

NIH Director Delivers Keynote Address at 2014 NF CONFERENCE AND NF FORUM DINNER

Dr. Francis Collins, MD, PhD,
Director of the National
Institutes of Health

The Children's Tumor Foundation was honored to have Dr. Francis S. Collins, MD, PhD, Director of the National Institutes of Health (NIH), deliver the keynote address at a joint dinner of the NF Forum and the NF Conference on June 7, 2014 in Washington, D.C.

Dr. Collins is a physician-geneticist noted for his landmark discoveries of disease genes, including the NF1 gene, and his leadership of the international Human Genome Project, a finished sequence of the human DNA instruction book. He served as director of the National Human Genome Research Institute at the NIH from 1993-2008, and in his role as the NIH Director he oversees the work of the largest supporter of biomedical research in the world.

Dr. Collins was introduced by his childhood friend, Linn Barton of Elgin, Texas, who lives with NF1. The two met in the sixth grade and hadn't seen each

other since high school. Dr. Collins did not know that Mr. Barton would be at the dinner and was visibly moved to see his old friend again.

In his speech, Dr. Collins spoke about the encouragement he takes from advancements being made in NF research, and mentioned how happy he was to see in attendance some of the scientists and clinicians that he worked with in the NF field including Dr. Peggy Wallace, PhD, Dr. David Viskochil, MD, PhD, Dr. Eric Legius, MD, and Dr. Brigitte Widemann, MD.

At the conclusion of his speech Dr. Collins stated, **"If you asked me as NIH Director which two areas are most 'on fire' as far as research excitement and promise, I would say neuroscience and cancer. Where do those two fields come together? NF. So that ought to lead to an increasing attention level of many scientists toward finding answers for the condition that all of you care deeply about, and I do too."**

\$2.5 MILLION MATCHING GIFT ANNOUNCED

Longtime supporters of the Children's Tumor Foundation, Jim Bob and Laurée Moffett, have exhibited their generosity once more in the fight against NF, with a \$2.5 million matching gift

donation to the Children's Tumor Foundation. Announced by Foundation president Annette Bakker at the NF Conference/Forum dinner on June 7th, in front of a crowd of over 600 attendees including NIH Director Francis Collins, the donation is in support of the Foundation's consortium science effort called Synodos for NF1.

"This generous pledge from the Moffetts comes at a transformative moment in NF research, and will have significant impact in the development of new treatments for NF," said Dr. Bakker. "On behalf of the entire NF community, we are deeply grateful for their ongoing and deep commitment in the fight to end NF".

Synodos is an innovative approach developed by the Children's Tumor Foundation in developing treatments for NF through a multidisciplinary consortium of scientists from various backgrounds and institutions, all committed to collaboration and data-sharing so as to lead to faster and better treatments. Synodos for NF2 is underway; this gift from Mr. & Mrs. Moffett will launch Synodos for NF1.

Additional details about how you can participate in and leverage this matching gift opportunity are to come throughout the summer and fall. Please visit ctf.org, our social media pages, and future editions of NF News for updates.

Thank you, Jim Bob and Laurée Moffett!

Awareness Month Photo Contest Winners

To see all the entries, visit [facebook.com/childrenstumor](https://www.facebook.com/childrenstumor)



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LETTER FROM THE PRESIDENT

Annette Bakker, PhD

The last few months have been just amazing. It is not only extremely rewarding to lead a staff that is so dedicated to ending NF; it is also very encouraging to work with a Board that is really committed. The NF community is in a real revolution - all stakeholders (clinicians, researchers, industry partners, government, and patients) are teaming up to defeat NF.

It is all about speed these days: We are building bridges, empowering the patients, breaking the walls, offering the platforms, and executing the processes to ensure that key discoveries in the academic labs get translated into the clinical benefit that patients need.

All the platforms (including the existing grant awards, the NF Biobank, the NF Registry, our drug compound scouting, etc.) and processes (NF Therapeutic Consortium, Synodos, etc.) have been implemented in a strategic business model that has received a tremendous amount of media attention. From the business model it is clear that ALL stakeholders are, and need to be, part of this master plan. No one can stay on the side and wait!

The patients are standing up, no longer content to "wait and see" anymore:

- We have approximately 4,000 registrants in the NF Registry! This is a tremendous motivator for industry to invest in NF. It is also a vital tool in finding people who are eligible to participate in clinical trials. Patients have already been invited to participate in six clinical trials.
- Because of YOU, we now have enough data to do a first-of-its-kind large statistical analysis to study which conditions are most represented, to understand if certain NF manifestations group together, and to identify who we are missing, etc. You want to have your confidential data in this mega analysis. Register or update your profile now at www.nfregistry.org.
- Many patients have agreed to share their dermal neurofibromas with our NF Biobank. Although the Biobank was only opened less than a year ago, today we already have over 150 dermal neurofibromas banked. Not only do we bank the tumors, the Foundation is now funding a pathology analysis by two top NF pathologists. The Foundation is committed to offering full analysis of all tumors and sharing the anonymized data openly with the entire community. The knowledge that we will gather from the analysis of these tumors will lead to new discoveries and better treatments.
- The patients have been exceptionally creative with active media, fundraising, and lobbying.

Our donors are remarkably generous. I am very proud and happy to announce that we have received a significant number of large and small donations in the first half of this year. I would especially like to thank Mr. and Mrs. Jim Bob Moffett who have decided to make a \$2.5 million matching gift donation to a consortium science effort called Synodos for NF1. There will be more information on this in the next newsletter.

Because of all of you, the Foundation was able to create three to five year commitments in consortia such as the NF Preclinical Consortium (NFPC), the NF Therapeutic Consortium (NFTC) and the Synodos consortia. The NF scientists and clinicians are revolutionizing the way in which research and development is done. As Dr. Austin (Director of the National Center for Advancing Translational Sciences) recently stated, "Scientific progress is only possible if science is done as a team."

As you will appreciate in this newsletter, the NF Forum/ NF Conference 2014 delivered amazing scientific updates and gave me a lot of hope that treatments are on the way. Enjoy the newsletter and know that our CTF staff is always available to help, inform, encourage, and listen.

FOLLOW US ONLINE:

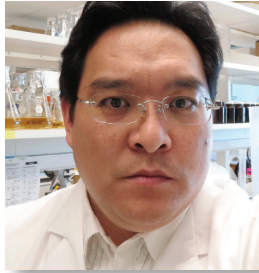
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The Children's Tumor Foundation is pleased to announce the funding of eight Young Investigator Awards (YIA) for 2014. YIA recipients focus on using animal models and cell and tissue cultures to advance understanding of the biology of NF1, NF2, and schwannomatosis, which is the first step toward better treatments for neurofibromatosis.

2014 Young Investigator Award Recipients

Chung-Ping Liao, PhD, University of Texas Southwestern **Tumor Microenvironment and Stem Cell Factor Contributions in Neurofibroma Development**

Dr. Liao is a postdoctoral fellow in the laboratory of Dr. Lu Le at the University of Texas Southwestern. Dr. Le studied with Dr. Luis Parada there, and has now established his own independent research lab. His project will use NF1 mouse models to better understand the cell microenvironment conducive to neurofibroma development, including the role of a growth factor called stem cell factor. Better knowledge about the influences in the tissue surrounding neurofibroma cells may lead to new therapeutic targets and strategies.



Manuel López Aranda, PhD, University of California, Los Angeles **The Possible Role of Immune Activation in Autism Phenotypes in NF1**

Dr. López Aranda is a postdoctoral fellow with Dr. Alcino Silva, at the University of California, Los Angeles. Dr. Silva is an established neuroscience investigator who performs basic and clinical research in NF1-related learning. In this project, to test a new hypothesis, the role of the immune system will be examined in NF1 patients who also have features of autism. If they find a link, it opens a line of research to consider therapies that modulate the immune system, as a potential intervention in children with NF1 that are on the autism spectrum.



Clare Malone, Brigham & Women's Hospital **Identifying Novel Drug Combinations that Target Cancer Cell Vulnerabilities in Malignant Peripheral Nerve Sheath Tumors**

Clare Malone is a graduate student with Dr. Karen Cichowski, a well-established NF1 investigator at the Brigham and Women's Hospital in Boston. Ms. Malone's thesis project is focused on finding drug combinations that can best kill MPNST cells, based on understanding of altered pathways in these tumors. Her work will involve study of cell lines as well as testing in mouse models. Since single agents are not proving very effective for NF1 patients with MPNST, effective combinations need to be investigated.



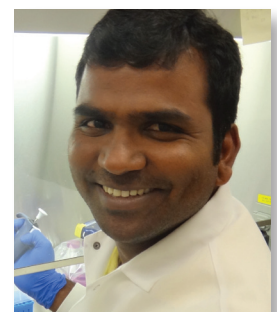
Mariska van Lier, Netherlands Institute for Neuroscience **Altered Critical Period for Ocular Dominance Plasticity in Heterozygous NF1 Mutant Mice**

Mariska van Lier is a graduate student in the laboratory of Dr. Christiaan Levelt, at the Netherlands Institute for Neuroscience in Amsterdam (and new to the NF field). Ms. van Lier's project will study the critical period of neuronal plasticity in mutant NF1 using synapse development in the visual cortex as a model. The hypothesis is that the critical period in NF1 mice closes too soon compared to wild type mice. If true, they will investigate environmental and pharmaceutical interventions that could modulate this period, and this will also lead to investigations of this phenomenon in children with NF1.



Krishna Chinthlapudi, PhD, Scripps Research Institute **Lipid-Directed Control of Merlin Tumor Suppressor Functions**

Krishna Chinthalapudi, PhD is a postdoctoral fellow in the laboratory of Dr. Tina Izard, a researcher at the Scripps Research Institute. Dr. Izard is relatively new to the NF2 field, bringing her expertise in cell biology in merlin-related pathways. This project will examine the role of lipids in controlling merlin's functions, which may shed light on possible new therapeutic targets and approaches for NF2.



2014 Young Investigator Award Recipients (continued)

Robert J. Allaway, Geisel School of Medicine at Dartmouth College Characterizing Novel Therapeutics that Exhibit Synthetic Lethality with NF1-Associated Tumors



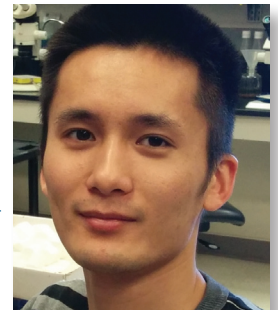
Robert J. Allaway is a graduate student in the laboratory of Dr. Yolanda Sanchez, a relatively new NF investigator, at the Geisel School of Medicine at Dartmouth College. His thesis project used a system called a synthetic lethal screen, that his lab developed with Dr. Nancy Ratner, to identify compounds that will only kill neurofibromin-deficient cells. His preliminary work in NF1 tumor cells identified several lead pathways/compounds. His YIA work will further investigate the effectiveness of these compounds in mouse models, as well as dissect the mechanisms involved in the cell death (e.g. autophagy and oxidative stress).

Susana Moleirinho, PhD, Scripps Research Institute Identification of Novel Therapeutic Targets for the Treatment of NF2



Susana Moleirinho, PhD is a postdoctoral fellow in the laboratory of Dr. Joseph Kissil, a well-known NF2 scientist at the Scripps Research Institute in Florida. Dr. Moleirinho's research is a translational study to identify new drugable targets in NF2 tumors. She will focus on three kinase proteins whose expression is altered in merlin-null cells, likely promoting their uncontrolled division. She will test the effectiveness of drugs known to inhibit these kinases on tumor formation in NF2 mouse models.

Jijie Xu, University of Chicago Investigating Functional Interactions Between Merlin, Apical Polarity Proteins and Their Regulation of the Hippo Signaling Pathway



Jijie Xu is a graduate student in the laboratory of Dr. Rick Fehon, an established NF2 investigator at the University of Chicago. The project will utilize the power of the *Drosophila* (fruit fly) genetically-malleable system to gain new information about the function of the merlin protein in growth. The study will focus on merlin's role in responding to signals from proteins that orient the cell, and transmitting those signals through the Hippo pathway to affect gene expression. Understanding more details about merlin's functional partners will fuel development of novel tumor therapies.

Children's Tumor Foundation Partners with Alzheimer's Drug Discovery Foundation

The Children's Tumor Foundation has partnered with the Alzheimer's Drug Discovery Foundation (ADDF) in the ADDF-Access program, a marketplace of contract research organizations (CRO) that provide services through all stages of drug discovery and development. The goal of this partnership is for CTF to help researchers accelerate the identification of effective treatments for NF.

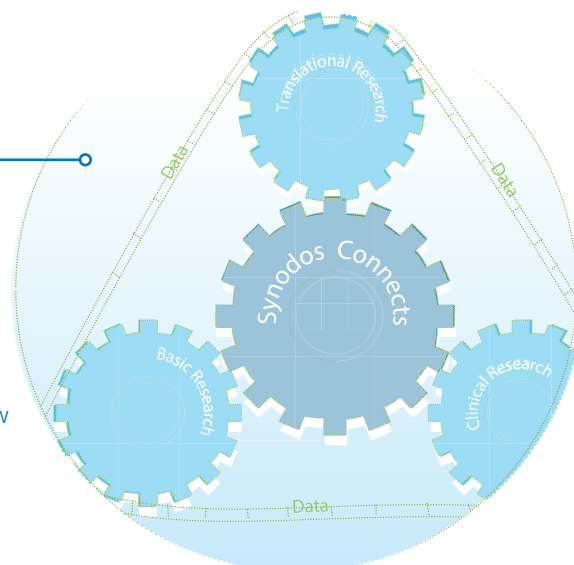
For more information: <http://alzdiscovery.org/research-and-grants/addf-access/>



Alzheimer's
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SYNODOS UPDATE

Experimental research in the labs began on May 1st and Sage Bionetworks has populated the Synodos Data Warehouse with pre-existing NF2 data, so work is well underway in this exciting new initiative. For more information please visit www.ctf.org/synodos



Highlights of the 2014 NF Conference

This year's NF conference, the premier annual event in the neurofibromatosis research and clinical calendar, was held June 6-10 in Washington, D.C. Over 300 people attended from around the world to present the latest developments in NF research and clinical care. The Conference's theme was "Connecting for a Cure" and included seminars by NF experts, as well as high-profile keynote speakers from related disciplines such as cancer and neuroscience, serving to stimulate thought and build connections between NF and other disorders. Many attendees praised this year's conference as one of the best NF meetings in years. The 2014 NF Conference Co-Chairs were **Dr. Yuan Zhu, PhD** of the Gilbert Neurofibromatosis Institute, Children's National Medical Center and **Dr. Bradley Welling, MD, PhD** of Massachusetts General Hospital/Harvard University.

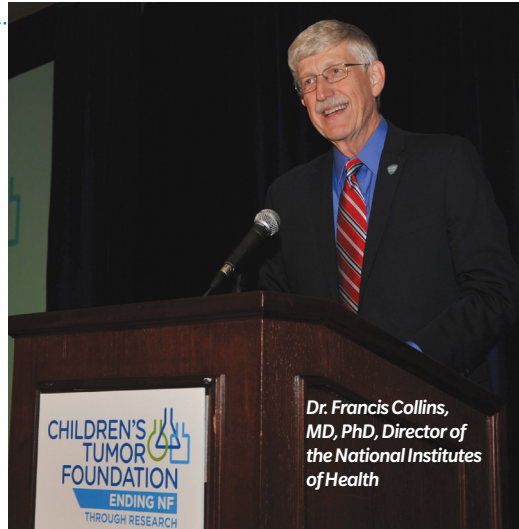
It was a pleasure to welcome **Dr. Francis Collins, Director of the National Institutes of Health**, to this year's NF Conference. Dr. Collins was a special guest for the Children's Tumor Foundation; not only has he been a very successful NF doctor, but he discovered the NF1 gene and subsequently donated the patent rights to the Foundation.

All the NF gene masters were present this year: **Dr. James Gusella** who discovered the NF2 gene, **Dr. Theo Hulsebos** who discovered the first schwannomatosis gene (SMARCB1), and **Dr. Ludwine Messiaen** who recently published the discovery of LZTR1 in schwannomatosis. In addition, the Foundation organized the first "Innovative Business Opportunities in NF" meeting for members of the financial, nonprofit, and pharmaceutical industry, as well as clinicians and researchers. (See page 7)

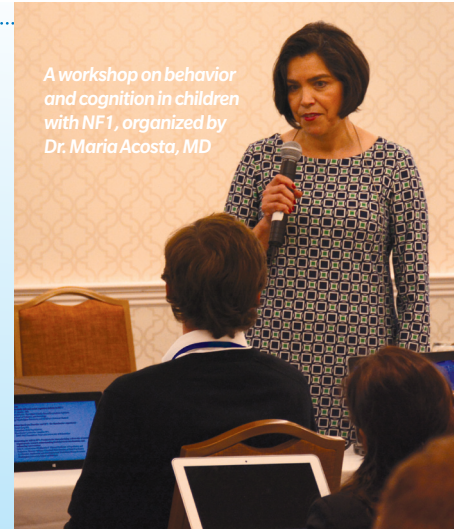
The following are highlights from the 2014 NF Conference.

CLINICAL SCIENCE

A workshop on behavior and cognition in children with NF1, organized by **Dr. Maria Acosta, MD**, reported that children with NF1 are more likely to have trouble distinguishing subtle facial expressions, which may interfere with social development. (Kristina Hardy, Children's National Medical Center). Autistic-like behaviors are associated with NF1, but are different than "classic" autism. They can start around ages 8-11 and often involve mainly social communication deficits (John Constantino, Washington University in St. Louis). Kathryn North, professor of Pediatrics and Health at the University of Sydney, reported that while the IQ of children with NF1 lags behind peers during the childhood years, it seems to "catch up" by age 30. Early diagnosis of cognitive difficulties can be made in children with NF1 as young as 21 months of age. Phonics training is helpful in these children, since many have particular difficulties with sounding out words.



Dr. Francis Collins, MD, PhD, Director of the National Institutes of Health



A workshop on behavior and cognition in children with NF1, organized by Dr. Maria Acosta, MD



Dr. Kairong Li



Dr. Bradley Welling



Dr. Vijaya Ramesh



Dr. Yuan Zhu



Dr. Aaron Schindele

RESEARCH NEWS

Highlights of the 2014 NF Conference

Continued on from page 5

BASIC SCIENCE

The basic science presented at the meeting highlighted the exciting new advances in the field as a direct result of CTF funding. Using funds provided by CTF's Young Investigator Award, **Dr. Kairong Li** developed a completely new class of mouse models mimicking human NF1 mutations. He created mice with mutations like those in NF1 patients in which there is a premature "stop signal." This type of mutation occurs in approximately 20% of people with NF1. The researchers will study mice with premature stop mutations, and test a group of drugs called "nonsense suppressors" in these mice. These drugs can read through a premature "stop signal," which would result in normal NF1 protein. The approach of using drugs that "read through" a stop signal, with the goal of restoring gene function, has been feasible in genetic disorders such as cystic fibrosis and Duchenne muscular dystrophy. In this way, CTF funding will lead directly to a completely new class of drugs to treat NF.

Another exciting new technique is being used by CTF-funded scientists to find new treatments for NF2. The innovative technique is called "kinome screening," and it's being used in the Synodos Consortium that CTF created. Kinome screening compares NF2 samples with unaffected samples, and searches for a type of gene (kinase genes) changed in NF2. These genes can then potentially be targeted with specific kinase inhibitors to treat NF2. Together with Dr. Gary Johnson's lab, **Dr. Vijaya Ramesh** has uncovered several candidate kinase genes. Inhibitors of these kinase genes are now being tested in animal models of NF2. These discoveries may lead to new treatments for NF2, and would not have been possible without the funding from CTF.



There were also presentations about advances in the field of impaired fracture healing and reduced muscle strength in NF1. Fractures often require multiple surgeries and potential amputation, and children with NF1 may have low muscle tone and coordination difficulties. The groups of **Dr. Aaron Schindeler** and **Dr. Kate Quinlan** in Australia, both recipients of CTF Drug Discovery Initiatives, have developed exciting new mouse models to further study these features of NF1 and screen for compounds to treat these aspects of the disease. Dr. Quinlan's group developed muscle-specific NF1 mutant mice and Dr. Schindeler's group developed a mouse model in which NF1 is mutated at the site of the tibial fracture. Using this model of tibial fracture, they found a very promising combination of drugs that heals the fractures and will soon lead to clinical trials. These mouse models will be available to the NF community of scientific researchers through the CTF Drug Discovery Initiative Toolbox, which was created in order to foster collaboration and accelerate drug discovery for the treatment of NF.

Another exciting advance in the field is the discovery of biomarkers for MPNSTs. Researchers have long wondered how to tell if a plexiform neurofibroma would turn into an MPNST. To identify key gene signatures of MPNST, **Dr. Karen Cichowski** has used "transcriptional profiling," which is a comparison of genes that are expressed in plexiform neurofibromas compared to genes expressed in MPNSTs. She has identified biomarkers that could potentially be used to screen plexiform neurofibromas and identify which might be at risk for developing into an MPNST. This ground breaking discovery would not have been possible without CTF funding.

THOUGHTS ON THE 2014 NF CONFERENCE



Dr. Bruce Korf, MD, PhD, of the University of Alabama at Birmingham and Chair of CTF's Medical Advisory Committee:

"Two things stood out to me at the recent NF Conference and NF Forum: First is the dramatic increase in the number of drugs that are being validated in animal models and may be ready for clinical trials; second is the

energy that resulted from having NF scientists as well as patients and families in the same room for the symposium dinner. I have no doubt that the scientific community was greatly inspired by this event, and by the meeting as a whole."

Mr. Randall Stanicky, Managing Director of RBC Capital Markets and CTF Board Member:

"It was inspiring to see the interest expressed during the 'Innovative Business Opportunities in NF' session as the potential for additional capital to come into NF research to help find new therapies



INNOVATIVE BUSINESS OPPORTUNITIES IN NF

This year's NF Conference hosted a satellite meeting outlining innovative business opportunities in the field of neurofibromatosis, including a presentation of the NF market model. **Foundation President Annette Bakker** opened the meeting by highlighting the various CTF initiatives aimed at bringing treatments to patients through industry involvement. She explained that all drugs currently under clinical investigation for NF are repurposed medications that were initially developed for other more lucrative diseases, (most notably cancer), and that drugs that are conceived specifically for NF should soon appear in the global research pipeline.



David Lapidus, a Principal at LapidusData, gave a presentation on the hard numbers of the NF market value, a CTF-commissioned study which is based on the epidemiologic data of NF and analyzed according to the various segments of the NF market (i.e. plexiform neurofibromas, optic pathway gliomas, MPNSTs, etc.)

These presentations served as grounds for a panel discussion led by **Randall Stanicky**, CTF Board Member and Managing Director at RBC Capital

Markets. Panelists included representatives from clinical care, (**Dr. Scott Plotkin** of Massachusetts General Hospital), the venture capital world, (**Sara Nayeem** of New Enterprise Associates and **Isai Peimer** of MedImmune Ventures Inc.), the industry sector, (**Mark DeSouza** of desouzatech and **Gideon Bollag** of Plexikon), the non-profit arena, (**Margaret Anderson** of FasterCures), and the healthcare market, (**David Lapidus** of LapidusData). These discussions highlighted a growing interest from industry in NF and a strong incentive for companies to invest in this sector.

is significant and this will no doubt continue to grow in the future. As a new Board Member I was struck by the amount of engagement from attendees across all areas of NF, and by how ideal the Conference was in providing a forum for discussion of the most promising opportunities for the future."

Dr. Karen Cichowski, PhD, of Brigham and Women's Hospital and Harvard Medical School: "The best aspect of CTF's NF Conference is that the basic scientists and clinicians get the opportunity to really interact. As a consequence, basic discoveries are now being translated into clinical trials, and new discoveries keep fueling new ideas."



UPCOMING AWARD APPLICATION DUE DATES:

Clinical Research Awards LOI (CRA)
August 4, 2014

Schwannomatosis Awards
September 1, 2014

Drug Discovery Initiative (DDI) Awards "B"
September 2, 2014

NF Clinic Stipend Awards
November 20, 2014

For more details visit
www.ctf.org/research

UPCOMING EVENTS:

September 4-7, 2014:
16th European Neurofibromatosis Meeting, Barcelona
www.nfbarcelona2014.org

October 10-12, 2014:
Annual NF2 Ohio Gathering
www.ohiogathering.com

New NF Walk Super Circle Program

The new Super Circle program recognizes participants and donors for their contribution to NF Walk events.



Super Fan

- Any individual who raises \$100
- Any team who raises \$1,000
- Special pin at the event and a matching electronic badge for social media and fundraising pages.

Super Stroller

- Any individual who raises \$500
- Special pin at the event, matching electronic badge, and a Children's Tumor Foundation tote bag

Top Team

- Any team who raises \$5,000 or above
- Special pin at the event, matching electronic badge, a plaque, and recognition on the NF Walk website

Top Walker

- Any individual who raises \$5,000 or above
- Special pin at the event, matching electronic badge, a plaque, and recognition on the NF Walk website

****Any team or individual who raises \$10,000 or above will also be honored in CTF's newsletter, get three free registrations for next year's event, and receive a handwritten thank you card from an NF Hero.**

Spotlight on Teams that Raised \$10,000+ Between May-June 2014

TEAM AIDAN formed by Lisa Nicotra in honor of her friend Suzanne's son, Aidan Fraser, participated in the Staten Island NF Walk. Team Aidan had 14 members and raised \$15,000 for NF research.



TEAM MOSS, raised more than \$17,000 and consisted of over 200 family and friends walking in support of the Moss family at the Birmingham NF Walk.



TEAM WALDROP, led by Stephanie and Wesley Waldrop and comprised of 43 members, raised \$12,000 for the Birmingham NF Walk.



SIGN UP TODAY!

7/27 Portland, OR
8/23 Utah
9/6 Seattle, WA
9/6 Monroe, MI
9/7 Denver, CO
9/13 Putnam, CT
9/13 Biddeford, ME

9/14 Rochester, NY
9/20 Milwaukee, WI
9/20 Iowa
9/21 Addison Oaks, MI
9/27 Central New Jersey
9/27 Idaho
9/27 Jacksonville, FL

10/4 Dallas, TX
10/4 Atlanta, GA
10/4 Richmond, VA
10/5 Columbus, OH
10/12 Los Angeles, CA
10/12 Phoenix, AZ
11/8 Las Vegas, NV

11/15 San Diego, CA

DATES TO BE ANNOUNCED
Minneapolis, MN
Jupiter, FL

The Racing4Research “Art Car” Continues to Fuel the Cure

Building on the momentum from Daytona, the Racing4Research program announced in April a continuation of the popular CTF “Art Car” program with long-time racing partners, Compass360 Racing.

The “Art Car” program, featuring an original painting by artist/NF Hero Jeffrey Owen Hanson, now extends to four race cars (one Porsche, two Hondas, and one Subaru) and will be racing throughout the United States and Canada during the 2014 season.

The inaugural race of the expanded program took place in Alabama and brought together participants from the Birmingham NF Walk and R4R drivers for a family dinner and VIP race day experience. The excitement continued on the west coast with northern California families joining the Racing4Research teams at Laguna Seca for a dinner with the drivers, a “meet ‘n’ greet” at the track that included actor/driver Patrick Dempsey, and live interviews with two of our NF Heroes on FOX Sports 1’s pre-race show hosted by Justin Bell.

With the race season now in full swing, look for Racing4Research to come to your area!

Upcoming races include:

July 25th - Indianapolis, Indiana at the Indianapolis Motor Speedway

August 2nd - Columbus, Ohio at the Mid-Ohio Sports Car Course

August 24th - Alton, Virginia at the Virginia International Raceway

August 30th - Brainerd, Minnesota at the Brainerd Raceway

September 12th - Salt Lake City, Utah at the Miller Motorsports Park



The NF Endurance Team is off and sprinting in 2014, with many successful events already in the books. In March, 46 team members raised over \$80,000 and raced through the Big Apple in the **NYC Half Marathon**, and Gainesville, GA hosted the 2nd Annual **Little Heroes 5K** which raised nearly \$18,000. In April, our **London Marathon** team spread NF awareness across the pond and raised over \$30,000 for CTF; meanwhile, more than 20 young athletes participated in the **St. Anthony's Meek & Mighty Triathlon** in Florida and 75 kids raced in the Krum, TX **Hero Dash**, proving that anyone can swim/bike/run to help end NF! And our flexible Choose Your Own Event Program is hitting record numbers this year, with over \$120,000 raised so far as athletes choose to represent CTF in the event of their choice (whether it's a local 5K or a spin-a-thon).

We're already looking toward fall when some exciting premier events such as **Chicago Marathon**, **NYC Marathon**, and **IRONMAN Florida** are sold out, with approximately 175 NFE athletes aiming to raise over \$875,000 to end NF!



Also new this fall, we're launching our brand new Fundraising Incentive Program. You can earn custom NFE prizes, such as compression socks, bags, shirts, and more. These products are only available through fundraising, so sign up for an NFE event this fall and get your hands on these exclusive prizes!

FUNDRAISING INCENTIVE PROGRAM

BRONZE BOLTER



SILVER SPRINTER



GOLD GALLOPER



PLATINUM PACER



DIAMOND DASHER

FOR MORE DETAILS, VISIT NFENDURANCE.ORG

GET A JUMP ON 2015

The NF Endurance Team is already gearing up for 2015, launching registration earlier than ever before for several of our premier events. We have many returning favorites on the docket, as well as some exciting new races that are now open for registration. But ACT FAST because spots are limited!

RETURNING

- **NYC HALF MARATHON**
March 15, 2015
- **LONDON MARATHON**
April 19, 2015
- **IRONMAN 70.3 HAWAII**
May 30, 2015
- **IRONMAN FLORIDA**
October 31, 2015

BRAND NEW

- **BIG SUR MARATHON**
April 26, 2015
- **IRONMAN 70.3 RALEIGH**
May 31, 2015
- **BERLIN MARATHON**
September 27, 2015

**race dates are tentative and subject to change*

2015 APPLICATIONS

Are you interested in bringing an NF Endurance Community or Kids Event to your hometown? We are looking for dedicated volunteers to help organize NFE events across the country so we can raise even more awareness and funds to end NF next year! You can apply to be one of our 2015 cities by contacting Angela Auzston at aauzston@ctf.org.

MEET THE STAFF

Sarah Rosenberg

HOMETOWN: Brooklyn, NY

CURRENT TOWN: Long Island, NY

EDUCATION: Bachelor's Degree with a double major in English Literature and Media Studies from Quinnipiac University (Go Bobcats!)

WORK WITH THE FOUNDATION: As Executive Assistant, my job is to assist our President in any way possible! I also work closely with the Board of Directors on major meetings and act as their main contact to the Foundation.

FAVORITE EXPERIENCE WITH THE FOUNDATION:

Going to Monterey, California for the NF Conference in 2013 allowed me to meet and speak in depth with scientists, parents, and Board members who are involved both professionally and personally with neurofibromatosis. It furthered my desire to help end NF, and made me proud to have this job.

FAVORITE HOBBY: Going to parks and museums, discovering new music, dancing, and traveling to any new place!



MEET THE BOARD

Colin Bryar

HOMETOWN: Chicago, IL

CURRENT TOWN: Seattle, WA

EDUCATION: BS and Master of Engineering in Operations Research and Industrial Engineering from Cornell University



WORK WITH THE FOUNDATION:

I joined the Board in 2010. Currently I serve on the Development Committee, and am also the Chairperson of the Public Awareness and Education Committee. That means I do whatever I can to help the Foundation raise funds, and disseminate relevant information to both the NF community and the general public. I try to bring my experience from the corporate world to the Foundation in any area that can be helpful.

FAVORITE EXPERIENCE WITH THE FOUNDATION: I first learned about neurofibromatosis a decade ago when a close friend told me his daughter, Aidan, had recently been diagnosed with NF1. He was running an NF Endurance race to help raise money for the Children's Tumor Foundation. Over the next few years, I became more involved with CTF and eventually started serving on the Board. My favorite moments are when I get a big hug of thanks and a smile from Aidan. It reaffirms my commitment to finding treatments for NF.

FAVORITE HOBBY: The thing I enjoy most is spending time with my wife and our two young children. It doesn't really matter what we are doing, as long as we are doing it together. As far as personal interests go, running is my favorite hobby.

NEW FACES AT THE CHILDREN'S TUMOR FOUNDATION

Welcome to the Foundation's newest staff members!



Angela Auzston
NF Endurance Manager,
Community and Youth
Events
aauzston@ctf.org



Kristin Stanley
Community Relations Coordinator,
Southeast Region
kstanley@ctf.org



Sean Thompson
Director of Technology
sthompson@ctf.org



Alissa Marks
Marketing Manager
amarks@ctf.org



Vanessa Younger
Program Assistant
vyounger@ctf.org

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.



ALASKA

CTF's Alaska Chapter hosted a Wiffle Ball Contest at Homer Education and Recreational Center (HERC) in Homer, AK which raised \$280 for NF research.

CALIFORNIA

On Saturday May 17th, the second annual West Coast Benefit was held at the LA Lofts in Hollywood, CA and attended by over 100 people. The event, hosted by actor Curtis Armstrong, included a silent and live auction, live music, and a catered dinner. Over \$30,000 was raised, including \$2000 for a painting by NF Hero Blake Robinson.



CALIFORNIA

On February 8th at the Anaheim Monster Jam at Angel Stadium, San Diego NF Walk Committee member Dave Groudas presented a Certificate of Appreciation to CTF supporter Kelvin Ramer, driver of the Monster truck "Time Flies."



UTAH

CTF's Utah Chapter hosted an "#EndNF with Travis" night at the Utah Grizzlies hockey game on April 12th in Salt Lake City, UT.



COLORADO

Members of the Colorado Chapter of CTF participated in the St. Patrick's Day Parade in Downtown Denver on March 15th. Approximately 75 supporters cheered on the McKaila Steffes Memorial Float, handed out candy, and played fun Irish music while Girl Scout Troop 1819 danced their hearts out!



CALIFORNIA

CTF's California Chapter hosted a Racing4Research Race Day Party on January 25th at BJ's Restaurant in Torrance, CA, in honor of all the NF Heroes in California.



ARKANSAS

Many thanks to Molly Umble who interned with Board Member Lesley Oslica and the Arkansas Chapter of CTF over the last year. Molly says, "During my internship, I met incredible people, attended meaningful events, and familiarized myself with a fabulous organization. From the Dancing with Our Stars Gala, the Go! Running event, the Wine and Art Party and the Little Rock Marathon, every opportunity I have had at the Children's Tumor Foundation has been a great experience."

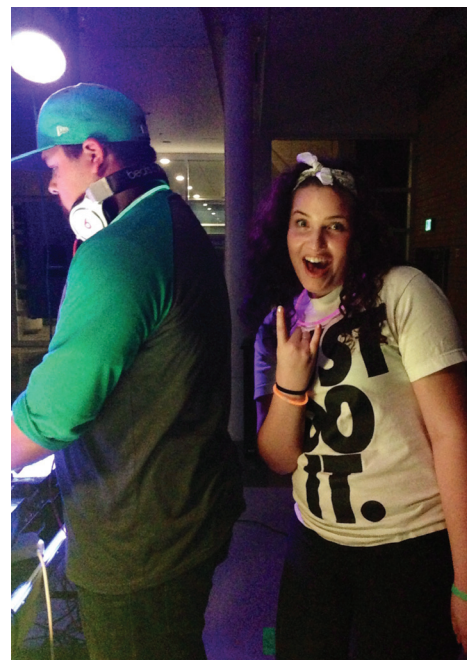


CALIFORNIA

The California Chapter of CTF hosted a medical symposium with the Children's Hospital of Los Angeles on January 26th in Los Angeles, CA. Over 100 people attended.

PENNSYLVANIA

Arden's NF Avengers are at it again! Arden's Tea Party with a Twist in Philadelphia offered live music from 360, an all you can eat meal, and flip cup tournaments. Those NF Avengers know how to put the FUN in fundraising.



ILLINOIS

Friday February 21st, The Meek and Licato Families joined forces to host Uncork a Cure, a wine tasting event in Arlington Heights, IL. In addition to the wine tasting, the guests enjoyed the music of Garret Drucker and had a chance to peruse the silent auction and indulge in massages. The event was wildly popular and they raised \$17,500 to help End NF.

OREGON

Courtney McKillip hosted "GLOW Crazy for NF" in Newberg, OR at Newberg High School on February 15th and raised over \$700 for CTF. Many thanks to DJ Rhino who donated his time to support the cause.

The 2014 NF Forum



Excitement, hope, and an overwhelming sense of camaraderie were palpable June 6-8 as more than 250 people gathered in Washington, D.C. for the Children's Tumor Foundation's sixth annual NF Forum.

For three days, the lobby, conference rooms and even the pools of the Omni Shoreham Hotel were awash in bright blue t-shirts sporting the Children's Tumor Foundation's new logo and the declaration "End NF." At every turn, people could be seen chatting, laughing, and sharing strategies to face the often-overwhelming challenges of living with NF.

The Forum officially began Friday night with inspirational keynote speeches by **Stephen Friend, MD, PhD, President of Sage Bionetworks**, and **Dejaun Anthony Evans, who lives with NF1 and is an MPNST cancer survivor**. Dr. Friend spoke with passion on the use of an open crowd-sourcing model to conduct large-scale collaborative biomedical research. Evans, whose devotion to fitness has helped him thrive, inspired all in attendance with his personal story of courage and strength. After this optimistic opening reception, attendees embarked on a nighttime tour of many of Washington's magnificent sites.

Singer Steve Gold kicked off Saturday morn-

ing, encouraging participants to transform any fear they might have into love using music. The whole room relaxed as they learned one of his most loved songs, "So Much Magnificence." Then the intensive learning sessions began. From panel discussions on coping skills to information on the importance of the NF Registry and Biobank, the joint morning sessions provided critical information to all participants. In the afternoon, attendees broke into specialized tracks for up-to-date information on the latest research in NF1, NF2, and schwannomatosis. Throughout the day, attendees were given ample opportunity to ask the experts questions.

For the second time now, the NF Forum and NF Conference were held at adjacent times in the same location. The NF Conference brings together NF experts, researchers, clinicians, and biotech and pharmaceutical representatives to present the latest developments in NF research and clinical care. Saturday evening's activities provided two rare opportunities for patients and their families to mingle with these experts who are working hard to find treatments and

cures. The first opportunity was a poster session, where researchers displayed their work and were available to take questions from NF families. The second was a dinner, where experts and families sat side-by-side, a record six hundred people from seemingly disparate worlds coming together for the same overarching reason: to END NF.

Director of the National Institutes of Health, Dr. Francis Collins, addressed the crowd, sharing his pleasure with how far the NF movement—both in research and awareness—has come. **CTF Ambassador Bailey Gribben** impressed the crowd with his sheer dedication to living an unhampered life, telling those in attendance that, although he hopes that all the experts will continue to work diligently to find answers, the patients, "hope you don't mind that we have gone back to living our lives to the fullest."

The following morning, the Forum attendees and their children had the opportunity to do just that at the **Washington, D.C. NF Walk** which included yoga, an NF Hero Ceremony, and a Kids' Dash. Then families walked to the Smithsonian Zoo. As the tide of blue t-shirts filled the sidewalks of Washington, D.C., the importance of coming together was clear: we have much more hope together than alone.

NF Advocacy Day 2014



While in Washington, D.C. for the NF Forum, members of the Children's Tumor Foundation staff and the NF community visited Capitol Hill to lobby Congress for an increase in neurofibromatosis research funding. They visited the offices of 34 Senators and Representatives to encourage support for the Congressionally Directed Medical Research Program – Neurofibromatosis Research Program (CDMRP-NFRP). The CDMRP-NFRP is a health research program managed by the Department of Defense that provides crucial funding for NF research. In part, the CDMRP-NFRP fuels the NF Clinical Trials Consortium, which works to bring drug treatments to patients. For more information, please visit www.ctf.org/advocacy.

Cupid's Undie Run 

VALENTINE'S DAY
WEEKEND 2015
www.cupidsundierun.com



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.

Editor

Mary Vetting, mvetting@ctf.org

Design Director

Susanne Preinfalk, spreinfalk@ctf.org

FOUNDATION STAFF

Annette Bakker, PhD, President and Chief Scientific Officer

Research and Medical Programs

Salvatore La Rosa, PhD, Senior Director of Research and Development

Pamela Knight, Clinical Program Manager

Patrice Pancza, Research Program Director

Sarah Rosenberg, Executive Assistant

Kimberly Scobie, PhD, Scientist

Development and Volunteer Relations

John Heropoulos, Senior Vice President

Michael Divers, Vice President of Major Gifts and Events

Traceann Rose, Program Director, NF Walk

Angela Auzston, NF Endurance Mgr, Community & Youth Events

Jill Beck, Program Director, Racing4Research

Jessica Beckerman, NF Walk Coordinator

Carolyn Castellano, Program Director, Major Events

Chrissie Connors, NF Walk Coordinator

Emily Crabtree, Program Director, NF Endurance

Angela Dumadag, NF Endurance Manager, New York

Garrett Gleeson, Program Director, Major Gifts

Ben Leathers, Cupid's Undie Run, Apparel Logistics & Reporting

Chad Leathers, Program Director, Cupid's Undie Run

Kelly Mills, Community Relations Regional Manager

Sarah Morley, Cupid's Undie Run National Events Coordinator

Marissa Moscatello, Community Relations Coordinator

Julie Pantoliano, Community Relations Coordinator

Kristine Poirier, Community Relations Coordinator

Kristin Stanley, Community Relations Coordinator

Lauren Walsh, NF Endurance Manager, Chicago

Public Education and Patient Advocacy

Simon Vukelj, Communications Director

Alissa Marks, Marketing Manager

Susanne Preinfalk, Design Director

Mary Vetting, Communications Associate

Finance and Administration

Judi Swartout, Chief Financial Officer

Mohamed Amin, Database Assistant

Monique Boucher, Database Supervisor

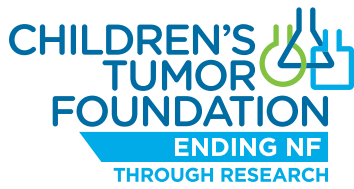
Sarah Bourne, Accountant

Danielle Meyer, Technical Support, National Programs

Rosa Amelia Perez, Project Administrator

Sean Thompson, Director of Technology

Vanessa Younger, Program Assistant



120 Wall Street, 16th Floor
New York, NY 10005
800-323-7938 | www.ctf.org

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SAVE THE DATE

UPCOMING
CHILDREN'S TUMOR
FOUNDATION EVENTS

DANCING WITH OUR STARS
Thursday, September 11, 2014
Statehouse Convention Center
Little Rock, Arkansas

NEW ENGLAND GALA
Saturday, October 25, 2014
Boston Marriott Cambridge
Boston, MA

THE BENEFIT - NEW YORK
Thursday, October 30, 2014
The Plaza
New York, NY

THE BENEFIT - DETROIT
Saturday, November 22, 2014
Detroit Marriott at
the Renaissance Center
Detroit, MI

JOIN THE **NF REGISTRY**
AND YOU CAN
HELP **END NF**

JASON COLE
Father of Owen,
who lives with NF1
Parker, CO

I entered my
son's information
in the NF Registry
because...

"THERE IS POWER IN NUMBERS."
www.nfregistry.org

