

The National Board of Directors Welcomes Three New Members!



Pictured above: The National Board held their winter meeting in Los Angeles this past January.

The Foundation is honored to have **María Amparo Escandón, Tara Skirzenski, and Rick Jaffa** join the National Board; each bringing an impressive set of credentials to the leadership of the Foundation.

María is the co-founder and Director of the Creative Review Board of *Acento Advertising*, which focuses on Hispanic marketing. María is the author of the best-selling novel, *Esperanza's Box of Saints*, and has been published in many magazines. Her second novel, *González & Daughter Trucking Co.*, is due out this spring. María has been involved with the CA Chapter for over 10 years, and currently serves as Vice-President.

Tara became involved with the Foundation in 1998. Her sister, Bernadette Tardio, chairs the *Tea Party for NF program*, and Tara has co-chaired a successful annual Tea Party in New Jersey for the last 5 years. She was recently elected President of the Chapter & Affiliate Council after serving as VP of the Council and Representative of the Tri-State Affiliate.

Rick is a screenwriter, he and his wife own *Shinbone Productions* in Los Angeles. They have written many successful TV and movie scripts, including *The Hand That Rocks the Cradle, The Relic and Eye for an Eye*. Rick has been with the Foundation for over 10 years and is a past president of the CA Chapter.

Inflammatory Cells Highly Promising Target in NF1

By **Cindy Fox Aisen**, National Media Liaison for Indiana University School of Medicine & **Eric Schoch**, Science Writer for Indiana University School of Medicine

Scientists at the Indiana University (IU) School of Medicine are closing in on potential treatments for neurofibromatosis.

Research by IU School of Medicine scientist D. Wade Clapp, M.D., and his colleagues David A. Ingram, Jr., M.D. and Feng-Chun Yang, M.D., Ph.D., have identified a promising target to treat the symptoms of neurofibromatosis. They hope to begin preliminary testing in humans by the end of this year, and are experimenting with potential drug compounds now.

Dr. Clapp, professor of pediatrics and of microbiology and immunology and Co-chair of the 2005 NNFF International Consortium for the Molecular Biology of NF1, NF2 and Schwannomatosis, said one target of their efforts will be mast cells, which are immune system cells that are involved in asthma and allergic reactions. Mast cells play a role in neurofibromatosis because they also are involved in blood vessel formation -- and tumors need blood vessels in order to grow.

"Our work may well be applicable to other types of tumors such as breast and ovarian cancers, because inflammatory cells play an important role in tumor formation in these malignancies," said Dr. Clapp.

Neurofibromatosis results from mutations in a gene called NF1. Everyone has two copies of the NF1 gene, which produces a protein called neurofibromin that controls

cell division. If both NF1 genes are defective, not enough neurofibromin is produced, cell division takes off and tumors develop.

To encourage development of the blood vessels they need, the tumors emit chemical signals that cause the mast cells to congregate in tissues surrounding the tumors. The mast cells create chemicals

called growth factors that enable the creation of blood vessels.

The IU investigators now are identifying drugs that can disrupt the function of mast cells and their proteins in ways that they believe will starve the tumors.

"We are beginning to have a better understanding of cell to cell interactions that lead to the development of tumors and are poised to answer some of the most perplexing questions that underlie neurofibromatosis," said Dr. Clapp.

"It's much easier to develop targets against a non-malignant cell than it is the malignant cell itself," said Dr. Clapp. That's because the biological activities of non-malignant cells are stable, while malignant cells are constantly changing due to the genetic instability common to tumors.

By using drugs that target the mast cells' ability to promote blood vessel growth, Dr. Clapp and his colleagues hope to prevent tumors from getting larger. Eventually, with continuing treatment, they hope the tumors will shrink or die from lack of blood vessel support. If effective, the drugs would be a boon for physicians and their patients working with a disease for which the genetic cause has long been known, but for which there have been few treatment options.

This article has been adapted from a news release issued by Indiana University.

Northwest Airlines KidCares

As many of you know, NF can sometimes have a devastating effect on a family; physically, emotionally and financially. There are many companies and organizations that work to help families in their time of need. Northwest Airlines has created a medical travel program, **Northwest Airlines KidCares**, to help families with a child who requires medical treatment and needs air travel assistance. **Northwest Airlines KidCares**



medical travel program provides air travel to children age 18 and younger who are unable to receive treatment in their home area. Availability of the program is based on donated **WorldPerks** mileage and consideration of each request is based on specific guidelines. Please visit the airline's website at www.nwa.com or call 612-726-4206 for more information.

Planning for the Future

Did you know that when the Children's Tumor Foundation is notified of being included in an estate plan, an additional and immediate \$500 gift is made to the Foundation by an anonymous donor?

Have you recently reviewed your financial plans while preparing your tax returns? If your estate plans include the Children's Tumor Foundation, please notify us in writing so that we may process this generous additional gift, which can be put to use immediately in our medical and research programs.

If you do not have a current will we urge you to talk with your advisors -

your attorney, accountant and other family counsel. You can prepare a will that protects your estate, provides for your loved ones and declares your own preferences for a personal legacy. Providing a Legacy Gift to the Foundation in your long-term plans and providing for loved ones does not have to be an either/or proposition. And remember that a charitable bequest gift reduces your estate taxes.

For more information or a confidential discussion about the many ways you can consider **making a Legacy Gift to the Children's Tumor Foundation contact: Nancy DeNatale, VP National Development at ndenatale@ctf.org / 800-323-7938 x231.**

NF2 CON

The NF2 Crew is holding its **11th Annual NF2 Con** at the Sahara Hotel in Las Vegas from March 31st to April 3rd, 2005. The meeting is open to all with NF2. Visit www.nf2crew.org, or email Pat Dillon at pdillon438@aol.com for more information.

If Matt can do it . . .



NF Marathon Team

— racing for research



Racing for Research means, "I can make a difference!" to Matt Leibowitz.



Matt crossing the finish line in the 2004 Virginia Beach Half Marathon.

People like Matt Leibowitz who live with NF share a particularly inspiring trait beyond the physical manifestations of their disorder; with inherent tenacity and forbearance, they overcome obstacles beyond all odds. Matt's personal story is inspiring, and he is one of our NF Heroes. NF has put the Leibowitz family through supreme physical and emotional challenges and Matt continues to struggle daily with complications, and periodic surgeries. But, he wanted to take on another challenge; the NF Marathon Team.

Matt joined the Team, using the walker he relies on, to finish the final mile of the 2004 Virginia Beach Rock n' Roll Half Marathon! This year, with his trusted walker and many NF Team members by his side, Matt is going to finish the San Diego Rock n' Roll Marathon. **Racing For Research** with the NF Marathon Team not only raises money to find better treatments and cures for our loved ones living with NF, the Team has significantly increased the general public's awareness of the disorder and the Foundation's work.

Want to help NF Hero Matt Leibowitz reach the finish line? Send a donation to the Foundation in his honor using Matt's runner number: RR 2093. Or support Matt and help him raise money through his personal website at <https://secure.justgiving.com/pfp/matthewl>.

Please contact the NF Marathon Team for more information at (800) 323-7938 x251 or awalsh@ctf.org



2005 Marathon Schedule!

Myrtle Beach Marathon & Half Marathon

Myrtle Beach, SC - February 19th

Los Angeles Marathon

Los Angeles, CA - March 6th

Montreal Marathon

Montreal, Canada - April 24th

Country Music Marathon

Nashville, TN - April 30th

Rock N' Roll Marathon

San Diego, CA - June 5th

Mayor's Midnight Sun Marathon

Anchorage, AK - June 28th

Rock N' Roll Half Marathon

Virginia Beach, VA - September 4th

LaSalle Bank Chicago Marathon

Chicago, IL - October 9th

Long Beach International Marathon & Half Marathon

Long Beach, CA - October 16th

ING New York City Marathon

New York, NY - November 6th

Philadelphia Marathon

Philadelphia, PA - November 20th

NF Marathon Team Kicked Off Its New Year In Disney!

Over forty runners on the NF Marathon Team competed in the Disney Marathon in Orlando, FL this past January. The successful event not only raised research money for NF but it also gave runners the opportunity to educate strangers about NF while running alongside them.



Pictured above: Runners smiling for one last shot before running the 26.2 miles race.

A Mother Fights For Her Child's Future

By Tabatha McInroy

Selena Rose McInroy is the youngest Social Security Insurance (SSI) recipient in the state of New York, but getting the judge to recognize Neurofibromatosis as an impairment disorder was a battle her mom fought hard.

"You are denied.

Reason: Neurofibromatosis is not considered disabled under state rules. The condition does not cause marked and severe functional limitations."

This was the decision I received on November 4, 2002 from the State of New York when I filed for Social Security Insurance (SSI) for my one-year-old daughter, Selena McInroy. I was not going to let someone without any experience make a decision that can affect my daughter and others for the rest of their lives. I wanted to fight full force.

This is my story....

My name is Tabatha McInroy and I want to share my story about my fight for my daughter Selena's SSI. My daughter Selena was born on October 8, 2001 with NF1. When Selena was born we knew right away that something was wrong. Her left eye was very swollen and out of place. Within two weeks I came to learn that Selena had a plexiform neurofibroma in her left orbit that extends back into her brain. Selena also has a tumor in the middle of her brain. Because of Selena's tumors and their locations she has many doctors that we see every month, and now she has many specialists that come to the house; including a physical therapist, occupational therapist, life specialist, and her case workers. Everyone has been so helpful in the last three years. Because of Selena's extensive medical needs, her doctor suggested that we should apply for Selena to receive SSI and Medicaid to help us pay her bills and make sure that all of her needs will be met. I did just that.

On September 23, 2002, I found a lawyer who could help us file for Selena to receive SSI. As time passed, I did not receive an answer from the SSI department. In the meantime, Selena under-

went surgery to debulk the tumor in her left orbit to try and help relieve some of the pressure that was starting to build up because of the size of her tumor and how fast it was growing. On November 4, I finally received the decision on Selena's SSI, and the State of New York turned



Selena down. I could not believe what I was reading. I *demanded an explanation!* I filed for an appeal on November 4. I knew that it was going to take time before I could go in front of a judge and tell him about Selena and all of her medical needs. I wanted to make sure that I kept track of everything so I would be ready for whatever we may need for evidence. I had records of all of Selena's doctors' appointments, MRIs and CT scans. Don't count on anyone to do this for you. Selena's lawyer was great but she never received all of the documentation she requested from all of Selena's doctors. I had to be the one to keep the lawyer up to date and send her copies of the paperwork that I had.

When I went to court to meet the

judge, I made sure that I brought Selena with me. This was a fight for her, and I wanted the judge to meet her for himself. After the judge looked over Selena's medical records and talked to Selena, myself and the lawyer, he made his decision. The judge ruled that under New York State law Selena's conditions, NF and a plexiform neurofibroma in the left orbit, medically equals the same criteria for impairment. Under regulations, Selena fell under listing 113.00 and 113.03 of the Appendix 1 subpart P of regulation number 4. And yes, Selena is disabled and will probably be disabled for the rest of her life. Selena does have "severe impairment". The judge also said that Selena was his first case dealing with a patient affected by NF. He was very proud to make this decision, and be the first to put this type of case on the books. He wished Selena good luck with everything that she does and hopes that life will get easier.

It took me over two years to get someone to recognize my daughter's disorder, and to get the courts to understand that NF does not go away but Selena is worth every fighting minute. Someone with NF cannot see into the future and what it holds, we can only hope that everything will be OK. I only hope that other patients with NF will fight as I fought for Selena. This is the only way to get the help that is needed to find a cure for this disorder.

To all of the parents with children that are affected by NF, PLEASE, keep your heads up and fight. You need to be the voice for your children. If we all fight, we can make the changes that are needed to help us give our children the best life possible. We need to make the Social Security Department recognize that NF is a serious medical condition and that it does disable a person.

DO NOT GIVE UP!!!

NF Workshop For Patients & Families

NF families hear from NF specialists at Los Angeles this past December

NF families all over southern California gathered together this past December for a *NF Workshop for Families* co-sponsored by the Children's Tumor Foundation and Children's Hospital Los Angeles, where a new NF Clinic is now launching.

The *NF Workshop for Families* kicked off with a special welcome from the Foundation's Vice President of Development - California, Stuart Rogoff, and the symposium coordinator and moderator Dr. Jonathan Finlay.

The event was a success, which included detailed presentations, Q/A, and a special lunch. Attendees came from all over southern CA - including Los Angeles, Long Beach, Bakersfield, and Orange County. NF materials produced by the Foundation were distributed to raise awareness and provide education to families, educators and youth workers.



Pictured above: (from Left:) Peter Bellermann (Foundation President), Dr. Tena Rosser, Dr. Bruce Korf, Dr. William Slattery, Dr. Jonathan Finlay, Dr. Floyd Giles, Stuart Rogoff (Foundation VP of Development-CA).

Research Call

CALL FOR PATIENTS WITH SCHWANNOMATOSIS

If you have Schwannomatosis, we would like to hear from you. If you are about to have surgery, we need donations of schwannoma tissue for research purposes.

Please contact:
Stephanie Ellis
Director, Schwannomatosis Research Program
Children's Tumor Foundation
Phone: 410-381-4476
Email: sellis@ctf.org
Web: www.ctf.org

HIGHLIGHTS:

Inflammatory Cells Highly...

A Mother Fights For Her Child's...

Northwest Airlines KidCares



The 9th Annual NF International Summer Camp

Sponsored by the Children's Tumor Foundation

New Camp

July 16th -July 22nd, 2005

Camp Tuition: \$600 (not including airfare)

Reunion Camp

July 23rd -July 29th, 2005

Camp Tuition: \$600 (not including airfare)

Send your child for a week of fun and learning at the NF Camp where they will visit Salt Lake City, UT. Campers will spend a few days at Camp K, enjoying the ropes course, arts and crafts as well as fun day trips to see AAA baseball games, visit 12,000 foot Snowbird mountain, lots of swimming, hiking, horse back riding, camp fires, dances, a talent show, fishing and more.

The purpose of the Reunion Camp is to reunite old campers. This camp provides an opportunity for friends to catch up. Campers will enjoy activities similar to those of the New Camp and also participate in a new and revised program.



A unique feature of our camp is the visit to the University of Utah's Eccles Genetic Science Learning Center, where campers take a tour of a working genetics lab, perform hands-on experiments and have the chance to talk one-on-one and ask questions of an NF researcher. The kids always enjoy being scientists for a day and learning about NF and genetics in a fun, interactive way.

For more information, please visit the Foundation's website at www.ctf.org or contact the camp's "Mama" Jacqueline Medina at jmedina@ctf.org or 1-800-323-7938 x232.

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The mission of the Children's Tumor Foundation, Inc. is to improve the well-being of patients and families affected by NF1, NF2, and Schwannomatosis. The Foundation 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 Children's Tumor Foundation is a founding member of the International Neurofibromatosis Association.