat Dillon, 401 Agate Drive, Carson City, NV 89706
Phone - 775 - 884 - 4110

Harrah’s Hotel & Casino
Reservations: (voice only) 888-458-8471
NF2 Crew Code: S3NF201
Nights of March 15, 16, 17
Room Rate: $89 (not including tax)

When making reservations, be sure and give the group code. The first night’s stay is required as a deposit. Reservations can be made at the group rate until February 13. After that reservations can still be made based on availability and at the current rate.
Dear Editor ...  

When a copy of your magazine (Late Fall 1999) arrived on my doormat, imagine my surprise when reading page 21 to find myself mentioned there?! Well, not exactly “mentioned” by name you understand, but that I am that ‘profoundly deafened woman with NF2 and a magnetless Clarion Cochlear Implant!’ Spooky, eh?  

So, I thought, after the mother of all coincidences, I’d write and introduce myself to you. I am 47-years-old, married to John and we have two daughters; Laura, 22, and Lucy, almost 20. NF2 was diagnosed in me in 1987 and since that date I have been involved with the UK Neurofibromatosis Association and am currently on their management committee. I am also joint Editor of the UK version of your mag, although I hasten to add that it is nowhere near as brilliant as yours – but we do try. The other main Editor is Jo Castle, The NF Association’s NF2 coordinator, who works tirelessly to increase awareness amongst the medical profession and other health professionals. She’s also a great asset to us NF2ers and we have come to rely upon her a great deal. We are overseen by the NFA and Roberts Tweedy, whom you already know of course.  

Going back to my CI, it is almost 3 years since it was implanted and at my last assessment I scored around 38% hearing without lip-reading. I can lip-read without having to concentrate, but understand only 38% (or thereabouts) of sounds without looking. Unlike a lot of “normal” CI patients, I cannot use the telephone aside from having a ‘yes, yes’ and ‘no’ conversations, which you can imagine is a pretty strange way to converse, but great in an emergency. This has nothing to do with my having NF2, but was due to a problem with ossification of part of the cochlea. Mechanical noise sounds almost the same as I remember it, although birdsong is a whole lot different. The tiniest birds sound terrifying, while some of the larger ones I can hardly hear at all. Must be something to do with pitch, I suppose? I can understand some speech without looking, particularly if I know the subject spoken and the speaker well. I’ve even begun to complain about noise pollution, which is something I thought I’d never do again … so it can’t be bad can it?  

If anyone would like to know more I’d be very pleased to hear from you. My E-mail address is karen@over8.freeserve.co.uk, and I hope to soon be able to join you in the NF2 chat room and add my “two pennyworth,” as we say over here.  

Looking forward to the next issue of the NF2 Review.  

Karen Over, England  

“We believe that in a former life she was an editor.”  

Reprinted from The New Yorker, 1999
When I was a child I developed this awful stutter. It was so frustrating – I would have all these words I wanted to say, but when I tried to corral them and get them to come out of the chute, instead, they would just come pouring out, all willy-nilly, and my Mom wouldn’t know what the heck I was trying to say.

I wonder … is it possible to stutter while typing?

There are so many things I want to say – need to say – but I find myself grappling with getting those words to come out of the chute. How can I possibly hope to corral them together enough to convey my thanks and gratitude to so many people who rallied behind me in my loss; who reached out a steady hand to hold onto through all of this? I’ve tried to deal with everything one-day-at-a-time, and one-day-at-a-time is where many of you came in … with prayers, hugs, e-mails, hand squeezes, phone calls, letters, wet shoulders – oops, sorry … I guess they were dry before I got there. Without all of that support, I could have so easily been overwhelmed. The paralysis of widowhood can make even the simplest task formidable – sometimes I feel more disabled than John ever was – but adjusting to life without John has been a hardship made easier by you.

Many thanks, too, for your encouragement in my endeavors to carry on John’s work with the NF2 Review. It is not easy, but it helps me to hold a part of John in my heart. In my quest to do my best as the ever-reluctant editor, I have been re-visiting past issues of the NF2 Review to get an idea on just how this editing “thing” is done (no, not to plagiarize … okay, maybe a little bit). A painful journey through the pages it has been, but one filled with wonder … victories and losses, hopes and hard life issues; humor and courage; anguished questions and uneasy answers; research breakthroughs and poetry … yes, poetry. Perhaps we can re-print some of the Review’s poetry classics in future issues, eh?

But I know that someday the mantle of editor of this publication will be placed on the shoulders of another. I say this not only because of personal uncertainty, but because I strongly believe that the Review should never lose its uniqueness. When John Petito, as editor-in-chief, tapped out (literally) the first issue of the NF2 Review, he brought a lot of dedication, skills and creativity to the job, yes. He knew the importance of providing up-to-date information about treatments and research. He recognized the importance of offering personal support and the value of shared experiences.

But he also brought something more … a perspective that only someone who lived with NF2 could communicate. And that is a uniqueness I am not sure I can uphold. Dare I try?

Well, I hope that I’ve been able to express my thanks and appreciation to you without getting too “willy-nilly” (smile).

Take care and God bless,

Mrs. Gail Petito
ARTICLES ABOUT NEUROFIBROMATOSIS TYPE 2
Compiled by Michael Baser, Ph.D.

The following articles have been published since the last scientific literature review appeared in the NF2 Review. You can access the summaries of these articles (the “abstracts”) through the internet, via the National Library of Medicine’s Medline literature searching service (http://igm.nlm.nih.gov/). Click on MEDLINE; type in the subjects of “neurofibromatosis 2” or “nf2” (or any other topic that you are interested in), then click on the “perform search” button.

American Journal of Human Genetics 2000;66:87391
Functional analysis of the neurofibromatosis type 2 protein by means of disease-causing point mutations.
Authors: Stokowski RP and Cox DR
These authors found that cells with mutant NF2 protein had altered cell adhesion, causing cells to detach from the substratum, and that different mutations in the protein increased the detergent solubility of the protein, which indicates a decreased ability to interact with the cytoskeleton. Some NF2 point mutations had cellular phenotypes that resembled gain-of-function, in contrast to the loss-of-function phenotype that has been assumed for all NF2 mutations.

Neurobiology of Disease 2000;7:483-91
Enhanced proliferation and potassium conductance of Schwann cells isolated from NF2 schwannomas can be reduced by quinidine.
Authors: Rosenbaum C, et al.
In a cell culture system, NF2 Schwann cells had enhanced proliferation and larger outward potassium current than normal Schwann cells. The potassium blocker quindine blocked the proliferation of NF2 Schwann cells, but not normal Schwann cells, in a dose-dependent manner. The authors suggest that quinidine or quinidine-like agents should be further explored as adjuvant therapeutic agents in NF2.

Genes and Development 2000;14:1617-30
Conditional biallelic NF2 mutation in the mouse promotes manifestations of human neurofibromatosis type 2.
Authors: Giovannini M, et al.
These authors have developed an important mouse model for NF2 through use of genetic techniques. The mice develop schwannomas, Schwann cell hyperplasia, cataracts, and osseous metaplasia (the last is not found in human NF2). This represents an improvement over a previous model that the authors developed, and provides a vehicle for exploring the mechanisms of NF2.

Journal of Neuroscience Research 1999;58:706-16
Neurofibromatosis 2 tumor suppressor protein, merlin, forms two functionally important intramolecular associations.
Authors: Gutmann DH, et al.
This group is attempting to develop a molecular model for NF2. In this study, they further characterized the intramolecular folding of the NF2 protein, merlin. They found that merlin forms two intramolecular associations between areas in different regions of the molecule. They also found that certain NF2 mutations greatly reduce the ability of the molecule to form these associations. Based on these findings, they propose a model for merlin folding that is essential to its function.

Neurology 2000;11:71-6
Population-based analysis of sporadic and type 2 neurofibromatosis-associated meningiomas and schwannomas.
Authors: Antinheimo J, et al.
Because NF2 is so rare, to date the only population-based data on the epidemiology of NF2 have been that of Gareth Evans and colleagues in the UK. These authors have added to the epidemiology of NF2 by carrying out a population-based survey in Finland. They found that 3% of patients with multiple schwannomas had NF2, and 2% had schwannomatosis without NF2. In addition, 1% of patients with meningioma had NF2, and 4% had meningiomatosis without NF2.

Additional Scientific Journal Articles

Human Molecular Genetics 2000;9:1567-74
The neurofibromatosis 2 tumor suppressor protein interacts with hepatocyte growth factor-regulated tyrosine kinase substrate.
Authors: Scoles DR, et al.

Cancer Genetics and Cytogenetics 2000;118:167-8
Neurofibromatosis 2 phenotypes and germ-line NF2 mutations determined by an RNA mismatch method and loss of heterozygosity analysis in NF2 schwannomas.
Authors: Hung G, et al.

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Human Molecular Genetics 2000;9:1495-500
Loss of DAL-1, a protein 4.1-related tumor suppressor, is an important early event in the pathogenesis of meningiomas.
Authors: Gutmann DH, et al.

Journal of Medical Genetics 2000;37:542-3
Clinical and molecular correlates of somatic mosaicism in neurofibromatosis 2.
Authors: Baser ME, et al.

Journal of Neurology, Neurosurgery and Psychiatry 2000;257-61
Focal amyotropy in neurofibromatosis 2.
Authors: Trivedi R, et al.

Intracranial sarcoma in a patient with neurofibromatosis type 2 treated with gamma knife radiosurgery for vestibular schwannoma.
Authors: Thomsen J, et al.

Neurology 2000;54:1132-8
Mild familial neurofibromatosis 2 associates with expression of merlin with altered COOH-terminus.
Authors: Sainio M, et al.

Journal of Neuropathology and Experimental Neurology 2000;59:504-12
Allelic losses in neurofibromatosis 2-associated meningiomas.
Authors: Lamszus K, et al.

Journal of Investigative Dermatology 2000;114:1017-21
Mutations and allelic loss of the NF2 gene in neurofibromatosis 2-associated skin tumors.
Authors: Kluiwe L, et al.

Genomics 2000;65:62-6
Molecular characterization of germline NF2 gene rearrangements.
Authors: Legiox P, et al.

Human Mutation 2000;15:474-8
Detection of novel NF2 mutations by an RNA mismatch cleavage method.
Authors: Faudoa R, et al.

Development 2000;127:1315-24
The neurofibromatosis-2 homologue, Merlin, and the tumor suppressor expanded function together in Drosophila to regulate cell proliferation and differentiation.
Authors: McCartney BM, et al.

American Journal of Human Genetics 1999;64:1230-3
Germ-line NF2 mutations and disease severity in neurofibromatosis type 2 patients with retinal abnormalities.
Authors: Baser ME, et al.

British Journal of Cancer 2000;82:998
Neurofibromatosis 2, radiosurgery and malignant nervous system tumors.
Authors: Baser ME, et al.

Neurogenetics 1999;2:101-8
Allelic expression of the NF2 gene in neurofibromatosis 2 and schwannomatosis.
Authors: Jacoby LB, et al.

Molecular and Cellular Biology 2000;20:1699-712
Cloning and characterization of SCHIP-1, a novel protein interaction specifically with spliced isoforms and naturally occurring mutant NF2 protein.
Authors: Goutebroze L, et al.

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**Journal Articles from page 19**

**Journal of Medical Genetics 2000;37:75-7**

**NF2 gene deletion in a family with a mild phenotype.**

**Authors:** Lopez-Correa C, et al.

**Archives of Disease in Childhood 1999;81:496-9**

**Paediatric presentation of type 2 neurofibromatosis.**

**Authors:** Evans DG, et al.

**Archives of Ophthalmology 1999;117:1650-3**

**Visual loss secondary to increased intracranial pressure in neurofibromatosis type 2.**

**Authors:** Thomas DA, et al.

**Journal of Histochemistry and Cytochemistry 1999;47:1471-80**

**Expression of the neurofibromatosis type 2 gene in human tissues.**

**Authors:** den Bakker MA, et al.

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Some articles may be available to readers upon request. Please mail or FAX all requests to:

**The NF2 Review**

c/o The House Ear Institute

2100 West Third Street, 2nd Floor

Attn. Steve Meza

Los Angeles, Ca. 90057  FAX (213) 413-0950

(Allow 2 months for delivery)

A Large Print Edition, text only, is also available upon request.

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For those who wish to, donations in memory of NF2 Review Founder, John Petito, may be made to the following Funds:

The John Petito Memorial Fund at the House Ear Institute supports genetic research conducted by Gene Hung, M.D., and the ongoing publication of The NF2 Review. Contributions may be sent to:

**The John Petito Memorial Fund**

c/o House Ear Institute

2100 West Third Street

Los Angeles, California 90057

Donations can also be made to the John Petito Memorial Travel Fund at NF, Inc., where donations will allow people with NF2 to attend NF2 gatherings. Contributions may be sent to:

**John Petito Memorial Travel Fund**

c/o Neurofibromatosis, Inc.

8855 Annapolis Road #110

Lanham, Maryland 20706-2924

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We'd like to know what you think. Let us know what topics you'd like to see discussed or tell us what you think of something that has appeared.

The NF2 Review is printed three times a year: Spring, Summer and Winter.

If you would like to contribute ideas, items or a letter, here's how to contact us:

**The NF2 Review**

c/o The House Ear Institute

2100 West Third Street

Second Floor

Los Angeles, CA 90057

(213) 483-4431 Voice

(213) 484-2642 TDD

(213) 413-0950 FAX

We welcome all opinions, suggestions and comments. If you write to The NF2 Review, please indicate if you do not want your letter published.

The opinions expressed in The NF2 Review do not necessarily reflect the opinions of the Editor, or the House Ear Institute, and belong entirely to the individual(s) credited.

Disclaimer:
The NF2 Review is a review of resources for living with Neurofibromatosis-Type 2 (NF2), and does not constitute medical advice. Informed doctors must be consulted for the diagnosis, management and treatment of Neurofibromatosis-Type 2.