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THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.

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NF

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Longtime friend and supporter of the NNFF and the Jaffa Family Fund, actress Julia Louis-Dreyfus and artist Greg Lauren at the Inaugural event of the NNFF California chapter's Young Hollywood Industry group.



Feel good by doing your Holiday Shopping with a % going to NF research.

www.nf.org/goto/shopping

\$20 Million For NF Research Via US Army's NF Research Program

The new defense-spending bill signed into law by President Bush on October 23, 2002 includes \$20 million appropriated by the United States Congress for NF research in the next fiscal year. The appropriation, which goes to the United States Army's NF Research Program, is the largest single funding source for NF research in the world and is open to all qualifying scientists regardless of nationality or site of laboratory.

Foundation President Peter Bellermann applauded the Congress for its continued support of NF Research. "The importance of these appropriations for effective treatments in both NF1 and NF2 cannot be overstated. The Army's Research Program is superbly staffed and operates by a rigorous peer review process, thus assuring the taxpayers the very highest returns for their investment. Since the inception of the program a number of major advances in NF1 and NF2 research were made possible by the annual appropriations," Bellermann said.

While the bill's primary sponsor in the House continues to be Rep. Jack Murtha of Pennsylvania, it enjoys widespread support among Representatives and Senators from



Texas Senator Kaye Bailey Hutchinson (right) with Foundation President Peter Bellermann (left)

both parties including Texas Senator Kaye Bailey Hutchinson (pictured above)

"I urge Foundation members and friends nationwide to express their gratitude to their own US Representative and their own two Senators," Bellermann said. "This program began in 1991 as an initiative by the National Neurofibromatosis Foundation and continues to be one of the Foundation's highest priorities. Our thanks and a heart 'Well Done!' go to the 13,422 Foundation members who were involved in this year's legislative process."

For more information about the program, please visit <http://cdmnp.army.mil/nfrp/>. 

New NF Mouse Models for Research

by Dr. Judy A. Small
Director, Clinical Trials and
Technology Transfer, NNFF

Who would have thought that the NF community would be excited about mutant mice? The laboratory mouse is the animal of choice in most research laboratories looking for models of human diseases. For NF, the early mouse models generated in the laboratories did not develop the tumors typical of NF1 or NF2 and were of limited use for studying the pathogenesis of the diseases. Recent work has overcome some of these limitations, and indeed mice are now being studied that develop tumors of the types found in human NF.

Since the identification of the genes responsible for neurofibromatosis type 1 and type 2, researchers have been working on studies to learn the roles that the two NF proteins, neurofibromin in NF1 and merlin/schwannomin in NF2, play in cells, and to understand what goes wrong when the proteins are abnormal or absent due to genetic mutations. Early work focused on identifying these mutations, and trying to find evidence that certain mutations caused each of the different manifestations of NF. However, it was soon evident that there was no relationship between most mutations and the symptoms that

appeared. Indeed, even members of the same family, and with the same gene mutation, often exhibited different severity of disease.

It was these findings, and the need to study NF in an animal model, that led scientists to develop better mouse models for NF. Recently, mice have been developed using a new strategy so that the mice are born with one or two normal NF genes, which can be turned off in a tissue-specific or time-dependent manner, or "knocked-out." It is with these knock-out mice that exciting new research opportunities present themselves, as specific types of tumors, relevant to the human NF tumors, appear in these mice.

Dr. Luis F. Parada (University of Texas Southwestern Medical Center) leads a research group that has developed a number of tissue-specific NF1 knock-out mice, and is also providing expertise to other laboratories looking for specific NF1 tumor models. Dr. Marco Giovannini (INSERM, Paris) leads a similar research group studying NF2 knock-out mice. Both researchers are part of the Neurofibromatosis Mouse Models Consortium, led by Dr. Kevin Shannon (University of California San Francisco) and also includes Dr. Tyler Jacks (Massachusetts Institute of Technology) and Dr.

Andrea McClatchey (Massachusetts General Hospital / Harvard), and supported by a grant from the US Department of Defense Neurofibromatosis Research Program.

Dr. Parada recently published a paper, in the May 3, 2002 issue of *Science*, describing studies in which the NF1 gene was mutated in Schwann cells using the knock-out technology. In these mice, there was the development of neurofibromas, the most common tumor found in individuals with NF1. He showed that it was the Schwann cell that was responsible for starting the tumor. However, as is the case in humans, the tumors contained other cell types in addition to the Schwann cell. One of these cell types, the mast cell, is an immune system cell that migrates to the nerve fibers even before the tumor starts to grow. It was a surprise to find the suggestion that it was the mast cell that might determine whether the tumor would grow or not. If the mast cell had two "good" copies of the NF1 gene, no tumors formed.

The current working hypothesis is that tumors form only if the mast cell has one "bad" copy of the NF1 gene, which is the case for all NF1 individuals. According to Dr. Parada, "these mice can now be used for two types of very exciting studies.

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NNFF Camp

Building Confidence, Friendships and Memories That Will Last A Lifetime

The sixth fun and adventure filled summer has come and gone at the NNFF International Summer Camp for Teens. The camp takes place every summer from mid-July to early August. Our campers have the experiences of a lifetime as they visit the Grand Canyon, go whitewater rafting down the Colorado River and explore Salt Lake City. When they are not out in nature the campers explore another frontier, genetics, during the "Day at the Lab Program." The campers become "scientists for a day" and perform hands-on experiments at the University of Utah's Eccles Genetic Science Learning Center.

The first session of camp began on July 17 with the campers arrival in Flagstaff, Arizona. Their anxiety and nervousness as first time campers melted away as they met new friends at the Flagstaff airport. From there the campers went to the Grand Canyon. They traveled via the Grand Canyon Railway, a historic steam engine that comes complete with a mock train robbery, to the south rim of the Canyon. The Grand Canyon expedition is one of the highlights of the camp. The Canyon is one of America's natural wonders, and the views left the campers and their NNFF chaperons breathless.

After admiring the view of the Canyon, the campers boarded a bus that took them to Moab, Utah to spend a night under the stars. The next morning the campers got their gear stowed for a wet and wild two-day trip down the Colorado River with SPLORE, a company that guides people with special needs on outdoor adventures. Two days of soaking up the sun and the



Campers participate in fun and educational activities at the Sixth Annual NNFF International Summer Camp.



Colorado River left the campers in desperate need of a shower.

After wringing out their clothes and drying themselves in the Utah sun the campers headed to their final stop: a few days at Camp Kostopolos, Camp K for short, in Salt Lake City.

While at Camp K the campers enjoyed the ropes course, arts and crafts, nature walks, horseback riding and karaoke. There were also day trips to see the AAA Salt Lake Stingers, the minor league baseball team for the Anaheim Angels; hike up 11,000-foot Snowbird Mountain; and to swim at a local pool. Camp K is the campers' home away from home and it is the centerpiece of the NNFF camp. The activities at Camp K are designed to focus on challenging the campers and to help them build confidence.

Just moments after the first session campers said a tearful good bye to their new friends, reunion campers landed at the Salt Lake City airport. Some of the campers literally counted the days until this moment because they looked forward to returning. The 51 weeks since they last saw their camp friends were over and it was time to catch up and reconnect. The campers met old and new friends with

open arms as the all headed off to spend the night at Camp K. The next morning the campers got up in the pre-dawn hours and headed down to Moab for their chance to shoot the rapids. The only difference between this year and past years was the prohibition of campfires, due to the unusually dry summer. But the campers still made due and had a great time huddling around a lantern. The river was shallow this year but it didn't stop anybody from having water fights or taking a quick

jump in the drink. After two days of shooting the rapids on the mighty Colorado, the campers headed back to Salt Lake.

Back at Camp K, the campers had a great time running the ropes course and participating in the other activities. The highlight of reunion camp was a trip to see the WNBA's Utah Starzz and a trip to a water park.

The "Day at the Lab" at the Eccles Institute was a little more advanced than the new camp's program. The campers investigated a fictional crime, using blood typing and DNA fingerprinting. The session culminated with their question and answer session with NF researcher Dr. David Viskochil.

Saying goodbye is never easy, the reunion campers waited a year to see their friends but after only a week they had to say goodbye again. Since the camp means so much to the kids and the friendships formed there are so important, the Foundation has set up a camp chat room on our website so the kids can keep in touch during the school year. **NF**

Foundation Launches Annual Appeal

In just two years, this child's stuffed animal has been through 5 MRIs, 3 CAT Scans, 5 X-rays, countless doctor visits, major surgery and 3 days in intensive care.... So has this little girl. With these words the NF Foundation launches its year-end giving appeal. The goal of the appeal, which is distributed nationwide, is to raise funds for NF research and other NNFF programs.

This year's appeal focuses on Colette Achee, the now two-year-old daughter of Randy and Cheryl Achee of Greensboro, North Carolina. Colette was diagnosed with NF-I

at four-months-old and had emergency surgery on her spinal cord just two months later. After the operation Colette spent 3 days recovering in the pediatric intensive care unit at the National Children's Hospital in Washington.

Although heartbreaking, the Achee's story is not unique. One in 4500 children are born with NF-I. The money raised in this appeal will help insure that Colette's future and the future of all those with NF are bright.

Keep your eyes on your mailbox for the NNFF 2002 annual appeal. **NF**

Keep your eyes on your mailbox for the NNFF 2002 annual appeal.



It's someone's Special Day on December 13. Find out who, go to

<http://www.nf.org/calendar/wc122002.htm>

NF-Specific Clinical Trials

The NNFF has a posting for active clinical trials on its web page http://lnf.org/clinical_trials/.

There are five trials currently open to patients with NF1 with actively growing plexiform neurofibromas:

Natural History of Plexiform Neurofibromas in NF1. The purpose of this trial is to study how plexiform tumors grow. This is not a treatment trial. They are still recruiting patients in the following categories: adults (18 years and over) with plexiform tumors in the head and neck area; adults with externally visible plexiforms in the trunk and limbs; both adults and children with internally visible plexiforms in the trunk and limbs. This trial is sponsored by the U.S. Army Medical Research Materiel Command and is recruiting at multiple locations. For more information about this trial, contact Tara Flynn at tflynn2@partners.org or (617)525-5750.

A Phase III Trial of PEG Intron for Plexiform Neurofibromas. The goals of this study are to determine the safety and effectiveness of PEG-Intron in patients with plexiform neurofibromas. This trial is sponsored by Schering-Plough and is recruiting at multiple locations. Individuals must be 3 years of age or above to participate. For more information about this trial, contact Beverly Brannon, R.N. at Beverly.Brannon@chp.edu or (412)692-7070.

RI 15777 in Treating Children with Neurofibromatosis and Plexiform Neurofibromas. The goal of this study is to determine the effectiveness of RI 15777 in treating children with progressive plexiform neurofibromas. This trial is sponsored by the National Cancer Institute and is recruiting at multiple locations. Individuals must be between 3 and 25 years of age to participate. For more information about this trial, contact Andy Gillespie, R.N., at gillesan@mail.nih.gov or 301-402-1848.

Combination Chemotherapy in Treating Patients with Neurofibromatosis and Progressive Plexiform Neurofibromas. The goal of this study is to determine the effectiveness of the combi-


nation of Vinblastine and Methotrexate in treating patients with progressive plexiform neurofibromas. This trial is sponsored by the Children's Hospital of Philadelphia and is recruiting at multiple locations. Individuals must be 25 years of age or younger to participate. For more information about this trial, contact Hang Ngo at ngo@email.chop.edu or (215)590-3129.

A trial to study the effectiveness of Pirfenidone in adult patients with plexiform or spinal neurofibromas at Mayo Clinic is now closed to recruitment. A pediatric trial of Pirfenidone will begin enrollment in the fall of 2002 at Children's National Medical Center in Washington, D.C. and other locations.

Two trials are currently open to patients with NF2:

Natural History of Vestibular Schwannomas in NF2. The goal of this trial is to study the growth of vestibular schwannomas in patients with NF2. This not a treatment trial. The trial is sponsored by the House Ear Institute and is recruiting at multiple locations. Individuals must be 5 years of age or above to participate. For more information about this trial, contact Dr. William Slattery at Wslattery@hei.org or (213)483-9930.

An Implant for Hearing Loss Due to Removal of NF2 Tumors. The goal of this study is to determine if penetrating auditory brainstem implants (PABI) are safe and effective in treating patients with NF2. This trial is sponsored by the FDA Office of Orphan Products Development and is recruiting at multiple locations. Individuals must be 18 years of age or above to participate. For more information about this trial, contact Dr. Chris van den Honert at cvdhonert@cochlear.com or (303)362-2114.

For more information about clinical trials open to individuals with NF, please visit the clinical trials portion of the NNFF website at http://lnf.org/clinical_trials/ or contact Stephanie Ellis at sellis@nf.org or 301-924-5273. 

Call for Schwannomatosis Samples

The aim of this project is to characterize the frequency and location of deletions, which occur outside the NF2 locus on chromosome 22. This research task aims to characterize additional 22q-located gene(s), which may contribute to the development of schwannomatosis and the severe phenotype of neurofibromatosis type 2.

We would like to obtain blood-derived DNA or a blood sample from patients affected with schwannomatosis; i.e. patients with two or more pathological-ly verified schwannomas, plus lack of radiographic evidence of vestibular nerve tumor at age >18 years. These can be familial or sporadic cases. We need >25 microgram of high-molecular-weight DNA from peripheral blood. Alternatively, we would like to obtain 30 ml of peripheral blood (in EDTA tubes) transported to us via overnight courier service. Basic clinical details of the studied patients are also necessary.

Our project receives support from the U.S. Army Neurofibromatosis Research Program, the Swedish Cancer Society, the Uppsala University and the Swedish Research Council. The use of material derived from human subjects has been approved by the Uppsala University Research Ethics Committee (Institutional Review Board).

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Why do your holiday shopping in a crowded mall when you can shop at the NNFF Online Shopping Mall?

CHAPTER NEWS

WAGING THE FIGHT AGAINST NF AT THE GRASSROOTS

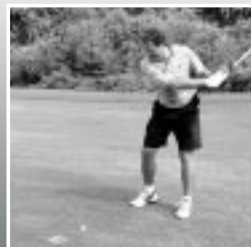
California



Starry Night In California

The Inaugural event of the NNFF California Chapter's Young Hollywood Industry Group raised research dollars as well as raising awareness about NF. Left to Right - California Chapter Regional Vice President Stuart Rogoff with event organizers and chairs Rick and Amanda Jaffa, Greg Lauren, and Mike Silver.

Florida



Pitching In For NF Research

Frank Viola, star Major League pitcher, AL Cy Young Award Winner and World Series MVR was one of the players in the NNFF Florida Chapter's 2nd Annual Charity Golf Tournament. The outing, which attracted a record crowd under sparkling Florida skies, was held on the renowned course of the Isleworth Country Club in Windermere, Florida. Isleworth is Tiger Woods' home course.

Illinois



Gator Gala, Taking A Bite Out Of NF

Rick and Lauren Jolcover (left) hosted the 1st annual Gator Gala at Gators in Palatine, IL. (voted Chicago's best wings). The event was a great success with additional funds raised through a silent auction and proceeds from bar sales and NF donation cards (right).

Missouri



We Are Family

Disco is back as Callia Raney, Sue Slocomb, Kathy Dewrock, Kim Sellini and Susan Morrow sing the Sister Sledge anthem, "We are Family," at the "Sing a Song for NF" night at Kokomo's West Bar and Grill in St. Charles, MO.

Pennsylvania



Hog, Hens & Birdies

Above far left: Chicken Barbeque for Research. Young Jordan and Jacob Sloop from Pennsylvania are thrilled to pose with the "Bud girl" at the second chicken barbeque at Carlisle's West End Cafe for NF research and programs. Center: Harleys and their riders are ready to hit the road at Jordan's Ride for Research in Carlisle. Far right: The winning team rallies behind the flag for NF research at Keller's Troff, a fundraising golf event near Valley Forge, PA.

Washington



Putting Their Best Feet Forward

People are suiting and warming up at the starting line of the Washington Chapter's 5th Annual Race for Research, a 10K & 5K run/walk held at Marymoor Park, Redmond WA on a beautiful September day.

Wisconsin



One Walk, One Run

Top: People commune with nature and park rangers at the Wisconsin Chapter's Nature Walk to Find a Cure. Bottom: A batter swings for the fences at the NF softball championship held in Kenosha, Wisconsin.

This Year Raise Funds As Well As Holiday Spirits

Why do your holiday shopping in crowded malls when you can shop in the comfort of your own home at the NNFF Online Shopping Mall? The NF web site features two NF shopping malls, GreaterGood.com and Amazon.com. Find great gifts for everyone on your Christmas list with a seemingly endless list of vendors at your disposal. Remember, a portion of each sale will help NF funding for research and programs at no additional cost to you.

Gone are the days of waiting in long holiday lines and running from store to store trying find the perfect gift! By taking advantage of the Foundation's GreaterGood.com or Amazon.com shopping malls, the perfect gift is just a mouse click away. Help Dad get more organized for the new year by picking out a high-tech pocket organizer at TheSharperImage.com (GreaterGood.com). Or send him to the golf course in style with his new Taylor Made

golf clubs from TheSportsAuthority.com (GreaterGood.com). Looking for a gift for Mom? No problem! Simply browse through the "Health & Beauty" section of Amazon.com for outstanding choices. Try Amazon's "Toys & Games" section for children's gifts.

New this year, the NNFF lets you raise your paws for a good cause — Send a Bear-Gram® gift from the The Vermont Teddy Bear Company®! Save 10% off any Bear-Gram gift & earn an additional 10% for the National Neurofibromatosis Foundation! Order online at www.VermontTeddyBear.com or call 1-800-829-BEAR. **Use Coupon Code: NEURO.** Show your Care — Send a Bear, The Creative Alternative to Flowers!

What are you waiting for? Come and enjoy the comfort of limitless selections at your fingertip. The possibilities are endless, from gift cards and gift certificates to clothes



and jewelry so visit the NF web site and try out one of our shopping malls this Christmas! Remember, a percentage of everything you purchase goes towards NF research!

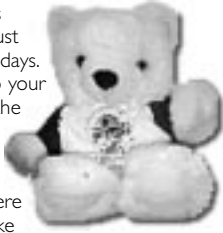
Please support the NF Foundation during the holidays by giving the chef in your life all their kitchen needs by attending a Virtual Fundraising Kitchen Show sponsored & presented by Independent Kitchen Consultant, Lorrie Poteet, for The Pampered Chef. All proceeds from the show will go directly to the NF Foundation. Please check out the Pamper Chef catalog at www.pamperedchef.com/our_products/catalog/catalog.jsp and please send all orders to drspoteet@fiberpipe.net

To shop at VermontTeddyBear.com, GreaterGood.com or the Amazon.com NF online mall, simply visit our web site at <http://www.nf.org> and click on the "Shopping For Research" button or look for the special "Holiday Shopping" section. 

The NEW NF E-Bears Have Arrived!

We can BEARly contain ourselves!

The new NF bears have arrived, and just in time for the holidays. This Christmas top your stockings off with the ultimate stocking stuffer, the NF E-Bear. E-bears can be shipped anywhere in the U.S. and make the perfect accompaniment to any item purchased from the NNFF Online Store. Simply, log onto our secure site at https://secure.nf.org/cgi-bin/web_store/web_store.cgi and pick one up today. Let this cuddly companion help you spread NF awareness throughout the holiday season!



Now every day is a party at the NF Bulletin Board!



For many users of the Bulletin Board, the other participants have become a special family. Celebrating special days like birthdays, anniversaries, weddings, bar mitzvahs, christenings, naturalizations et al., is one of the things that families do together. This calendar is designed to let Bulletin Board members post their birthdays, anniversaries and other special days, or to post for someone else like a child or an elderly parent.

Others can then partake in the joys of someone else's special day by looking at the calendar regularly and sending appropriate messages to those whose special days are listed.

You can view the calendar by going here on the NF web site: <http://www.nf.org/calendar/calendar.htm>

To make a post, you must first register for the NF Bulletin Board. Once you are a registered member, go here to post your birthday, anniversary, or special day: http://www.nf.org/calendar_submissions/form.htm

Become an E-member for NF this Holiday Season!

When you add your name to our roster of e-Members you help the NNFF advocate on your behalf to other public, private, and government agencies that are interested in funding programs for NF.

The larger our Membership, the louder your voice. What's that? You're already an E-member. Then show your support for the NF Community by giving someone you care about a gift of Membership in the NNFF. The recipient will receive a personalized card notifying them of your gift, along with a Membership Card. They will receive all of the National and Local benefits listed below, and you will have the satisfaction of giving a gift that contributes to the efforts to find treatments and a cure for NF.



To find out more visit our web site at <http://www.nf.org/contribute/emember.htm>.

BENEFITS OF MEMBERSHIP

- A NNFF Lapel pin
- National quarterly newsletter (electronic version) and chapter newsletters; *
- Be a part of the team to help find treatments and a cure for NF;
- Strengthen our roster of members as we advocate on behalf of all those affected with NF throughout the U.S.;
- Receive a personalized NNFF Membership Card;
- Automatic Membership in your local State Chapter;*
- Invitation to the NNFF Annual Membership Meeting;
- Notification of special patient support services;
- Notification of special publications and events;
- Enjoy a 10% discount on Bookstore items and educational materials;
- Your Membership is a fully tax-deductible contribution as allowed by law.

* Not all states have active chapters and/or newsletters. **NF**

A Tea Party So Big One Month Just Can't Hold It

The Mad Hatter of Alice in Wonderland had the right idea... tea parties are so fabulous that one should have them all the time. Three years ago the NNFF's "May Tea Party" campaign met with great success. Moms across the states were given the chance to relive their childhood daydreams and throw virtual tea parties. Amidst all the fun they were having, they managed to raise a bit of money as well for NF — nearly \$300,000 to date.

Now, no one has to wait until May to join the tea party. This fall the Foundation will launch a partnership with MacNab's Tea Room of Boothbay, Maine. In addition to hosting a tea party in May, MacNab's Tea Room has created a special blend of tea for the Foundation as part of the year round Tea Party campaign.

This new tea, specially chosen for the Foundation, cleverly entitled, "Chari-Tea", is a blend of black tea that will most certainly become a favorite in your teapot. The delectable taste is not the only benefit of Chari-Tea. As its name may imply a portion of the proceeds will be donated to benefit the Foundation.

The beauty of tea is that unlike hot chocolate it can be enjoyed all year round. Tea is the perfect beverage to warm you in the brisk air up on the front porch while watching your children jump through piles of fall leaves, to relax you on a cold winter's night after a long day, or to perk up your spirits when you just can't take another rainy spring day.

Chari-Tea would be a perfect tea for these occasions. It is not just for May Tea Parties, but is also a great way to introduce your friends and loved ones to NF throughout the year. Chari-Tea would make a great addition to a holiday basket or as a house-warming gift and with each purchase you'd be helping an individual with NF.

In addition to creating Chari-Tea, MacNab's Tea Room will be hosting a May Tea Party in partnership with New England Chapter to benefit the Foundation. Chari-Tea will flow from the teapots and conversation will fill air that afternoon in their quaint,

Beginning after Thanksgiving, Chari-Tea will be offered for sale on the MacNab's Tea Room web site (www.macnabspremiumteas.com) or you can call them directly at 1-800-884-7222 to purchase it. It will come in a tin adorned with a special gold NF label. The cost is \$8 (plus shipping) for a 4-ounce tin that makes approximately 75 cups of tea.




rustic tearoom in Boothbay. The tearoom features a full menu, including scrumptious homemade scones, and visits from the real Scotty dog that is featured on their logo.

"We are excited to be able to support such a worthy cause," said Laurie Cartier, Manager of MacNab's Tea Room.

The Foundation discovered MacNab's Tea Room through its relationship with Pearl Dexter and her magazine "Tea—A Magazine". Pearl appreciates owner Fran Browne's passion for tea and knew that together they could concoct a wonderful brew.

The NNFF thanks Fran and Laurie of MacNab's Tea Room for their generosity. **NF**

Lillian Fitzgerald's elegant lithographs grace the cover of our May Tea Party Brochures. A limited number of signed offset lithographs by Ms. Fitzgerald are for sale on the NF website. All proceeds will go to benefit the NF Foundation.



NF PROFILE

Taking Strides for NF Research

Hundreds have walked or run 26 miles in marathons to raise money for NF, but imagine covering more than 2,000 miles of pavement to raise funds and awareness of the disorder. Certainly it would be a daunting challenge, but then imagine trying to walk while you had trouble with your balance and had a constant buzzing in your ears.

For 25-year-old preschool teacher Melissa Pecoy-Jungjareon of Albany, Oregon these factors did not deter her from setting out on the walk of her life that would take her all the way to Chicago. "I decided to walk across America because it was the best way I could imagine to draw attention to NF."

Melissa's own experience with NF2 and the family's history of the disorder kept her focused on the goal of walking all the way to the Windy City. In 1987 Melissa's late father was diagnosed with NF2 and her older brother, Dan, was diagnosed with NF 2 in 1991. Today, after two surgeries Melissa has partial facial paralysis, tinnitus in her left ear and impaired balance.

Despite these health issues, Melissa laced up her walking shoes and started her journey from the Apple Tree restaurant in Albany. Melissa, her husband, Byron, and their beagle, Jazz, started the trip that led them through six states and almost 2,200 miles. She also got a tremendous amount of support from NNFF Chapter members along the way.

Once her walked started Melissa made sure the local news covered her arrival in various cities. In one of her favorite moments in the walk, with the help of NNFF Wyoming Chapter President Norma Good, Melissa was interviewed



Melissa Pecoy-Jungjareon

by the local news in Casper, WY. The next day Melissa was recognized on the street and it gave her the opportunity to tell more people about NF.

Three months and ten days after she started Melissa's walk finally ended in the outskirts of Chicago. "I truly believe that it is of the utmost importance to educate and bring awareness to everyday people if we hope to find a cure for NF," Melissa said. "Most people I know have never heard of NF until I explain to them that I have it and what it is. Being the kind of person who wants to get things done, I needed to get out there and raise awareness and research

funds on my own. I felt as average person, I had to do something really big to get people's attention — walking from Albany, Oregon to Chicago, Illinois fit the bill."

Melissa accomplished every goal she set for herself on her walk. She was given the opportunity to educate people, she completed her walk, and she had raised over \$8,000 for the NNFF.

"The walk has had a huge impact on my life. Two things I discovered are that my belief that one person can truly make a difference was affirmed and that most people are willing to lend a hand to help support a good cause, if you just ask," said Melissa. "I feel like I have the power to do and be anything I want to. I hope this is a lasting feeling that I can use to empower and positively affect the people I come into contact with."

If you wish to make a donation to the NNFF in honor of Melissa's NF Walk America 2002, please contact Michelle Messenger at the NNFF, 800-3223-7938 x 239. NF

The first studies, underway in collaboration with Dr. Wade Clapp at Indiana Medical Center will determine the nature of the role of mast cells in these tumors. The second set of experiments are designed to test therapeutic compounds to prevent or cure neurofibromas in these mice. This new tool will certainly enhance the probability of discovering useful therapies quickly that can be transferred to patients."

Dr. Giovannini has also been busy, looking for strategies that would cause the development of NF2-specific tumors in mice. He is using a system where he adds the cre enzyme to the NF2 targeted gene using a virus called adenovirus as the delivery agent. By injecting this virus into different parts of these mice, he was able to induce the growth of meningiomas similar to human meningiomas. This work was reported in the May 2002 issue of *Genes and Development*. Dr. Giovannini says that he plans to study and model the mechanisms of malignant transformation of human meningiomas as the next steps in using this mouse meningioma model.

Other NF researchers are excited about these new mouse models, and it is hoped that these mice can be used to screen compounds with a potential to treat or prevent tumors, in order to more quickly move the most promising drug candidates into human clinical trials. NF

Where are the

NF

CLINICS?

FIND OUT BY GOING TO
http://www.nf.org/us_clinics/

Baby Look At You Now

It is an established fact that all kids are cute, but no kid is as cute as yours. It is now time to put your money where your mouth is. The NNFF is proud to announce the search for **Photokid of the Year**, presented by the American Performing Arts Network; all proceeds benefit The National Neurofibromatosis Foundation. This is your chance to prove that your child is the cutest kid out there.

Here's how it works, you submit your photographs of your infant(s) thru 12-year-old(s) to compete in these 6 categories: How Precious Is That, Make Me Laugh, Faces Going Places, Fashion Statement, The Eyes Have It and Love That Smile.



There are two ways to win, the "Judges' Choice Award" and the "Voters' Choice Award." A panel of modeling professionals will judge the photos during the display of photographs. The "Voter's Choice Award" is based on the number of votes that each

photo collects. Upon entering the contest you will receive a Vote Ticket Sales Sheet to raise money for The National Neurofibromatosis Foundation. This is your chance to "stuff the ballot box". All money submitted will be used to buy votes for your child at \$1.00 a vote. Parents should collect as much as they can to try and win the "Voters' Choice Award." The winner of the "Voter's

Choice Award" gets their photo in US Airways' *Attaché* Magazine, which reaches 1.6 million readers monthly.


The "Judges' Choice Award" is determined by the highest scores (based on the most points) given by the judges. The photograph that receives the most points given by the judges is given a modeling contract with a top New York agency. All of the photographs submitted are automatically eligible for the judges choice award.

Photographs of all the contestants go on display for judging and voting, at Planet Hollywood, in Walt Disney World, Orlando, May 16 thru 18, 2003. Trophies, ribbons, plaques and medals will be awarded to the winners by mail. To enter or find out further rules please go to www.photokid.org, or call toll free 888-532-4KIDS. NF

United Way and Workplace Giving

Numerous companies and corporations, large and small, offer their employees an opportunity to contribute through either a payroll deduction or employee giving drive. Some companies participate in a campaign where you can designate funds to the health agency of your choice through what is called the Combined Health Appeal (CHA). The NNFF is an active member and participant in local CHA campaigns nationwide. State and Federal employees can contribute to the NNFF through a vehicle called the Combined Federal Campaign (CFC).

For most workers, however, the United Way campaign is the most common and well known. Although the NNFF is not a member United Way agency, as is the case with most national health agencies, you can still contribute to the Foundation through the United Way campaign through what is called "donor choice" or "donor option."

Sometimes designating the Foundation is as easy as writing the NNFF name and our address on your donor pledge card. In other United Way campaigns it involves putting a designated agency code number on your donor card. This code number varies from campaign to campaign. Even if the Foundation is not listed on the brochure, we may still be eligible for contributions. Contact your human resource department to inquire about having a choice in supporting the NNFF. 

Our numbers are as follows:

CHA - 0550
CFC - 0550
United Way - 006138

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The purpose of the National Neurofibromatosis Foundation, Inc. (NNFF) is to improve the well-being of patients and families affected by NF1 and NF2. The Foundation therefore sponsors scientific research aimed at finding the causes and cures for the neurofibromatoses, promotes the development of clinical activities, works to create public awareness and provides patient support services.

The National Neurofibromatosis Foundation is a founding member of the International Neurofibromatosis Association.

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