

Newsletter,

Volume 20, No. 1; Fall, 1998

Contents:

1. Army Grant Makes Possible First Natural History Studies in NF1 & NF2
2. Brazilian NF Center Gears Up
3. Young People Give 2nd NNFF Summer Camp A Four Star Rating
4. Putting Neurofibromatosis and Pregnancy In Perspective
5. Join Our Celebration!
6. Chapter News: Waging The Fight Against NF
7. Rounds Of Golf Around The U.S.
8. Investing In NF: Creating A Legacy
9. Kids' Council Corner
10. Northern Plains Becomes 31st NNFF Chapter
11. NF2 News In Brief: Notes From The NF2 Lab
12. NF Profile: John Hugg, Jr. Teenager Makes A Splash As A Lifeguard
13. In Memoriam
14. Your Turn -- Perspectives, Questions and Comments from Patients and Families
15. Pen Pals

Army Grant Makes Possible First Natural History Studies in NF1 & NF2

Neurofibromatosis Type 1

A \$ 3.6 million grant from the United States Army will fund the first natural history study in neurofibromatosis type 1. The natural history study will measure the growth rates of neurofibromas in 300 people with NF, in order to determine the normal growth rates for neurofibromas. It will be coordinated by Dr. Bruce Korf, Harvard Medical School/Children's Hospital Boston.

"This information is crucial since it is particularly difficult to prove the efficacy of any medication for the treatment of neurofibromas given their seemingly unpredictable growth rates," Dr. Korf said. "Once we have these measurements, we can more easily determine if a medication has an effect."

The natural history study will be conducted over a four-year period at eight centers in the U.S., as well as in sites in Europe, Australia and South America. "We have recruited the clinicians from around the world that have the most experience with NF and have access to the largest patient population," Dr. Korf noted.

Dr. Korf anticipates that the first patient will be enrolled in the study by Spring 1999. Patients that participate will have their neurofibromas measured on a periodic basis. However, Dr. Korf emphasized that no treatments will be given during the natural history study.

"We encourage people who are interested in participating in the natural history study to speak with their physician," Dr. Korf said. "While we will not be testing any medications, the contribution each patient makes to the study lays essential groundwork for future clinical trials. And that is vital to the advancement of NF research to find effective treatments."

Neurofibromatosis Type 2

William Slattery, MD, director for clinical studies at The House Ear Institute in Los Angeles, will direct the natural history studies in NF2. The study will focus on patients who have been diagnosed with NF2 within the past two years.

According to Dr. Slattery, the goal of the natural history studies in NF2 is twofold:

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

"The study is significant as the results will give patients and their physicians better information that can be used to decide how and when to treat this type of tumor," Dr. Slattery said.

The three-year study will be conducted at three centers in the United States, as well as centers in Hamburg, Germany and Manchester, England. Dr. Slattery noted that, while no new treatments will be part of the NF2 natural history studies, patients may continue their current treatment during the study.

The first NF2 patients will be enrolled in the natural history studies later this fall.

Patients interested in participating should contact Gloria Yoon, a research assistant at The House Ear Institute by phone at 213-483-4431 or by e-mail at

gyoon@mailhouse.hei.org

Brazilian NF Center Gears Up

A brand new Brazilian NF Center under the direction of Dr. Mauro Geller, a highly respected Brazilian epidemiologist, is off to an impressive, running start. Dr. Geller also serves on the Board of Directors of INFA, the International Neurofibromatosis Association (Luxembourg).

The Rio de Janeiro-based center has a number of ambitious components. It includes a new NF Clinic headed by Dr. Ana Luiza Cotta de Alencar Araripe and three Resident assistants. Shortly after opening its doors, the demand for the clinic was such that visiting hours already had to be doubled.

In addition, the Brazilian center is a Natural History Study Site (see page 1 for related story) which will be part of the U.S. Army-funded study of plexiform neurofibromas in NF1, headed by Dr. Bruce Korf in Boston. The Brazilian Center also has a Clinical Trials Site which will test various medications and chemical compounds as potential treatments for both NF1 and NF2.

The NF Center is a contributing site for the NFFF International NF Database, a collaborative system for collecting important data on patients and families with NF. The database's key patient questionnaire has been translated into Portuguese, and a number of medical students have been recruited to fill out the questionnaire and transmit the data to the Database coordinator, Dr. Jan Friedman in Canada.

Finally, the Brazilian Center includes a new lay organization under the leadership of Ms. Elane Frossard Barbosa in Rio de Janeiro.

The doctors are already making a contribution to educating their Brazilian peers. They have submitted several NF articles to Brazilian medical journals targeting different medical specialties. The articles are designed to improve patient care by familiarizing physicians with the diagnosis and management of NF1 and NF2, and to highlight the expertise of the Brazilian NF Center. Four of the articles have already been accepted for publication.

"This has to be one of the most impressive starts of any NF program in the world", INFA Chairman Peter Bellermann said at the center's grand opening. "We all congratulate Drs. Geller and Araripe, as well as Ms. Frossard Barbosa on their extraordinary efforts. What is especially noteworthy is that this center meets the full spectrum of needs for Brazilians with NF, their families, and medical professionals. At the same time this new center is poised to make major contributions to scientific and clinical studies worldwide."

Young People Give 2nd NNFF Summer Camp A Four Star Rating

If campers at the 1988 NNFF International Summer Camp were reviewers for a glossy travel magazine, their rave reviews of the experience would garner the camp a four star rating.

The camp, which was attended by young people with NF1 and NF2 from throughout the United States and European countries, was a whirlwind 11-day series of events in Utah. And the young travelers were eager to share their thoughts about the experience at a farewell party the last night.

A 14 year-old boy from Kansas noted, "This was my second year. It was the greatest experience in my life." And, a 16 year-old girl Californian enthusiastically revealed, "This was the best week of my life. I do not want to leave."

While all agreed the trip was fun, many brought home renewed self-esteem, along with their souvenirs. This sentiment was best expressed by a 12 year-old California camper who said, "If I could, I would rewind these eleven days over and over. You have made me feel like I am somebody."

The impact of the camp was summarized by the mother of a 17 year old Illinois camper. She wrote, "Through your combined efforts and sensitivity to the needs of the population, a wonderful experience resulted for our son...he is (now) better able to understand and accept his condition...For a young man struggling to find his identity, self-worth and motivation to succeed despite obstacles, this adventure in Utah was both timely as well as instrumental in bringing some priorities into focus."

So what did the campers do that brought such praise? Along with the chance to befriend peers with NF, their adventure combined three major programs: a week at Camp Kostopulos, a three day trip down the Colorado River, and medical information/science sessions.

Their stay at Camp Kostopulos, located on a spectacular site inside Utah's Emigration Canyon, featured swimming, horseback riding, fishing, hiking, dancing, a night around the campfire and under the stars, arts & crafts, and group skits. In addition campers enjoyed an outing to a AAA Utah Buzz baseball game, a trip up 11,000 foot high Snowbird Mt., and a visit to the zoo.

Another highlight was the three-day trip down the Colorado River near Moab in southern Utah. Even with temperatures peaking at 103oF, campers stayed cool on the river with water fights, which were encouraged as an effective way of combating the heat. A side trip to see the impressive natural wonders in Arches National Park also ranked high on everyone's list.

A special feature of the NNFF Camp was that each Camper has two counselors. One was always a young adult, 18 to 25 years old, who also had NF and was thus particularly sensitive to the younger one's needs and abilities. The arrangement also gave the young adult with NF invaluable leadership experience.

Perhaps the most unique feature of the NNFF camp was the opportunity to learn more about the concepts of genetics and NF. During the new hands-on lab experience, the young people worked with scientists to each extract DNA from peas

and onions, looked at DNA samples under the microscope, and studied Zebra fish to better understand the role of animal models in the development of treatments for genetic problems. The science session attracted front page news coverage in two Salt Lake City dailies. The campers in the lab were also stars on two TV stations in Salt Lake City, which featured the science sessions on their evening news broadcasts.

The campers impressed the scientists with the depth and variety of questions they raised during two lecture sessions with Dr. David Viskochil, a world-class scientist and leading NF specialist from the University of Utah.

Parting was hard, and many tears were shed at the airport, but "Camp Mother" Jackie Medina assured everyone, "Wait `til next year. It'll be even better. We are going to add a visit to Arizona's Grand Canyon to the program. So, we hope to see you all again."

Putting Neurofibromatosis and Pregnancy In Perspective

One of the most common questions women with NF ask their doctors is if becoming pregnant will affect the course of their disorder, and if having NF increases the risk of complications associated with pregnancy. Two physicians from the University of Colorado Health Sciences Center/Children's Hospital bring these issues into perspective with their article, "Neurofibromatosis Type 1 and Pregnancy", in the American Journal of Medical Genetics.

Dr. Lorraine Dugoff of the Department of Obstetrics and Gynecology and Dr. Eva Sujansky in the Department of Pediatrics suspected that existing medical data on NF1 and pregnancy did not accurately reflect the NF1 population at large. They were concerned that the literature mainly documented women who sought medical attention because of the complications they experienced.

The researchers, therefore, mailed a questionnaire to women with NF1 who had at least one pregnancy. The 105 women who returned the completed questionnaire were from 30 different states. The medical records of the women who completed the questionnaire were reviewed to verify the women's recollections of the pregnancy complications and outcomes. However, the patients' reports of new or increased neurofibroma growth were not part of the medical records provided by the physicians.

The authors reported the following conclusions:

- The study did not show the previously reported increased incidence of preeclampsia, pre-term delivery, intrauterine growth restriction, pregnancy-induced high blood pressure, stillbirth, miscarriage, or perinatal mortality
- The 105 women had a total of 247 pregnancies that resulted in 182 live births, 44 miscarriages, 21 elective terminations, and 2 ectopic pregnancies
- The rate of cesarean section was approximately 15% higher than in the general population
- Sixty percent of the women reported growth of new fibromas during pregnancy
- Fifty-two percent reported enlargement of existing neurofibromas

"In general, our study indicates that relatively common pregnancy complications are not more frequent among women with NF1 than in the general population," Dr. Dugoff notes. "However, there may be a small group of women with NF1 that are at

increased risk because of manifestations of NF that affect their reproductive health. These woman may require close monitoring at a high-risk obstetric center."

Join Our Celebration!

The National Neurofibromatosis Foundation cordially invites you to join our 20th Anniversary celebration. It will be the icing on our cake to receive an Anniversary message from you. Your Anniversary messages will be published on the Neurofibromatosis Web Site (www.nf.org) throughout 1998 and may be used in other NNFF materials. Following are some messages we have already received: (Please send your Anniversary messages via email: nnff@aol.com or by mail to Suzanne Cohen c/o NNFF, 95 Pine St, 16th Fl., NY, NY 10005)

- Dear NNFF: Congratulations on your 20th Anniversary. We've watched the Foundation grow over the years and are proud to be a part of the Race To Find A Cure. Let's cross the finish line SOON! -- Steve and Elka Sandler, CT
- The Ohio Chapter extends congratulations to its Foundation for 20 years of extraordinary growth. May the 21st Century bring to us an answer to our quest for a treatment. -- Dolores Goldfinger
- Greeting from Australia! Congratulations! You are doing millions of people around the world a big favor and hopefully one day your years of support and hard work will change these people affected with NF forever. My sister included! -- Debbie
- Felicitaciones ensu 20 aniversario..Deseo que todos sus proyectos y esfuerzos en la lucha contra esta enfermedad, sigan dando frutos. Exitos! -- Adriana Cuellar de los Rios, Colombia
- Congratulations on your excellent work with NF research. Best of luck with future projects. -- Lana Paton
- My sincere gratitude to NNFF for being there for my patients, myself and my family. Appreciate all your good work and look forward to another 20 years of great accomplishments. -- Dr. Priscilla Short, American Medical Association & University of Chicago
- I'm a 25-year-old woman with NF. I never knew there was anything out there for people with NF. I was always told there's nothing you can do. Well, that's a lie. Because of your milestones, we have NF, but it doesn't have us. -- Rae Walker
- Congratulations on your great site. More power more success and more service to humanity. -- OMFS staff, St. Martin de Porres Charity Hospital, Manila, Philippines
- Congratulations, you do a wonderful job of informing the uninformed. -- Carol Stowell
- Congratulations on 20 years of providing support and information to families. Keep it up! -- Karen Potter, MS and Stephen Braddock, MD, University of Missouri
- I have a nine-month-old daughter who has been clinically diagnosed with probable NF1. What a blessing to have found your web site! MY husband and I had never heard of NF and are grateful for the wealth of knowledge, given in lay terms, we found there. Best wishes for another twenty successful years, and thank you! -- Michele Carney

CHAPTER NEWS:

WAGing The Fight Against NF

There are many ways to raise funds for NF research programs and promote awareness of neurofibromatosis within your community. Recently several state chapters and individual members of the Foundation organized activities that are excellent examples of activities to support the fight against NF.

Involve Community Leaders: Mayor Joins Chapter Board

The Board Members of the NNFF Missouri Chapter voted The Honorable Clarence Harmon, Mayor of St. Louis, to join their Board of Directors, thus giving the Chapter a greater presence within the community. The Missouri Chapter's efforts highlight the importance of encouraging public officials to get actively involved at the Chapter level.

Capitalize on Popular Local Events: Crab Cioppino Dinner

A Crab Cioppino Dinner and Auction attracted 600 happy diners in Gilroy, CA , which is known as the "garlic capital of the world", earlier this summer. Crab Cioppino dinners are popular among the area's large Portuguese community. So, Jody Rocha, her family and friends created this special event, now in its sixth year, to benefit NF.

Live Radio Broadcast

Every summer, 99 Rock WPLR, a top Connecticut radio station, selects a local charity to be highlighted during its annual on-air promotion , WPLR Buried At The Beach. For one week this summer, the Connecticut NNFF Chapter was highlighted. President Steve Sandler was interviewed, informational materials were distributed and canisters for donations were circulated on the beach. The chapter was given great exposure, not just in Connecticut, but around the world, since the event was also simulcast on the Internet.

Turn Fun Into A Fundraiser: In-Line Skating

Combining his love of roller skating with his desire to further NF research, Roger Piacentini of Plainview, NY, laced up his in-line skates and hit Long Island's roadways in early September. His 100-mile fund raising trip was in honor of his 5-year-old son, Anthony, who was recently diagnosed with NF. His trip was underwritten by his employer, AOE Ricoh.

Race For A Cure

Anita Carter, President of the Illinois Chapter, took her love of running races and organized a 10 Mile Walk/Run. The 2nd Annual "Race for Research", was held in the scenic forest preserve of Busse Woods in Elk Grove, IL.

Educate The Public: North Carolina County Fair

Theresa Helton of Granite Falls, NC and Mae Combs of Hudson, NC took their NF public awareness crusade to a local County Fair to distribute literature on NF. They set up a booth and circulated through the crowds handing out materials. They encountered several new families affected by NF and persuaded thousands to learn more about it.

Use A Special Occasion To Raise Funds: 45th Wedding Anniversary

Family and friends of Rita and Bill Needel of Quincy, MA gathered to celebrate the couple's 45th Wedding Anniversary in August. In lieu of gifts, the Needel's sons Scott and Jay, who planned the surprise fete, requested that donations be made to the NNFF for NF2 research.

ROUNDS OF GOLF AROUND THE U.S.

Golf tournaments continue to be a popular means to raise funds for research programs and create public awareness of neurofibromatosis. Numerous tournaments were held during the summer and early fall across the country:

The "**Friends of NF Celebrity Golf Classic with Mark Chmura**" was held in September. Eight years ago, Joe Byrka of South Windsor, CT joined forces with the Green Bay Packer All-Pro Tight End, Chmura, to create an event that has raised record funds for NF research. This year's tournament was no exception with an impressive number of sponsors including Prudential Relocation, Prudential Real Estate, New England Golf Supply, Robert T. Samuels and Assoc., Foxwoods Resort and Casino, Siracusa Moving and Storage, Tom and Bette Wolff, New England Bank, Delta and American Airlines, United Technologies, Sikorsky Aircraft and The John Joseph Group. Thirty six celebrities from NFL, NBA, NHL and NCAA teams and television participated. Among those were John Davidson, *NY Rangers*, Ty Detmer, *SF 49ers*, Ron Springs, *Dallas Cowboys*, Derek Sanderson, *Boston Bruins* and actor Tom Wopat, *Dukes of Hazard*.

In its fifth year, the **Florida Chapter's Charity Golf Scramble** attracted 120 players at the Rio Pinar Country Club. The day of golf, great food and a silent auction was the "best ever" according to Alice Weir, the tournament organizer.

The **Massachusetts Chapter** held its annual golf outing at the Belmont Country Club with a record 152 golfers turning out for a beautiful day of golf followed by a dinner and auction. The highlight of this year's auction was a chance to win a Plymouth Prowler sportscar or \$50,000 in cash.

The **Missouri Chapter's 8th Annual NF Celebrity Golf Classic** was held at the Fox Run Golf Club in Eureka this fall. The Gateway PGA designated it a tourney for their pros, enabling one pro to play with each of the 35 foursomes, making for a very exciting round of golf.

The First Annual Jerry Shannon Memorial Golf Tournament Benefiting NF was held in upstate New York on May 30th. The event, which encompassed a great day of golf, a live and silent auction and great raffle prizes, was conceived and organized by Colleen Lacy of Webster, NY in memory of her father. It also represented a major stride for NF awareness in the Rochester metro area.

Muttontown Country Club on New York's Long Island, was the site of the **Fifth Annual NNFF Golf Classic**. Donaldson, Lufkin & Jenrette was a major sponsor this year, thanks in large part to the hard work of Committee Chair, Brian Behrens. Other corporate sponsors included Fish & Neave, Steve Hornstein & Family, ABM Co. New York, Access Direct Systems, Ambassador Construction Co., Chapdelaine & Co., Meriden Capital Partners, RJR Nabisco, Waldon Press and Spirit Airlines.

Myrtle Beach, SC was the site of the "**Official All Star Café Golf Tournament and Charity Auction**", combination golf tournament and sports auction. The event which was hosted by NNFF celebrity spokesman Mark Chmura, a member of the Super Bowl XXXI Champion Green Bay Packers. The activities marked the inauguration of the NNFF South Carolina Chapter.

Matt Sampsell, weekend sports anchor/reporter for The Ten O'Clock News on UPN 11 served as celebrity chair of the **3rd Annual NF Golf Classic** at the Federal Way's Twin Lakes Golf & Country Club in September. Not only was the event a great fundraiser, but thanks to Matt, it also served to raise public awareness via a segment about NF which was broadcast on the local TV evening news and a radio interview.

INVESTING IN NF: CREATING A LEGACY

Part of you can live longer with a bequest to the NNFF. A legacy to the Foundation is a wonderful way for you to assure that the things you stand for and the ideals you hold high will continue. There is also an incentive. An anonymous donor has pledged \$500 to the Foundation every time someone notifies NNFF that the Foundation has been named a beneficiary in a will, a trust, or any other long-term bequest. For more information contact the Development Office, 800-323-7938 ext.31.

Kids' Council Corner

If you know a child with NF between the ages of 6 and 17 years, the Kids' Council is the perfect way for him or her to make a new friend with NF. The Kids' Council is a program run by and for young people with NF. This kids-only haven offers children a way to connect with their peers to receive emotional support; educate others about NF; and contribute their energy, talent and distinct voices to the work of NNFF. The Kids' Council has more than 100 members that hail from several countries, including the United States, Israel, and Australia. The impact of the group has been tremendous. A counselor wrote that "the simple act of filling out the (Kids' Council Membership) form helped our client immensely. He left here on a real high and with great anticipation".

The most visible Kids' Council activities to date have been the recent art contest and the group's colorful newsletter. New activities are planned as the group grows and ideas for new projects are always welcomed.

For more Kids' Council information or for a membership form, please contact the NNFF at 800/323-7938 or at NNFF@aol.com.

Northern Plains Becomes 31st NNFF Chapter

The National Neurofibromatosis Foundation is pleased to announce the inauguration of its 31st Chapter, the Northern Plains Chapter which encompasses North Dakota, South Dakota and Nebraska. Bobbie Milton and Earl Colgan of Sioux Falls, SD are the new Chapter's co-presidents. Bobbie has targeted her primary goal as Chapter leader "to increase public awareness of NF in the region and give support to patients and their families". As a result, she and Earl have already distributed information packets to all family physicians in the Sioux Falls area and have packets ready to go to all public schools. The first steering committee meeting was held in late October, where a Board of Directors was elected and plans were made for additional public awareness campaigns, as well as fundraising activities.

NF2 News In Brief:

NOTES FROM THE NF2 LAB

By: Mia MacCollin, MD
Assistant in Neurology
Massachusetts General Hospital

The past year has been an exciting one for NF2 research! As a result of U.S. Army funding, an international collaboration has been formed to study the effect of NF2 gene mutation on the resulting problems that NF2 patients develop. With the help of a number of patients with NF2, a comprehensive NF2 database that incorporates everything from surgical outcomes to hormonal exposure was developed over the summer, and all centers are actively entering patients into it. My laboratory continues to search for new and better ways to find mutations in mildly affected NF2 patients, and we will be presenting preliminary results on some of these techniques at the American College of Human Genetics meetings in October in Denver.

I continue to be fascinated by the many people who "don't quite" have NF2. We have found that many of these folks are "mosaics" -- that is some of their genetic material contains NF2 mutation, but other parts do not. This state of mosaicism often protects them from getting bilateral vestibular schwannomas, but they do get a multitude of other NF2-related tumors. Detecting this state is often a painstaking process, but because of our own results, and similar work done by Lan Kluwe and Victor Mautner in Germany and Gareth Evans in England, we are coming to the realization that persons wanting mutation analysis of NF2 should try to get this done on their tumor tissue not blood.

Being a pediatric neurologist, I continue to be dismayed by how many children with NF2 are being mismanaged and misdiagnosed by health care providers. Victor Mautner and I will be publishing a paper this winter aimed at child neurologists, and presenting our own experience with many NF2 affected kids at the Child Neurology Society in Montreal this fall.

In addition to our work on NF2 and mosaicism, my lab received funding from the NIH this spring to formally begin a schwannomatosis research project. We are beginning to recruit schwannomatosis families willing to come into the NF clinic to be studied, and are actively searching patients' tumors and blood samples for disease causing mutation. Stayed tuned, because I am sure there will be much more to say on this topic in future issues.

And now to you, dear reader--are you an NF2 or schwannomatosis patient with upcoming surgery? Or are you one of those patients that "no one can figure out?" Give us a call, we would love to hear from you and if you are willing to donate that tissue after surgery, I have a spot in my freezer for it! You can reach me at: tel: 617-726-5736, fax: 617-726-5736 or email: macolli@helix.mgh.harvard.edu

NF Profile: John Hugg, Jr.

Teenager Makes A Splash As A Lifeguard

Thousand of teenagers dream of a summer job as a lifeguard. But preparing to become a lifeguard requires much more than faithful viewing of Baywatch, an understanding of suntan lotion SPF levels and mastering the whistle twirl.

In fact, the Red Cross lifeguard certification course includes 33 hours of physically demanding training. Just the thought of this rigorous training would be daunting to most, but 16-year-old John Hugg, Jr. of Yonkers, N.Y. was determined to follow in the footsteps of his older sister, Jaclyn, who holds a lifeguard certification.

John's training, however, included a hurdle with which neither his sister nor his peers had to contend. John had to pass all the physical tests without the benefit of his right leg, which was amputated four inches below the knee due to complications of neurofibromatosis.

John triumphed and today is perhaps the only person with one leg in the United States to hold Red Cross certification as a lifeguard.

John's accomplishment is due, in part, to the enlightened staff at the Yonkers YMCA. John's mother, Pat, sat down with the YMCA's Executive Director, Greg du Sablon, to explain the situation and fully expected that the Director would discourage them from pursuing John's dream. Instead, he invited John down to take a crack at the training. "In my 35 years as an instructor, I never met someone with such determination to reach his goals to be a lifeguard. I wanted to make sure I did everything in my power to help John reach this goal", du Sablon said.

To pass the certification test, John had to master a variety of skills including cardiopulmonary resuscitation and deep water diving. But the greatest challenge was the two-minute, legs only water-treading test, a task that seemed nearly impossible using only one leg.

While John wears a prosthesis on his right leg, he does not wear it for swimming. So, he spent hours in the pool, arms crossed over his chest as required by the test, practicing kicking his left leg in a circular motion to stay afloat.

The certification and John's summer job as a lifeguard at a local apartment complex are a remarkable end to a sometimes difficult road with NF. John was diagnosed with NF when he was 10 months old, and, later, problems with his right leg required several surgeries.

"Throughout his childhood, John had undergone numerous surgeries on his leg and at the age of 14, his doctors recommended amputation to improve the quality of his life", Pat said. "Knowing this was the best option, we went ahead with the surgery. John recovered quickly and was back in school in a few weeks with a temporary prosthesis."

John's achievement has earned him coverage in two Westchester County newspapers, and he was the subject of a late summer news story on New York City's WPIX-TV (Warner Brothers). While John was not called upon to save anyone during his summer job, the pool patrons assured the WPIX reporter that they were completely confident in John's ability to do so.

This fall John hopes to move his trusty watch to an indoor pool. With John on duty you can bet the water, and the swimmers, will be just fine.

In Memoriam:

Mary E. Heroux

Founder of the NNFF Rhode Island Chapter

The National Neurofibromatosis Foundation mourns the recent passing of Mary E. Heroux of Cranston, Rhode Island. In November 1986, Mary Heroux wrote an article in the Providence-Journal Bulletin inquiring about interest in an NF support group. She had already enlisted the help of her two State legislators, Representative Jerome P. Egan and Senator John F. Reed. About twenty people responded to her newspaper article and the first Rhode Island support group meeting was held that year. Early in 1987 the Chapter was officially formed and in the eleven years following, Mary's dedication to the fight against NF never waned. Her presence will be greatly missed.

YOUR TURN

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

My 3 year old daughter was diagnosed with NF1 at the age of 9 months. I was wondering what the fibromas look like when they appear. - R. O'Dell, Boardman, OH. *Neurofibromas can occur along nerves anywhere in the body and can occur at any time in life. The most common place to first notice them is on the skin. Initially they are small bumps, which may resemble mosquito bites and itch; but they do not go away. They are soft and fleshy to the touch and often the overlying skin has a pink or purple hue. Most people with NF1 will eventually get at least a few skin neurofibromas, but it is impossible to predict how many an individual will get.*

I am looking for resources that I can share with my children's school about learning disabilities and NF. - S.Long, Houston, TX

The NNFF has 2 publications which discuss learning disabilities in children with NF. "Achieving In Spite Of...A Booklet on Learning Disabilities" is a 32-page booklet offering a practical, how-to approach to a variety of learning disabilities, making it a perfect guide for parents, educators or any professional who wants to help children with LD achieve their potential. "NF1: A Guide For Educators" is a 12-page brochure designed to help educators learn more about NF1 and how it may affect students in the classroom. To obtain these publications, please send a \$1 per booklet (to cover shipping & handling) to: NNFF 95 Pine St; 16th Fl., NY, NY 10005.

My 2 year old daughter just had an MRI and her doctor is concerned about her growth rate. I understand growth problems can happen in NF. What is this due to? - L.C., Lexington, KY

Growth is a complex process that depends on a number of factors: genetic makeup, nutrition and hormonal growth factors. One of these growth factors is growth hormone (GH), without which individuals remain short in stature, but retain normal proportions. Children with NF may have short stature for other reasons. X-rays may reveal evidence of an independent growth problem in the long bones, spine or both, or children may have what is termed a constitutional delay, indicating that the child will likely mature a bit later and have a longer growth phase his or her peers. Good screening studies for treatable growth deficiency include blood thyroid hormone level, bone age determination and a somatomedin-C level, which is an indirect means of measuring GH secretion.

I am 45 years old and was wondering if there is any wisdom out there about NF and Hormone Replacement Therapy (HRT) in menopause? - M.L., El Cerrito, CA

There is no conclusive information regarding HRT and NF. It is suggested that women weigh the benefits of relieving menopausal symptoms with HRT against the hypothetical risks pertaining to NF. Ultimately, the decision is a personal one.

* A 38 year old finds a lot of support from penpals who deal with NF. Will write to all.

- Debbie Hammonds; 1203 Willow Tree Pl., Bloomington, IN 47403

* Student would like to hear from others. - Jennifer Bratton; F52 Bayshore Dr., South Amboy, NJ 08879

* I'm 41 years old and would like to relate to others with NF1. - Harvey Alexander; 201 Thomas Dr., PO Box 98; Lyndhurst, VA 22952

* I'm 30 and have NF. We thinking of having children and are seeking input from others. - Chris Farinella; 3619 Parkview Dr., Bensalem, PA 19020

* Recently diagnosed with NF2 want to talk to others. - psray@holli.com

- * Would like to receive letters from parents who have lost an only child to NF - Sharon Szablewski; 128 Stratford St., Buffalo, NY 14216
- * Diagnosed with NF2 in '95 would like to correspond with others. - Susan Froelich; 796 Merrill Crk. Rd.; Marathon, NY 13803
- * Teen looking for penpals. - Sharon Morris; 5850 Centre Ave., #514; Pittsburgh, PA 15206
- * 48 year old woman will answer all who email. - lilnsylk@bright.net
- * I have NF1 and would like to hear from others. - Chuck Huesers; 509 Lovell St., Crowley, LA 70526; cajunguy21@hotmail.com
- * Parent of two sons with NF needs support. - Joe Krepp; 1000 W. 21, Lot 35; Connersville, IN 47331; jwkrepp@webworks2000.net
- * I have a friend with NF and would like to offer friendship and support to others. - Colleen Rue, 12 Charlotte Ave., Trenton, NJ 08629