

SUCCESSFUL GALA SEASON RAISES MILLIONS FOR NF RESEARCH

Glamorous Night at The Plaza in NYC Raises Over \$925,000

Moffett Family Matching Fund Drives Total to \$1.3 Million



Hundreds gathered at The Plaza hotel on October 30, 2014 for The Benefit New York, one of the Children's Tumor Foundation annual galas, and helped raise over \$925,000 to support research to end neurofibromatosis (NF). The Plaza's glamour added to the splendid evening of poignant speeches, auction bidding, and live music.

This year's medical Children's Humanitarian Award was given to Jaishri Blakeley, MD, Director of the Johns Hopkins Comprehensive Neurofibromatosis Center, for her contributions to advancing the development of clinical trials and drug research for neurofibromatosis.

Highlighting the unique contributions of the racing community, who as part of the Foundation's Racing4Research program utilize professional auto racing as a vehicle to amplify awareness and raise funds for NF

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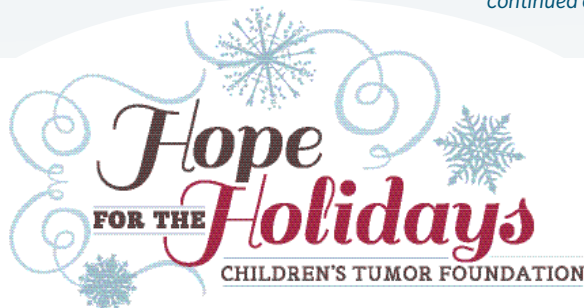
The beNeFit II: A Superhero Soirée to Conquer NF Raises \$3 Million in Detroit

Batman and Superman were spotted in the Motor City with more than 1,100 Detroiters, many in superhero costumes, who opened their hearts and generously donated \$3 million to defeat neurofibromatosis (NF) at the second annual Detroit beNeFit to raise awareness and funds for the Children's Tumor Foundation (CTF) on November 22nd.

The event, titled "The BeNeFit II: A Superhero Soirée to Conquer NF," was hosted by Jennifer and Dan Gilbert and countless volunteers, supporters, and donors, and featured an appearance by their son, Nick Gilbert, who lives with NF and is a longtime CTF ambassador.

The caped crusader and Clark Kent weren't the only superheroes in Detroit that night. The Moss family - Philip Sr., Renie, Philip Jr., age nine (also known as "Little Philip") and Helen, age six - came from Birmingham,

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Meet Bennett, age six. He lives with NF 1. After enduring 58 weeks of chemotherapy that ended just before Christmas last year, Bennett learned over the summer that his treatments were working: no new growths; tumors under control. This year, his hope for the holiday is to receive an electric race-track and some Hot Wheels Color Shifter cars.

At this time of year, children all over the world search through catalogues, peer into store windows and compile a list of gifts they hope to receive during the holiday season. Bikes, dolls, chemistry kits, and video games top the lists of so many young ones.

ctf.org/hope

The millions of people living with neurofibromatosis often have different lists: less chemotherapy, fewer doctor appointments, reduced tumor size, more days without pain. Our NF Heroes and their families hope for a time when they don't have to worry about NF at all. At the Children's Tumor Foundation, we are working relentlessly to fulfill that hope.

For more information on Hope for the Holidays, and a chance to double your donation, please visit www.ctf.org/hope.

"There is hope in dreams, imagination, and in the courage of those who wish to make those dreams a reality." —JONAS SALK

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LETTER FROM THE PRESIDENT

Annette Bakker, PhD



Visionary...Bold... Hopeful.

I heard these incredible adjectives repeatedly at our recent NYC Gala as our guests reflected on the dynamic large-scale artwork created by our 2014-15 Ambassador, Jeffrey Owen Hanson. It is easy to be drawn into Hanson's work. Vividly colorful, three-dimensional, and entirely unique, his art is an inspiration to all of us at the Children's Tumor Foundation.

I sense a profound connection between Hanson's masterful paintings and the work we are doing at the Foundation. Driven by a bold belief in the value of greater collaboration between scientists, over the last three years we have transformed from a foundation that funds cutting-edge science to one that catalyzes the drug discovery process. We designed and implemented a visionary new business model to ensure that every group of stakeholders in neurofibromatosis research—patients, scientists, doctors, pharmaceutical companies, and the biotechnology field—is integrally involved in the drug discovery process.

This model is revolutionary; it is transforming the world of NF research. Over 75% of all NF clinical trials were informed by investments from CTF. We have built an incredible network: over 4,300 registrants in our NF Registry and growing, 47 NF Clinics across the country, top researchers working in collaboration through Synodos for NF1 and NF2 as well as the Neurofibromatosis Therapeutic Consortium, and rapidly increasing interest from both biotechnology and pharmaceutical companies. Today, we are providing drug discovery, data visualization, and contract negotiation services to our academic scientists and investing in early phases of preclinical research to de-risk potential compounds for the pharmaceutical industry.

Our business model is, by design, multifaceted. As each of these facets grows, our need for sustained funding increases. We would not, for example, open a tissue biobank, then put it on pause for a year due to lack of funding. We cannot tell an industry partner we aren't able to follow through on our commitment to the development of a promising new compound. It wouldn't make business sense. Additionally, we have bold goals for 2015. We need to continue to grow the NF Registry and NF Biobank: the more highly populated these resources, the greater the interest from all other facets of our system. We also plan to provide open access to tissue sample data for researchers all over the world. This effort will accelerate the drug discovery process exponentially.

An increasing number of donors have been inspired by our creativity and our bold vision of the future. We are deeply grateful to the Moffetts for their \$2.5 million matching gift fund and equally thankful to every single donor who has given to the Foundation. Our hopes are high; we know wholeheartedly that the collaboration driven by our model is how we will End NF.

New Chair of the Children's Tumor Foundation Board of Directors

The Children's Tumor Foundation is pleased to announce Linda Halliday Martin as the new Chairperson of the Board of Directors. Martin, a Partner at Simpson Thacher & Bartlett, received her Bachelor of Arts, *cum laude*, from Harvard University, and received her Juris Doctorate, *cum laude*, from Duke Law School. Martin's youngest son was diagnosed with NF1 in 2000, and she has been involved with the Foundation since 2007. For more information please visit bit.ly/1Aup9qk.



"Learn from yesterday, hope for tomorrow." – ALBERT EINSTEIN

FIRST OPTIC PATHWAY GLIOMA MULTI-CENTER CLINICAL STUDY

Co-Funded by the Children's Tumor Foundation and the Gilbert NF Institute

On November 3rd, a group of 50 physicians involved in a major study of optic pathway gliomas (OPG) gathered at a CTF-sponsored kick-off meeting hosted by Dr. Michael Fisher at the Children's Hospital of Philadelphia. The group was eager to join forces and tackle questions that NF clinicians have been pondering for years.

Optic pathway gliomas are low-grade astrocytomas that occur in 15-20% of children with NF1. The majority of OPGs are diagnosed before the age of seven years. Although rarely life-threatening, these tumors can cause significant health issues including vision loss, disfiguring proptosis, and precocious puberty. OPGs are not typical tumors. Half to two-thirds show minimal tumor progression. When they do progress, they tend to grow slowly.

As of today, the decision to institute therapy is still a tremendous challenge for clinicians because the effects of OPGs are highly unpredictable and no real prognostic markers for progression (predictors) have been identified.

Some clinicians advocate treatment when there is either radiographic progression (by MRI) or visual deterioration, while others reserve treatment only for patients that clearly have visual deterioration.

Because of the lack of clinical management consensus among NF1-OPG clinicians, there is a tremendous unmet medical need to



determine the criteria that the clinicians need to make the decision to initiate treatment of their OPG patients.

For that reason, CTF and the Gilbert Family Neurofibromatosis Institute have bundled their efforts to co-fund the biggest clinical OPG study ever.

The study is led by two top principal investigators of the NF field: Dr. Michael Fisher, a neuro-oncologist, and Dr. Robert Avery, an ophthalmologist. Twenty-five top clinical OPG centers from across the world will work together for five years to develop clear consensus criteria for OPGs.

Anticipated outcomes include the following:

- At the end of this five-year study, clear criteria will exist to decide whether an individual patient should be treated or not
- The consortium members will use the prior-developed REINS (Response Evaluation in Neurofibromatosis and Schwannomatosis) Initiative criteria to measure vision loss
- CTF will have added to the study budget to allow blood collection for future biomarker studies to further support the decision making

OHIO NF2 GATHERING 2014

The Ohio NF2 Gathering is an annual social and educational event for those with NF2, their families, and their friends. This year it was held October 10-12 in Grove City, OH at the Drury Inn & Suites and had a record attendance of 71 people from 20 states and Canada.

The weekend included a presentation by Dr. Stephen Smith and his Fellow, Dr. Chaz Stucken, from Ohio State University (OSU), on facial issues and surgery procedures for NF2. In addition, Dr. Brad Welling, MD, PhD, gave a video presentation, and Salvatore La Rosa, PhD, from the Children's Tumor Foundation, spoke about the Synodos for NF2 program. Also, Dr. Oliver Adunka was introduced as the new head of Otolaryngology at Ohio State University, and Dr. Long-Sheng Chang, who is part of CTF's Synodos for NF2 initiative at OSU/ Nationwide Children's Hospital, also attended the meeting.



2014 SCHWANNOMATOSIS AWARDS:

Founded in 2007, the Children's Tumor Foundation Schwannomatosis Awards have funded over \$1 million worth of research into this area of neurofibromatosis. The Foundation is pleased to announce the latest grantees of this award.

Miriam Smith, PhD
University of Manchester

Schwannomatosis Genomes

Schwannomatosis is characterized by non-vestibular, non-intradermal schwannomas. Schwannomatosis is caused by germline mutations of SMARCB1 and the newly identified gene, LZTR1. This Schwannomatosis Award aims to identify new genes involved in schwannomatosis using whole genome sequencing. The discovery of a new gene predisposing to schwannomatosis will help doctors better understand the disorder and introduce a new clinical approach to disease management.



James Walker, PhD
Harvard Medical School

Developing a Schwannomatosis Cell Model Using CRISPR/Cas9 Genome Editing

Schwannomatosis is a late-onset tumor predisposition disorder, distinct from neurofibromatosis types 1 and 2. CRISPR/Cas9 is a powerful technique for precise editing of the genome of cells. Dr. James Walker will use immortalized human Schwann cells to model schwannomatosis by introducing patient-specific mutations targeting NF2, SMARCB1 and LZTR1 using CRISPR/Cas9. In this way, he will generate a series of Schwann cell lines that have mutations in NF2 and SMARCB1 or LZTR1, mimicking the situation in schwannomas, and forming the basis of an in vitro schwannomatosis model.



2014 DRUG DISCOVERY INITIATIVE AWARDS: Round 2 Recipient

The Drug Discovery Initiative (DDI) awards program is focused on seed funding preclinical drug testing studies on neurofibromatosis in cell or animal models, and is one of the most successful Children's Tumor Foundation programs to date. The Foundation is pleased to announce the most recent recipient of this important grant.



Florent Elefteriou, PhD
Vanderbilt University

A Dual Trametinib-BMP2 Treatment to Promote Bone Union in NF1

Children with neurofibromatosis type 1 (NF1) can present with skeletal dysplasia, including bowing of the tibia that often leads to fracture and does not heal (pseudarthrosis). This condition requires repeated and invasive surgeries, and is associated with extreme morbidity. Dr. Elefteriou has recently shown that combined MEK inhibition with BMP2 stimulation promotes bone healing in models of NF1 pseudarthrosis. This DDI award will allow Dr. Elefteriou to collect crucial preclinical data to support the use of Trametinib and BMP2 to promote bone repair in children with NF1 pseudarthrosis, which may lead to a clinical trial.

Plastic Surgeon's Work on NF1 Patients Promising

In September, the French plastic surgeon Professor Laurent Lantieri gave a spectacular presentation at the European NF meeting in Barcelona during which he showed the incredible benefit of surgery in certain cases of NF1. Dr. Lantieri has operated on over 600 patients including two face transplants in extreme cases. His work is able to show clear statistics on outcomes. Dr. Annette Bakker invited him to New York and organized a meeting with Dr. Michael Fisher, a top neuro-oncologist in the NF field, on November 4th to identify next steps.



CTF RESEARCH AWARD APPLICATION DEADLINES

Synodos for NF1 applications due Friday, January 16, 2015. Please visit ctf.org/Research/Synodos-for-NF1.html to apply

Young Investigator Award pre-applications due Monday January 19, 2015. For more information please visit www.ctf.org/YoungInvestigatorAwards

Neurofibromatosis Therapeutic Acceleration Program-National Center for Advancing Translational Sciences Cell Culture Meeting

The Neurofibromatosis Therapeutic Acceleration Program (NTAP) was established with a goal to identify and accelerate effective therapeutics for plexiform neurofibromas (pNF) by bringing NF experts and researchers together at The Johns Hopkins School of Medicine in 2012. As a part of the NTAP program, the cell culture initiative was launched to generate cell culture systems that represent pNF complexity and can be utilized to both screen new compounds and identify novel therapeutic targets. Since the initiation of the project, human and mouse cell lines for pNF and malignant peripheral nerve sheath tumors (MPNST) have successfully been screened for potential candidate drugs at the National Center for Advancing Translational Sciences (NCATS).

The NTAP-NCATS Cell Culture Meeting was held at NCATS on September 18, 2014 to review the project's progress and determine the best path forward. All participating investigators (and a CTF scientist) attended the meeting, reviewed the drug screen data generated to date, and discussed the next steps for making the choice of which drug candidates to bring forward to in vivo studies.

The NTAP team made an informed decision about the future direction based on the provided input at the discussion. Ultimately, the project will provide open data access to facilitate data sharing and streamline the process of therapeutic development within the NF scientific communities.

Biobank Consensus Meeting

As the Children's Tumor Foundation (CTF) Biobank begins to expand, the need for a set of standard operating procedures has become clear. Thus CTF decided to bring together a group of leading experts for a Biobank Consensus Meeting last October. The international group met to agree on recommended guidelines for sample processing, data collection, and data sharing for all CTF Biobank materials.

When the CTF Biobank was launched in 2013, its first project was to collect dermal neurofibroma tissue from a single surgeon's practice. This initial project gave the Foundation experience in banking tissues and data in a way that allows consistent, high-quality samples to be made available to qualified researchers. As the Biobank moves toward being able to accept samples from a wide range of medical centers, having best practices guidelines in place will ensure that the same high quality and consistency continues.

The consensus meeting, held in London on October 25th, was very productive. At the end of the day, the group had agreed on standard operating procedures and on the clinical data to include with each sample. The group also explored the concept of "virtual" biobanking in which the samples are stored in different institutions, but shared among research groups.

HOW DOES A BIOBANK WORK?

A biobank is an organized collection of human biological material including blood, urine, and tissue (such as tumors removed during surgery). Patient confidentiality is maintained because the materials are identified only by barcodes. Samples sent to the biobank are portioned into many small containers and stored at subzero temperatures. At that point, researchers from all over the world may request their use. Because all receive identical samples, it is possible to get a truer comparison of experimental results from different groups of researchers.

SAVE
THE *Date*

2015 NF CONFERENCE
JUNE 6 - 9, 2015

PORTOLA HOTEL & SPA | MONTEREY, CA

"Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence." —HELEN KELLER

RESEARCH NEWS

FLASHES OF HOPE FUNDS KEY PROJECTS



FLASHES of HOPE

Flashes of Hope is an organization that raises funds to accelerate a cure for children's cancer while honoring the unique life and memories of every child fighting cancer through photography. Founded in 2001 by the parents of a child with cancer, Flashes of Hope has photographed 39,505 children and raised millions of dollars for pediatric cancer research.

This year, at their annual "Big Shots and Little Stars" event, Flashes of

Hope chose to designate the \$300,000 raised during their auction to malignant peripheral nerve sheath tumor (MPNST) research. Additionally, Flashes of Hope will add funds from other initiatives to bring their total contribution to CTF to \$400,000!

This donation will support specific research projects within Children's Tumor Foundation-sponsored research including Young Investigator Award grants and NF Therapeutic Consortium (NFTC) preclinical drug trials in the areas of MPNSTs and plexiform neurofibromas. The Foundation salutes and thanks Flashes of Hope for their ongoing support.

FOUNDATION NEWS

Glamorous Night at The Plaza *(continued from page 1)*

research, Park Place Motorsports, Vess Energy, and Compass360 Racing were recognized with a Children's Humanitarian Award for their steadfast support and commitment to the well-being of NF families. Patrick Lindsey, Mike Vess, and Karl Thomson, respectively, accepted and spoke poignantly about the impact meeting NF families has had on them, both on and off the track.

In addition, philanthropic artist Jeffrey Owen Hanson was honored as the 2014-15 Children's Tumor Foundation Ambassador for demonstrating great courage in dealing with obstacles while living with NF. Jeff created the original artwork

that adorns the CTF Art Cars, a collection of four race cars that captured eleven podiums, four of which were from the two cars that were parked outside The Plaza on the night of the gala.

Excitement and generosity surged throughout the evening, first during the Paddle Raise and later during the live auction. The Moffett Family Matching Gift Fund doubled the money donated during the Paddle Raise to support the Foundation's consortium science effort Synodos for NF1, driving the total



contributions from the event to \$1.3 million.

Veteran sports broadcaster and former Indy-Car driver Brian Till served as Master of Ceremonies, and the Dexter Lake Band provided musical entertainment for an evening that was enjoyed by all.

The beNeFit II: A Superhero Soirée *(continued from page 1)*

Alabama to accept the second annual CTF "Strength and Honor" award.

Little Philip, Philip Sr., and Helen have all been diagnosed with NF. Little Philip is currently undergoing chemotherapy for a tumor in his neck. Helen and Philip Sr. don't currently show any manifestations of NF.

"When we see you all here tonight, we are strengthened knowing that your support brings us close to a cure in our children's lifetime," said Renie Moss, while accepting the award. "Thank you for honoring our family, along with the more than two million people living with NF worldwide."

Annette Bakker, CTF President and Chief Scientific Officer, was also there to wish the Moss family well. "Nights like tonight give me the hope that, indeed, together we will make NF history," Dr. Bakker said.

Linda Halliday Martin and Stuart Match Suna, current and past CTF Board Chairs, were at the event, as was Laurée Moffett. Laurée and her husband, Jim Bob Moffett, joined an anonymous donor in offering a match for the research auction, resulting in donations to that auction being tripled.

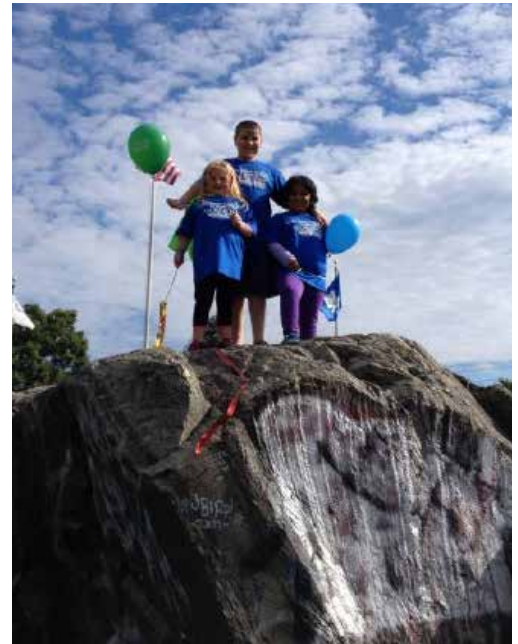
To learn about the Moss family's battle with NF, please watch this video: bit.ly/1z8y9Oc



"Don't give up. Don't lose hope. Don't sell out." –CHRISTOPHER REEVE

WALKING TOWARDS AN END TO NF: Every Step Makes a Difference

Whether you walked, ran, donated, volunteered, sponsored, or helped organize an event, the NF Walk team would like to express its sincere gratitude for all of the time, effort, and passion that you put into making this yet another successful year. Thanks to your efforts, the NF Walk program raised nearly \$1,000,000 for NF research!



CONGRATULATIONS

*and Thanks to all of our
Autumn NF Walk Events!*

- Addison Oaks NF Walk
- Atlanta NF Walk
- Bideford NF Walk
- Central Jersey NF Walk
- Columbus NF Walk
- Dallas NF Walk
- Denver NF Walk
- Idaho NF Walk
- Iowa NF Walk
- Jacksonville NF Walk
- Los Angeles NF Walk
- Milwaukee NF Walk
- Phoenix NF Walk
- Putnam NF Walk
- Richmond NF Walk
- Rochester NF Walk



“There was never a night or a problem that could defeat sunrise or hope.” –BERNARD WILLIAMS



Choose Your Own Event

Two Choose Your Own Event participants went above and beyond to help NF Endurance surpass its fundraising goal of \$150,000; currently almost \$200,000 has been raised! Morgan Phelps participated in the St. Louis Rock 'n' Roll Marathon & Half Marathon in honor of her cousin, Maria, and raised \$14,000 to help end NF. Participant Kristina Rath completed the Nu Hartford Marathon for her NF Hero daughter, Jane, and raised nearly \$20,000 and counting.



RACE ACROSS AMERICA

NF Endurance team members Lesley Oslica, Angela Earle, Evelyn Brinkley, and Hannah Turnbough will participate in a 3,000 mile bike ride in June 2015. The women will sprint from Oceanside, CA to Annapolis, MD in eight days on behalf of their NF Heroes, Katie and Kylie, daughters of two of the riders.

The team's goal is to raise at least \$100,000 for NF research. Longtime CTF supporters Jim Bob and Laurée Moffett have pledged a \$2.5 million matching gift to the Foundation. Therefore, all donations made to this RAAM team will be matched dollar for dollar. Please visit <http://ctf.kintera.org/nfeRAAM2015> to make a contribution.



THE TCS NEW YORK CITY MARATHON

The TCS NYC Marathon took place on Sunday, November 2, 2014. Fifty-one NF Endurance team members toed the start line in Staten Island for a 26.2 mile tour of New York City, and raised \$185,000 and counting for NF research!



IRONMAN Florida

The Children's Tumor Foundation was the official charity partner for the 2014 IRONMAN Florida event which took place on November 1st. The NF Endurance team included 117 athletes who raised \$700,000! Because of this partnership with IRONMAN, CTF had the opportunity to address 2000 athletes at a dinner for participants about the mission of the Foundation and the NF Hero Program. NF Heroes also held the finish tape for the first female and first male finishers of the race.

The Children's Tumor Foundation was the beneficiary of the IRONKIDS race at IRONMAN Florida as well. Four hundred children participated in the race wearing CTF T-shirts or their Halloween costumes.

The Children's Tumor Foundation will again be the official charity partner for IRONMAN Florida in 2015!



“Hope is patience with the lamp lit.” – TERTULLIAN



SIGN UP TODAY!

There is still time to sign up for the upcoming 2015 Rolex 24 at Daytona weekend on January 23-25. Join the Foundation in Florida for all of the fun, excitement, and comradery of race weekend! Visit racing4research.org or contact jbeck@ctf.org to learn more!
FUN IN FLORIDA #ENDNF #FUELTHECURE



Racing4Research Thanks Our Partners Who Donated to The Benefit New York Gala



"I hope I can make an impact in this world. Even one painting at a time." –JEFFREY OWEN HANSON

MEET THE BOARD

Tracy Galloway



HOMETOWN:

Greenville, SC

CURRENT TOWN:

Cornelius, NC

EDUCATION:

B.S.B.A. in Finance and Statistics from the University of South Carolina

WORK WITH THE FOUNDATION:

I have been a Member of the Board of Directors since 2011, and I primarily represent families affected by NF2. My work with the Foundation has revolved around promoting the Foundation and its mission with researchers, scientists, and clinicians to encourage an atmosphere of collaboration. On behalf of CTF, I have attended several NF2 State of the Art conferences both in the U.S. and abroad, have attended four NF scientific conferences, and have visited many research labs across the country. I have enjoyed working with the Development Department to raise funds, have lobbied in Washington, D.C., and am currently working with the Board's Government Relations Committee. I also sit on the steering committee for Synodos for NF2. I consider myself a jack-of-all-trades and am here to happily serve my fellow NF families in whatever capacity CTF needs.

FAVORITE EXPERIENCE WITH THE FOUNDATION:

It was a true honor to represent the NF2 community, and my daughter, when I gave a presentation about the need for immediate treatments at the kickoff meeting for Synodos for NF2 this past February in Boston.

FAVORITE HOBBY:

I am an amateur apiarian (beekeeper)! I really enjoy learning more everyday about these extremely important contributors to our planet.

MEET THE STAFF

Salvatore La Rossa



HOMETOWN:

Messina, Italy

CURRENT TOWN:

Astoria, Queens, NY

EDUCATION:

MSc in Chemistry from the University of Messina in Italy, and a PhD in Medicinal Chemistry from the University of Strathclyde in Scotland

WORK WITH THE FOUNDATION: I am the Senior Director of Research and Development. I focus primarily on the interaction of Pharma/Biotech companies and academic researchers who have interesting ideas on potential treatments for NF. I also manage some of the Foundation's science consortia including Synodos for NF2 and the NF Therapeutic Consortium. My expertise is in helping translate early ideas into clinical benefit, making sure that we have all the elements needed for projects to successfully progress.

FAVORITE EXPERIENCE WITH THE FOUNDATION:

I joined the Foundation in April 2013 and attended my second NF Conference this year. I remember my first NF Conference as a very busy event, trying to catch up and meet everybody for the first time. This year, instead, I was able to enjoy the gathering a bit more, especially since it was held in conjunction with the NF Forum. Having the whole community of researchers and patients together at the event's joint dinner was an exhilarating experience. Seeing everybody contributing to the cause and observing the group together really gave me a boost. Listening to speeches by Bailey Gribben, the CTF Ambassador, the NF researchers, and Dr. Francis Collins, the Director of the National Institutes of Health, was an incredible experience. I left the weekend feeling that we are close to a major advance in the fight against NF.

FAVORITE HOBBY: While in Messina, I completed a full course of study in piano at the Music Conservatory. Then I decided to pursue a career in science. Since then, playing the piano has become my favorite hobby.

NEW FACES AT THE CHILDREN'S TUMOR FOUNDATION

Welcome to the Foundation's newest staff members!



David Webber

Vice President of Finance and Operations
dwebber@ctf.org



Rebecca Silver

Public Relations Manager
rsilver@ctf.org

"The capacity for hope is the most significant fact of life. It provides human beings with a sense of destination and the energy to get started." —**NORMAN COUSINS**

I ENCOURAGE ALL NF FAMILIES TO GO TO THE NF FORUM! By Alexandra Sedor

On a beautiful June morning, our family joined dozens of other NF families wearing the Children's Tumor Foundation's signature blue T-shirt and marched through the streets of Washington D.C. to the National Zoo. It was a fantastic day and the culmination of a wonderful weekend at the Foundation's annual NF Forum.

The factual information we received at the Forum was important: well-known doctors and researchers provided the latest updates on clinical trials, NF treatments, and medical advances.

However, for our family, it was the personal interactions that made the weekend so worthwhile. On the very first evening, I connected with other NF patients in the intensely personal way that only comes from having a shared disease. For our

children, the chance to meet so many other NF families showed them that they are part of a larger community, that other families are successfully living with NF, and that we are all in this together. Most of all, we had lots of fun throughout the weekend and realized that some very positive experiences come from being an NF family.

SAVE THE DATE

APRIL 17-19, 2015
NF FORUM | SCOTTSDALE, AZ

Save the date for our **7th Annual** NF patient and family support forum at the DoubleTree Resort in Scottsdale, Arizona. **Meet other NF families, learn from NF experts, and more!**



I'm so grateful that we were able to attend the NF Forum and I encourage all NF families to go to the next one if you can!

STORIES OF NF: *Jai Thomas*

"I was born with neurofibromatosis. Growing up, I was always told what my limitations were and I believed what I was told. I never tested my abilities to see what I was capable of doing. I felt alone, lost, with no place of acceptance or belonging. Through my school years, I was the only one with a physical disability. That's not how I wanted to be perceived.

"I let other people's comments prevent me from growing, exploring, and achieving my life's purpose. It wasn't until my sister, Monique, pushed me out of the nest that I learned to spread my wings and fly. She found me an apartment and helped me move into it. I was terrified at first; I didn't know

how I was going to manage on my own. Little by little, I started breaking out of my comfort zone. I was growing, learning, and living my life. My attitude changed and I accomplished independence.

"We all have different challenges in life whether physical, mental, or emotional. I believe that everyone has abilities, including me. I just have to focus on the things I can do, not the things I can't. I look at myself as being 'abled,' not disabled. We should all focus on our strengths. Accomplishing any challenge, no matter how big or small, is the best feeling a person can have; this is what I believe."



"Hope is important because it can make the present moment less difficult to bear. If we believe that tomorrow will be better, we can bear a hardship today." –**THICH NHAT HANH**

REGIONAL NEWS

Great Events from Across the NF Community

The Foundation has a presence in nearly all 50 states and facilitates local patient support groups, medical symposia, and fundraising events. Learn more about the Children's Tumor Foundation Chapter in your area by visiting www.ctf.org/communityrelations.

CALIFORNIA

The California Chapter participated in the Annual CBS 4th of July Festival at CBS Studio Center for the third year in a row. The entertainment included a kids fun zone, magic shows, face painting, a pirate dunk tank, mermaids, and much more.



INDIANA

In October, Stephanie and Matt Reeve held a fundraising dinner party at their home to benefit the Children's Tumor Foundation. Catered by local restaurant Chuy's, over 60 people enjoyed an evening of cocktails, food, and camaraderie while raising more than \$4,500 for NF research.



CALIFORNIA

The California Chapter hosted their 2nd Annual Elks Mega Golf Tournament in honor of NF Hero Dakota Anderson on September 27th in Atwater, CA. The event raised \$6,000 for the Racing4Research program.



NEW YORK

On November 15th - December 31st, an exhibit entitled *Unwavering Truth: Archive of Our Own* will be on display at the Queens Museum in New York City. It seeks to present an honest look at people with NF2 and presents works of art by artists with NF2 or artwork related to NF2, meant to depict the emotional truth underlying the thought processes of someone with NF2, while demonstrating that there is more to the artist than just the disorder. In an accompanying video to be played at the exhibit, Kristina Diaz discusses her experience with the disorder throughout her life. She will tell her story in relation to artist Nathalie Trytell who passed away fighting the disorder in 2011 while striving to maintain her artistic voice despite diminishing physical ability to do so. Viewers will see the progression over time as NF2 has long-term effects that take their toll on people both physically and emotionally.



"There is no medicine like hope, no incentive so great, and no tonic so powerful as expectation of something tomorrow." –ORISON SWETT MARDEN



COLORADO

The Colorado Chapter hosted their Annual Summer Picnic on August 2nd at Mid Field Park in Bloomfield, CO. Over 50 members of the Denver NF community attended, many of whom were new families. Entertainment included a storyteller and a visit from Hello Kitty.



FLORIDA & WASHINGTON, D.C.

In September and October, the CureNFwithJack team held their annual golf tournaments in West Palm Beach, FL and Washington, D.C. to benefit the Children's Tumor Foundation. More than 200 golfers, including golf legend Jack Nicklaus, participated in the tournaments and the events raised over \$50,000 for NF research!



UTAH

The Utah Chapter hosted their annual NF Symposium on September 20th in Salt Lake City at Shriners Hospital for Children.



COLORADO

Children's Hospital in Denver hosted a support group on Oct. 5th so that members of the Colorado NF community could meet and share. Special thanks to Chili's Restaurant for donating the evening's food.

"Hope is a talent like any other." –STORM JAMESON



MASSACHUSETTS

On October 25th, over 200 people attended the Foundation's annual New England Gala at the Boston Marriott Cambridge. The event raised \$90,000 for NF research and honored Dr. Andi McClatchey of Massachusetts General Hospital, the Burke family of CureNFwithJack, and Risha and Paul Samuelson. The evening included live and silent auctions, music provided by Karisma Events, a photo booth, and delicious food.

NEW YORK

Saturday, November 1st, was a night to remember in Huntington, Long Island, at Coindre Hall. Laura Perfetti, Cristina Spoto, and Jill Hannity threw an amazing event entitled Cocktails for a Cure and raised approximately \$160,000 for NF research! The evening included delicious catering at a lovely venue and exciting auction prizes. The Foundation is beyond grateful to Laura, Cristina, and Jill, and can't wait until Cocktails for a Cure 2015!



WASHINGTON

The Washington Chapter hosted an indoor charity cycle event on September 13th at Columbia Athletic Clubs at Pine Lake in Sammamish, WA. The Pine Lake Club has two families that are affected by NF. One hundred percent of the proceeds were donated to the Children's Tumor Foundation.



CALIFORNIA

The California Chapter hosted a Spanish NF Symposium on September 20th at Children's Hospital Los Angeles. Several new families attended and found it very helpful.

“Hope is the thing with feathers that perches in the soul - and sings the tunes without the words - and never stops at all.” –**EMILY DICKINSON**

SHOP TO END NF

This holiday season (and all year round), your online purchases can benefit the Children's Tumor Foundation.

Here's how:

The Children's Tumor Foundation Official Store

Whether it's an End NF t-shirt or a Children's Tumor Foundation baseball cap, you'll look great and spread awareness. Buy for your friends as well!

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NF News is the official publication of the Children's Tumor Foundation and is published quarterly. All issues are available on our website at www.ctf.org. Please direct any questions or feedback to the editor (listed below).

The Children's Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to finding effective treatments for the millions of people worldwide living with neurofibromatosis (NF), a term for three distinct disorders: NF1, NF2, and schwannomatosis. NF can cause tumors to grow on nerves throughout the body and may lead to blindness, bone abnormalities, cancer, deafness, disfigurement, learning disabilities, and excruciating and disabling pain. NF affects one in every 3,000 people, more than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's disease combined. The Children's Tumor Foundation funds critical research into neurofibromatosis. In addition to benefiting those who live with NF, this research is shedding new light on several forms of cancer, brain tumors, bone abnormalities, and learning disabilities, ultimately benefiting the broader community. For more information, please visit www.ctf.org.

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