

NF FAMILIES COME TOGETHER RACING4RESEARCH AT DAYTONA



Neither rain, blown transmissions, nor an errant opossum could stop the fun and excitement at this year's annual Racing4Research weekend at the Rolex 24 Hours At Daytona. The Foundation was well represented on the track throughout the three-day weekend, January 23 - 25. Friday's Continental Tire SportsCar Challenge race featured the four Compass360 Racing cars, each carrying the Children's Tumor Foundation and End NF logos. Two of the cars additionally carried the artwork of NF Hero and current CTF Ambassador Jeffrey Owen Hanson. Friday night featured the Family Dinner hosted at the track with families from around the country—California, Utah, Texas,



From Left:
Laurée Moffett, Corinne Moffett,
Jeffrey Owen Hanson, Julie Hanson

Kansas, Nebraska, Michigan, Virginia, South Carolina, Louisiana, New York and Florida—joining together for an evening that was highlighted by our NF Hero families sharing their stories of fundraising and hope. *Continued on page 9*

Meeting the Moffett Challenge

Jim Bob and Laurée Moffett, longtime supporters of the Children's Tumor Foundation, want to do even more to help End NF. In



2014 this incredible couple promised to match up to \$2.5 million in donations to fund Synodos for NF1, an innovative way to approach NF research.

The Moffetts have attended the NF Forum, the NF Conference, Racing4Research, the New York and Detroit Galas, and other Foundation events and are "all in" to do their part in finding treatments and a cure for NF. They believe that it is only through active giving and dedicated participation that, together, we can End NF.

The Foundation, with the help of many individual contributors, is proud to announce that over \$1.2 million has been raised since the Matching Gift campaign began in October. The goal of the Foundation, with the continued generosity of the entire NF community, is to fully complete this match campaign by October 2015!

Please join the over three hundred donors who have helped the Foundation come this far in completing the Matching Gift campaign. To help make this exciting day arrive even faster, please make an online donation at www.ctf.kintera.org/synodosnf1. To make an offline donation or for further information, please contact John Heropoulos at jheropoulos@ctf.org or 617-456-4706.

OMICS INITIATIVE: NF Biobank Accelerates the Search for Solutions

The NF Biobank, formed by the Children's Tumor Foundation in 2013, is already playing a crucial role in NF research. The dermal neurofibromas that have been donated – over 140 tumor samples so far – will help researchers better understand the complexities of NF. In the coming year, the tumor samples from the biobank will be completely characterized using omics technologies.

Omics analysis will tell us the structure, function and dynamics of tissue, further increasing our knowledge of NF. The analysis will include whole exome and genome

sequencing, RNA sequencing, SNP arrays, and proteomics.

In the first phase of this initiative, 40-50 samples from the biobank will be profiled using omics technology. That data will be immediately available to the research community.

It is our goal to characterize all biobank tissue samples. Each characterization, however, costs approximately \$4,000. Your support of the Children's Tumor Foundation helps accelerate this key discovery process exponentially!

Children's Tumor Foundation BOARD OF DIRECTORS

Linda Halliday Martin, *Chair*
Colin Bryar, *Vice Chair*
Rachel B. Tiven, *Vice Chair*
Steven L. McKenzie, *Treasurer*
Tracy Galloway, *Secretary*
Bruce R. Korf, MD, PhD, *Chair,
Medical Advisory Committee*
Stuart Match Suna, *Chair Emeritus*
Jill Markland, *Chapter Council
President*
Allan Rubenstein, MD, *Director
of Medical Affairs Emeritus*

Daniel Altman
Laura Ganio Bona
William Brooks
Suzanne Earle
Daniel Gilbert
John Golfinos, MD
Matthew Hay
John McCarthy
Lesley Oslica
Laura Perfetti
Kenneth Rudd
Robert Schaffer
Randall Stanicky
Dave Viskochil, MD, PhD
Nate Walker
Peggy Wallace, PhD

Annette Bakker, PhD,
President and Chief Scientific Officer

Honorary Directors

Richard A. Horvitz
Michie Stovall O'Day
Alan Robbins, MD
Carolyn E. Setlow

Ed Stern
Pro Bono Counsel

LETTER FROM THE PRESIDENT



Annette Bakker, PhD

Just over a year ago I became President of the Children's Tumor Foundation (CTF). Already the Chief Scientific Officer, I held a prodigious vision for the Foundation. I wanted CTF to grow from a non-profit that funds science to one that actively breaks down barriers in the drug research and development process. I wanted to catalyze the process rather than simply support it. With the encouragement of our dedicated Board and the support of incredibly generous donors, our leadership designed and put into action a revolutionary business model that is already changing the field of NF research.

Many aspects of this vision have already come to life as the model has taken shape: on the following pages, you will see updates on the Foundation's numerous initiatives, as well as articles about some of our most recent advances. You will read about a thrilling new development for our Biobank, the promising results of our recent Synodos for NF2 meeting, important developments at the Neurofibromatosis Therapeutics Consortium, and other proof that the Children's Tumor Foundation is the driving force behind the NF drug research and development process. The Foundation's focus on fostering collaboration and teamwork is paying off in monumental ways.

We believe that the real value of the Foundation is our ability to break down walls by designing and managing large-scale collaborative consortia, gathering a multitude of top experts to plan, discuss, collaborate, and come up with groundbreaking solutions for complex problems. Synodos for NF2 was launched in February 2014; as you will read, the team has already made incredible progress. Because of the generous investment of Mr. and Mrs. Moffett, in 2015 we will launch not one but two Synodos consortia for NF1: one that is aimed at accelerating the discovery of NF-relevant treatments and the other one to fully characterize low grade gliomas.

Donors like Mr. and Mrs. Moffett believe in the model. They are as impatient as we are to get treatments to those who need it! We are honored to have donors who believe in the business model we are developing and have been extremely encouraged by the many donors who are joining us on our path to a better world... a world without NF!

Just as we've infused that collaborative spirit into how we fund and develop NF research, this past year we've strengthened that collaborative energy among our staff as well. Our dedicated and creative team formed numerous cross-departmental groups, with employees stepping outside their day-to-day roles in order to bring fresh perspectives to the decisions we make as a Foundation. The results were incredible! Throughout 2015, you'll be seeing the results of their hard work.

We are committed to fostering a continued spirit of creativity and collaboration among the Foundation's employees and all its stakeholders, from patients to volunteers to donors to researchers. CTF is indeed a microcosm of the collaborative model of our numerous consortia: a collaborative, multidisciplinary team dedicated to ending NF.

FOLLOW US ONLINE:

childrenstumor
 @childrenstumor
 @childrenstumor
 children's-tumor-foundation
 ctforg

CLINICAL RESEARCH AWARD WINNERS ANNOUNCED

Resiliency Training for Adolescents with NF1 and NF2 via Skype

A Clinical Research Award of \$148,000 was granted to **Ana-Maria Vranceanu, PhD**, a clinical psychologist at Massachusetts General Hospital. Dr. Vranceanu will test the ability of a Relation Response Resiliency Program (3RP) to improve quality of life for adolescents ages 12-18. The program teaches coping skills that have already been shown to improve quality of life and ability to deal with stress and symptoms in various other medical conditions. People with NF may experience depression, anxiety, stress, lower self-esteem, and pain. Psychological approaches such as relaxation exercises and cognitive therapies are potentially very helpful for these problems, but not everyone has convenient access to therapists trained in these mind-body techniques. For this reason, Dr. Vranceanu and colleagues are testing delivering these services via Skype. Her current CRA builds on a CTF Clinical Research Award to study 3RP with adults with NF1 or NF2. In the new study, Dr. Vranceanu's group will adapt the method for adolescents. If the program shows a greater benefit than a comparison group, Dr. Vranceanu plans to extend the program and to develop similar services for children and for deaf patients.



Phase 1 Trial of Combined MEK and mTOR Inhibition in MPNSTs

AeRang Kim, PhD, a pediatric oncology researcher at the Children's Research Institute in Washington, DC, was awarded a \$150,000 Clinical Research Award to investigate a combination of drugs for treatment of malignant peripheral nerve sheath tumors (MPNSTs). These aggressive tumors can occur in NF1 and are difficult to treat successfully. Dr. Kim and her colleagues will use this award to test the safety in humans of a combination therapy that has shown promise in an animal model of NF1 MPNSTs. Both drugs target the RAS pathway, which is over-activated in NF1. One is temsirolimus (Torisel®) a type of mTOR inhibitor. The other is selumetinib (AZD6244), a MEK inhibitor. The study will test the ability of this combination to shrink MPNST tumors, and try to identify the optimal dose to use in future studies.



A Study of INFUSE Bone Graft in the Treatment of Tibial Pseudoarthrosis in NF1

Bruce Korf, MD, of the University of Alabama at Birmingham, a leading NF researcher, received a \$200,000 Clinical Research Award to fund a study of a potential treatment for tibial pseudoarthrosis. This condition occurs in 2-5% of people with NF1 and can lead to multiple surgeries or amputation due to poor bone healing. The study will test the ability of a device called the INFUSE Bone Graft to improve bone healing when applied at the time of surgery. The device has a collagen base that contains the compound bone morphogenic protein-2 (BMP-2) and has previously shown to aid healing of complex tibial fractures in non-NF1 patients. The study will compare the results of INFUSE BMP-2 at the time of tibial repair surgery in children with NF1 to a control group of patients treated surgically without BMP2.



UPCOMING RESEARCH & GRANT DEADLINES:

**Drug Discovery Initiative (DDI)
Monday April 15, 2015**

To apply please visit:
www.ctf.org/Research/Funding/

UPCOMING EVENTS



NF FORUM

Friday, April 17 - Sunday, April 19
Register at www.ctf.org/nfforum



NF CONFERENCE

Saturday, June 6 - Tuesday, June 9
Register at www.ctf.org/NFConference



Biobank Can Now Accept Body Donations

A collaboration between the Children's Tumor Foundation (CTF) and tissue-recovery experts at the National Disease Research Interchange (NDRI) now enables people with NF1 to arrange to donate their bodies specifically for neurofibromatosis research after their deaths.

Over the years, CTF has received many calls from people who wanted to donate their bodies to NF research. It was heart-breaking to have to tell them that there was no real way to fulfill their generous last wishes. Perhaps the hospital where they were treated would accept the donation, but other than that, there was no procedure for making a donation that would benefit the entire NF community.

At the same time, CTF identified that the lack of NF1 tissue availability for research was a real roadblock to advancing scientific discoveries and hence treatments. The Foundation saw an opportunity to remove this roadblock

by storing NF1 tissues in a central biobank, making them available at no cost to all qualified NF researchers.

The body donation program is a two-part procedure. Part one is handled by CTF. If a person contacts us about body donation and agrees to participate in the program, CTF staff conducts a detailed medical history questionnaire by phone. NDRI staff then contacts the patient and explains part two of the process. If the patient agrees to this portion of the process, NDRI makes a plan with next-of-kin so that at the time of death, NDRI is able to send a team to collect the body, remove tissues needed for research, ship these to the CTF biobank, and return the body to a funeral home chosen by the patient's family—all within 24 hours. CTF covers all costs for body donation, except for the funeral or cremation.

NDRI made the first post-mortem collection for this project in November 2014. The donor's family expressed appreciation for being able to make this contribution to NF1 research, which they had supported in other ways for many years. Another person who has agreed to participate said he feels very content knowing that when he dies, he can still do something "for those with NF, so they won't have to go through what I've been through."

To learn more about the body donation program, contact the Foundation's Clinical Program Manager, Pamela Knight, at 212-344-6633 extension 8555.

NF THERAPEUTICS CONSORTIUM FUELS DATA DRIVEN THERAPY SELECTION FOR NF1

Mid-Year Review Meeting – January 2015

The Neurofibromatosis Therapeutic Consortium (NFTC) was established by the Children's Tumor Foundation in 2008 with the goal of accelerating the development of effective therapeutics by repurposing advanced drugs in the clinic. The focus of the NFTC has been to identify treatment opportunities for patients with NF1, to offer the most relevant high-quality preclinical studies, and to provide scientific rationale and preclinical evidence in order to accelerate the drug development process and fill the clinical pipeline. All participating members agree to openly share unpublished data, discuss future opportunities, and assess

with the clinicians on the NFTC committee which drugs/drug combinations may show benefit for NF1 patients. The NFTC is an extremely beneficial interdisciplinary consortium that brings value to the NF1 community by helping clinicians decide which treatments to propose to their patients based on data. To date, more than 80 NF1 studies have received support from the NFTC funding mechanism to evaluate potential drug candidates.

The NFTC review meeting was held in Cincinnati, OH on January 9, 2015 for mid-year review of the projects. Extremely promising findings--both new mechanisms and effective drug combinations--were discussed. Additionally, Dr. Nancy Ratner, host of the NFTC meeting, organized a half-day educational seminar on NF at Cincinnati Children's Hospital Medical Center.

The NFFinder:

Exploring How NF Patients Can Benefit from Drugs Developed for Other Diseases

Drug repositioning or repurposing is a strategy to use novel, potentially effective drugs to target diseases other than those for which they were originally designed. NFFinder is a new bioinformatics tool for drug repositioning based on comparison of transcriptional genetic profiles. This tool allows researchers to compare genetic profiles of different NF tumor and tissue types against a database of genetic profiles from many other types of diseases and cancers. Once a similar genetic profile is identi-

fied, the tool allows researchers to investigate whether a drug for another disorder may be effective in treating the different manifestations of NF. NFFinder was created by Alberto Pasqual-Montana and his team (National Center for Biotechnology, Madrid) in collaboration with the Children's Tumor Foundation.

The NFFinder bioinformatics tool will be available for use by NF researchers worldwide at <http://nffinder.cnb.csic.es/>

RESEARCH GRANT PROGRAMS AT CTF: INVESTING IN NEW DISCOVERIES TO FUEL INNOVATION

The Children's Tumor Foundation continuously aims to deliver high quality services to researchers and the NF community. Part of this effort is directed towards constant improvement of our programs and funding mechanisms. The very successful Young Investigator Award (YIA) program was established over 30 years ago by the Foundation. In 2006, the Drug Discovery Initiative (DDI) awards were introduced, expanding the scope of CTF's research funding towards translational science. Since 2006, CTF has awarded 137 grants to these two programs alone.

The two programs are complementary. On one side is the YIA: a basic science program that aims at recruiting young investigators before they are appointed to their first faculty position. The primary goal of the YIA program is to further expand our scientific community and invest in basic scientific discovery to be able to build the knowledge that is critical to triggering more translational science. The beneficiaries of this award are pre-doctoral and post-doctoral researchers who are

trained in well-established NF laboratories, working to unravel the underlying mechanism of NF. This program supports their salary during those critical years when they establish the field of expertise upon which they will build their career. Historically, this mechanism brought incredible scientists such as Karen Cichowski, Peggy Wallace, and Dave Viskochil to the NF scientific community.

On the other side, the DDI program is mostly focused on translational science. This program has an accelerated submission-to-acceptance timeline that encourages quick proof-of-principle experiments for innovative and creative ideas. The DDI focuses on development of new animal models, cell lines, or testing of drugs and treatments for NF in a very concise and meaningful way. This program aims at producing the critical data required to apply for a larger comprehensive study with CTF or through other funding agents. In addition, the 2015 DDI recipients will benefit from the opportunity to link successful *in vitro* studies to *in*



in vivo follow-up studies through the DDI award. This change will draw more applicants and encourage more in-depth studies, aligning the scope of the program more towards its translational nature.

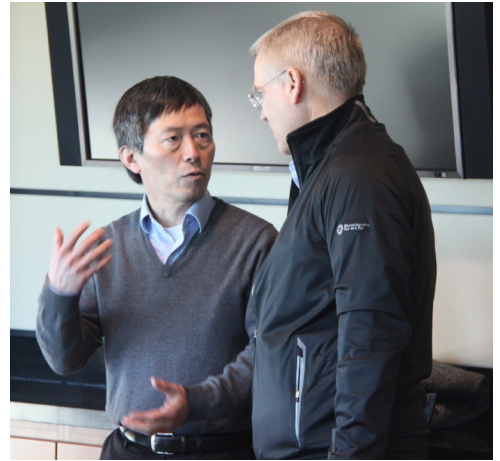
DDI FUNDING INCREASED

To continue to attract high quality, innovative ideas and to compensate for the rising costs of research, the Children's Tumor Foundation has increased the funding levels of the DDI awards. *In vitro* studies will now be funded at \$40,000 (up from \$25,000) and *in vivo* studies at \$85,000 (up from \$50,000).

Synodos for NF2: COLLABORATION / CONNECTION / KNOWLEDGE

January 2015 Researchers' Meeting in Orlando, FL

Synodos for NF2, which is funded and managed by the Children's Tumor Foundation, is a groundbreaking research consortium comprised of a team of multidisciplinary scientists from twelve world-class labs who have joined together to develop effective new treatments to end NF2. The consortium held its first researchers' meeting on January 19, 2015 at the College of Medicine, Burnett School of Biomedical Sciences in Orlando, FL. Together, the group analyzed the body of data generated so far, and based on this analysis, chose three drugs to move ahead with in animal studies. This important first milestone was achieved several weeks ahead of schedule. The project will have a tight timeline with new critical data coming in the next six months. The researchers will convene again in June during the NF Conference in Monterey, CA for an update.



NF CONFERENCE ENCOURAGES NETWORKING & FOSTERS NEW COLLABORATIONS

The 2015 NF Conference is being held June 6-9 in Monterey, CA, where hundreds of the top researchers and clinicians in the NF field from around the world are expected to attend. This year's Conference will present attendees with an exciting program in a single-track format, focused on themes that are important to clinicians, basic scientists, and all of those who straddle both spheres. A range of speakers from the NF

community and beyond will provide a variety of perspectives; however, key aspects of NF biology and therapeutics will remain the focus.

The Conference will wrap up with a report card updating attendees on current NF initiatives such as the NFTC, Synodos for NF2, the Optic Pathway Glioma Consortium, Biobank, and the DOD Clinical Trials Consortium.

To register for the NF Conference go to www.ctf.org/NFConference

2015 NF CONFERENCE SESSIONS:

- **Diagnostics** – Understanding NF
- **Optimizing Tools for Discovery**
- **Biology and Discovery**
- **Along the Pathway**
- **Therapeutics** – From Target to Clinic
- **Clinical Therapeutics**
- **Pathway to Approval**
- **The Path Forward**

2015 WALK DATES

This is going to be an incredible year for NF Walk! With events already scheduled all over the country, our team is gearing up for a year of excitement, adventure, fun, and friendship! More dates will be coming your way in the next few weeks. To register and stay up-to-date, check out our website at www.ctf.org/walk.

Staten Island, NY:	May 16, 2015
Kernersville, NC:	May 16, 2015
Cincinnati, OH:	May 17, 2015
Boston, MA:	June 14, 2015
San Jose, CA:	June 20, 2015
Philadelphia, PA:	June 27, 2015
Casper, WY:	July 25, 2015
Salt Lake City, UT:	August 29, 2015
Putnam, CT:	September 12, 2015
Idaho:	September 12, 2015
Addison Oaks, MI:	September 20, 2015
Denver, CO:	September 26, 2015
Central Jersey:	September 26, 2015
Dallas, TX:	October 3, 2015
Rochester, NY:	October 3, 2015
Richmond, VA:	October 3, 2015
Columbus, OH:	October 4, 2015
Los Angeles, CA:	October 25, 2015

If you would like to help out at one of these events, or don't yet see your city listed, email nfwalk@ctf.org to learn more about joining a planning committee.

2014 WALK Moments



Super Circle Recognition Program

Congratulations to members of our Super Circle Recognition Program who not only achieved Top Team and Top Walker status in 2014 but also raised over \$10,000!

Teams

Cure NF	Michael and Kelly Peterson	Los Angeles	\$10,232.50
Maddox Is Strong	Nicole Steinert	Los Angeles	\$11,746.00
Team Waldrop	Wesley Waldrop	Birmingham	\$13,417.24
Team Aidan	Aidan Fraser	Staten Island	\$14,966.00
Team Sammy	Frances Kallman	Los Angeles	\$16,165.00
Team Moss	Renie Moss	Birmingham	\$17,524.00
Team Isla	Matt Riley	Seattle	\$19,585.00

Individuals

Matt Riley	Team Isla	Seattle	\$11,125.00
Frances Kallman	Team Sammy	Los Angeles	\$14,980.00





NF Endurance Team Introduces New Team Ambassador

We are proud to announce our newest NF Endurance Ambassador, **Pedro Gomes**. Pedro, a professional triathlete, is excited to partner with the Children's Tumor Foundation and provide assistance to all of our triathletes throughout the season. He has an impressive racing history, including his most recent win at IRONMAN Kalmar in 2013.



EVENT HIGHLIGHTS

The **California International Marathon** started off with a BANG! While carb-loading at the team pasta dinner, 65 runners shared their motivational stories with one another and watched a slideshow highlighting the team's participation in the event throughout the years. Event co-chairs Dawn Lowell and Michelle Pinerel also helped organize fundraising initiatives throughout the year. This team raised a total of \$47,000.

The NF Endurance Team entered a new era with our holiday-themed **Turkey Trot & Jingle Jog Virtual Races**. We encouraged participants to sign

up for any race of their choice (or even create their own)



and to post a shot of themselves in action on social media using the hashtag #NFJingle. Any runner who completed their event received a Jingle Jog medal. We loved seeing the photos of our virtual races as participants braved the cold weather for this very worthy cause!

Of the \$213,000 raised for the **2014 NYC Marathon**, special shout-outs go to our Top Fundraisers and our Top Fundraising Teams for helping us get there:

- Team Brielle, led by George Gaine | \$32,011
- NF Tuminators, led by Katie Kim and Cristina Ferruggiari | \$27,463
- Mary Schafer | \$16,200
- Mary Spoto | \$13,865

UPCOMING EVENTS

Is 2015 going to be the year you decide to do something BIG? Whether it is your first 5k, your 10th marathon, or your first IRONMAN, we have entries available for many popular races. The following events include free entry into the race AND free race training:

- **United Airlines NYC Half Marathon** - March 15th
- **London Marathon** - April 26th (only a few entries left!)
- **Big Sur Marathon** - April 26th
- **Panasonic NYC Triathlon** - July 19th
- **IRONMAN Raleigh 70.3** - May 31st
- **IRONMAN Hawaii 70.3** - May 31st
- **Bank of America Chicago Marathon** - October 11th
- **TCS New York City Marathon** - November 1st
- **IRONMAN Florida** - November 7th

Contact us at nfendurance@ctf.org for more information or visit our website at nfendurance.org to see the entire list of our 2015 events.

FLYWHEEL: A Charity Ride to END NF

The NF Endurance team is proud to announce our partnership with Flywheel Stadium Cycling. On April 25th and 26th, we will be hosting indoor cycling events in Dallas, Chicago, LA, and NYC. To learn more, please visit our website: ctf.org/flywheel15 or email us at nfendurance@ctf.org. Spots will fill up fast!



RACING 4 RESEARCH



NF FAMILIES COME TOGETHER RACING4RESEARCH AT DAYTONA

Continued from page 1

Saturday morning the families and teams were greeted by rain but the brief inclement weather did not dampen the spirits of the assorted group. The storm gave way to bright, sunny skies as our NF Heroes and families toured the hectic garage, meeting the various drivers and teams representing the Foundation during the twice-around-the-clock endurance race. Both the No. 73 Park Place Motorsports Porsche and the No. 44 Magnus Racing Porsche carried the CTF logos. In what has become an annual Racing4Research tradition, the Magnus Racing team also had the honor of carrying the names of 111 NF Heroes on the car's rear bumper; prior to the race, each of the NF Heroes present was able to sign the car.



It was a hard-fought race for the No. 44 team, battling through the loss of not one but two blown transmissions. While lost transmissions are not unusual during a 24-hour race, the team also endured one of the strangest racing incidents: an errant opossum caused major front-end damage to the Porsche in the middle of the night. Most teams would have stopped racing given the damage, but the Magnus team would not give up. They knew that the NF Heroes, whose names were on the car, were counting on them to finish. While a chance at victory was no more, the team endured once again and finished the race, taking the checkered flag in 11th place and winning in the eyes of every CTF family.



MEET THE STAFF

Traceann Rose



HOMETOWN:

Kingston, Jamaica

CURRENT TOWN:

Mount Vernon, NY

EDUCATION:

B.A. in History and International Relations, University of the West Indies, JA; Associates Degree in Business and Management, Barnfield College, UK; Paralegal

ROLE AT CTF:

Director of NF Walk and Co-Chair of NF Forum

FAVORITE EXPERIENCE WITH THE FOUNDATION:

I've been with CTF for over nine years, and one of my favorite experiences was creating and facilitating the NYC support group that later transitioned to NYU. It was the first time I was able to bring a group of people together who made lasting friendships. Through that experience I found my purpose here at CTF; to bring people in the NF community together for encouragement and support.

FAVORITE HOBBY:

I love DIY home improvement projects. Needless to say I spend a lot of time watching HGTV.

FAVORITE MOTTO OR APHORISM:

"We never know how high we are; Till we are asked to rise; And then if we are true to plan; Our statures touch the skies"—Emily Dickinson

FAVORITE BREAKFAST FOOD:

Eggs with spinach

IF YOU COULD HAVE ANY SUPERPOWER, WHAT WOULD IT BE?

To be able to see into the future. That would be so cool.

GO TO KARAOKE SONG:

"One Love" by the legendary Bob Marley

MEET THE BOARD

Randall Stanicky



HOMETOWN:

Born and raised in Vancouver, British Columbia

CURRENT TOWN:

Soho, New York City with my wife Shabnam and two children, Caden and Kaiya

EDUCATION:

Bachelor of Commerce from the University of British Columbia

WORK WITH THE FOUNDATION:

I'm particularly pleased to have the opportunity to help connect the Foundation to executives within the business community as we increase our outreach.

FAVORITE EXPERIENCE WITH THE FOUNDATION:

Every time that I'm able to contribute to our efforts to expand our message, and specifically the opportunity to moderate the Opportunities in NF panel at the NF Conference last June.

FAVORITE HOBBY:

I love to travel and am looking forward to exploring new countries with my family in the years ahead.

FAVORITE MOTTO OR APHORISM:

Not so much an aphorism as a recurring question - "What's the bottom line?"

FAVORITE BREAKFAST FOOD:

Yoghurt parfait, I love yoghurt parfait.

THE PERFECT DAY:

No question - spending the day with my family doing absolutely anything.

IF YOU COULD HAVE ANY SUPERPOWER, WHAT WOULD IT BE?

That's a scary thought. The power to heal, followed closely by precognition, which sounds pretty cool.

IF YOU WERE STUCK ON A DESERT ISLAND, WHAT THREE THINGS WOULD YOU HAVE WITH YOU?

1. A satellite phone with a very strong signal (that would sort of solve the problem wouldn't it?) 2. My family 3. Matches (always the overlooked item on all the survivor shows I've seen)

NEW FACES AT THE CHILDREN'S TUMOR FOUNDATION

Welcome to the Foundation's newest staff members!



Catherine Blessing
Human Relations Manager
cblessing@ctf.org



Allison Cote
Community Relations Coordinator, Midwest
acote@ctf.org



Katherine Sanderlin
Writer
ksanderlin@ctf.org

Susanne Preinfalk
Design Director
spreinfalk@ctf.org



MEET AN NF HERO: *Kaleb*

Kaleb is nine years old and was diagnosed with NF at the age of ten months. Kaleb has a brain tumor but with the help of chemotherapy it has shrunk and is stable. He loves to play video games and watch Oklahoma University games with his dad. He is also a talented athlete and was chosen for the “select group” on his baseball team where he plays pitcher.

His grandmother, Lisa Siebert, says, “I love watching him play. He is such a tough kid. He played baseball even when he was undergoing chemo. He has had two surgeries on his ankle due to the curve in his leg and will have at least one more, but that has never slowed him down. He is an inspiration

to so many and he is my rock and my hero.”

FIVE QUESTIONS FOR KALEB:

What is your idea of the perfect day? Playing baseball with my friends

What is your favorite breakfast food? Biscuits

What sound or noise do you love? Music



If you could have any superpower, what would it be? To pitch fast

What was the last movie you saw? “Teenage Mutant Ninja Turtles”



STORIES OF NF *Chakriwat Vivacharawongse*

My name is Chakriwat Vivacharawongse, I am 31 years old, and I live with neurofibromatosis type 2 (NF2).

To date, I have had ten open tissue surgeries and a handful of radiotherapies (Gamma Knife, Cyber Knife) to remove or cut blood supply to the benign tumors that were impeding important structures in my central nervous system. Although it is true that NF has given me both physical and emotional hardships, I firmly believe that I would not be the person I am today if I was not born with this disorder.



Being so afflicted (or blessed), I found my passion in medicine. I graduated from the University of Miami in 2006 with a BA in Psychology and Biology and went on to graduate from medical school in 2013 and accomplish my dream of becoming a doctor. As you can imagine, I have had to overcome various physical and emotional challenges to reach this point in my career. It was both frustrating and draining to have to put my

educational goals aside as I received treatments. I have had to employ various coping mechanisms to keep me motivated.

The bottom line is that through good rapport with your physician, regular MRI scans, utilizing today’s technology, and most importantly, cultivating good coping skills, I believe a person with NF can accomplish anything their heart desires.



WHY I ATTEND THE NF FORUM

Erin Powers

I attend Forum because I have NF2, and am greatly affected. I have been very involved with the Foundation and feel like the Forum is a great opportunity to meet people who are also affected by this disease, and find out how I can best contribute to help end NF. The Forum gives me an opportunity to learn more about my disease, new treatments that have been found, and how best to cope with having NF2.

To register for the NF Forum go to www.ctf.org/nfforum

COMMUNITY 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.

MASSACHUSETTS

On December 10th, the Prudential Tower was lit blue in support of NF Awareness as a part of the Annual Prudential Center's 31 Nights of Lights.



WASHINGTON

Skyline High School in Sammamish, WA hosted a service-learning fair on October 15th to spread awareness about various organizations. Seattle NF Walk team captain Leslie Miniken volunteered to share information about CTF.



CALIFORNIA

In December, Cayla Kallman, Naomi Attal, and Teagan French (#CNTnation) celebrated their 12th birthdays by co-hosting a party for friends in Los Angeles. In lieu of presents, the young philanthropists requested donations to CTF in honor of Cayla's older brother Sammy, who has NF1. The girls received their inspiration when participating in a winter concert at their school entitled Be The Change. They have certainly made a difference – they raised over \$2,500!



PENNSYLVANIA

Chapter Council members in Pennsylvania spent cold winter nights planning three fun-filled events for Spring: the 4th Annual Tea Party with a Twist at Café Michelangelo in Philadelphia (April 25th), the first ever Philly Casino Night (May 8th) and an NF Awareness Benefit Concert featuring cellist Eugene Friesen and friends (May 17th).



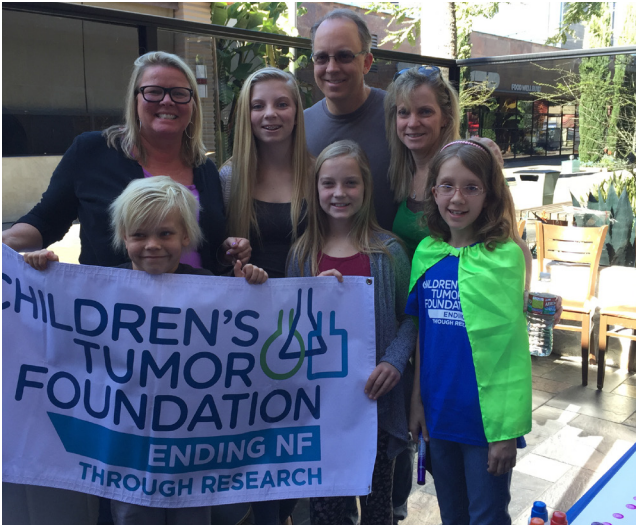
NEVADA

The Las Vegas NF Walk took place on November 9th at Cactus Wren Park, in Henderson, Nevada. The Las Vegas Walk was a great community event with lots of new faces. Thank you to all who made this Walk a great day for everyone who came out.



MISSOURI

In November, Paperdolls Boutique celebrated the grand opening of their University City location and helped raise awareness and funds for CTF. Employees sported the newest holiday-friendly frocks as they styled attendees with fashionable new gear. Guests enjoyed an evening of fun, fashion, and great raffle prizes.



CALIFORNIA

An R4R Race Day Party was held on January 24th at BJ's Restaurant in Torrance, CA. This event was in honor of all the CA NF Heroes. All the food was donated by BJ's and the children enjoyed kids' activities, face painting and received NF Hero medals.



MISSISSIPPI

In December, Jason and Meg King participated in the Grenada Lake 5K as part of CTF's Jingle Jog Challenge. Jason and Meg helped to raise awareness for the Mississippi CTF Chapter and NF!

COLORADO

The Colorado Chapter hosted their 10th Annual Gingerbread Decorating Event on December 6th at the Crown Plaza in Denver, CO. With 75 people in attendance, it was a record event! Each family made their own gingerbread house; the results were incredible. With everything from gingerbread house kits, portraits with Santa, food, children's gifts, photography, and even the room itself donated, the event was a huge success. Special thanks to our generous donors: Ken Bailey, Jerry & Karen Benson-Montgomery, Kristi Hopkins, Chili's, and Crowne Plaza DT Denver.



CUPID'S UNDIE RUN:

\$3.2 Million Raised in 2015

This February marked the 6th consecutive Cupid's Undie Run to benefit the Children's Tumor Foundation. Over 45,000 undie runners raised more than \$3.2 million for NF research. In 35 cities across the U.S. as well as three in Australia, Cupid's offered an incredibly unique way for NF families--as well as those those entirely unaffected by NF--to raise research-specific funds.

Cupid's Undie Run is presented nationally by Me Undies, Quicken Loans, Fathead, and Bombas Socks. Described as a fundraiser, a party, and a "mile-ish" run in your skivvies, the outpouring of runners and millions of dollars in donations over the past six years has been remarkable.

Although the national team is based in Denver, the program has had a huge impact throughout the nation. Executive Director Chad

Leathers recently remarked, "It is truly unbelievable seeing a dream become reality. Our internal mantra is 'Fun, Good, Quality, Creative.' Whether staff, volunteer, vendor, or race director, we believe if we make decisions based on these principles, we cannot help but succeed. That success is being seen and will be seen through the advancements in CTF's research program."



"I love Cupid's!" exclaims Silicon Valley Race Director Debbie Parsons. "Being a part of something this HUGE, helping people in ways we never knew--it warms my heart completely and I am proud to be a part of it."

Cupid's Undie Run: a funny event with serious results! If you're interested in learning more or want to know how to get involved next year, please visit <http://Cupids.org>.

JOIN THE **NF REGISTRY** AND YOU CAN HELP **END NF!** www.nfregistry.org



I joined the registry because...

"I BELIEVE IN A FUTURE WITHOUT NF."

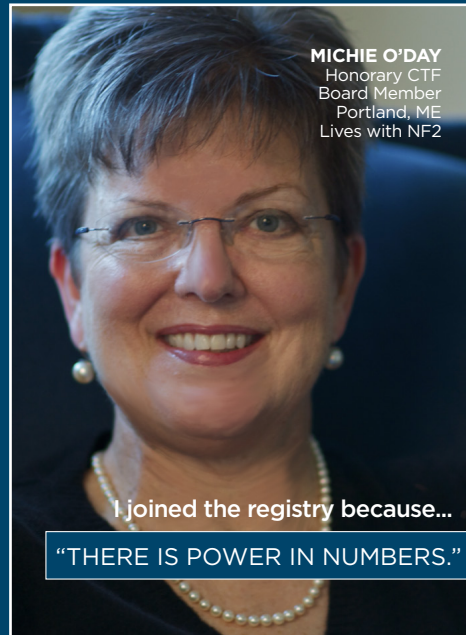
DREW LEATHERS
Atlanta, GA,
Lives with schwannomatosis



I joined the registry because...

"I WANT TO FIGHT NF."

JOANNE PASTEL
Minneapolis, MN
Daughter Jacqueline
lives with NF1



MICHIE O'DAY
Honorary CTF
Board Member
Portland, ME
Lives with NF2

I joined the registry because...

"THERE IS POWER IN NUMBERS."

SHOP TO END NF



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!

ctf.org/store

Goodshop

Shop your favorite stores (including Amazon, Target, Macy's, Best Buy, and more) and a donation gets made to the Children's Tumor Foundation each time. It's easy!

goodshop.com



AmazonSmile

You shop. Amazon Gives. Amazon will donate a percentage of your purchases to Children's Tumor Foundation.

smile.amazon.com



REGISTRATION OPEN:

THE 2015 NF CONFERENCE

PORTOLA HOTEL & SPA | MONTEREY, CA

JUNE 6 - 9, 2015



For more
information and to register, visit
www.ctf.org/NFConference

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 info@ctf.org.

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.

FOUNDATION STAFF

Annette Bakker, PhD, President and Chief Scientific Officer

Research and Medical Programs

Salvatore La Rosa, PhD, Vice President of Research and Development

Pamela Knight, Clinical Program Manager

Hyrim Lee, PhD, Science Project Leader

Patrice Pancza, Program Director, Research

Sarah Rosenberg, Executive Assistant

Kimberly Scobie, PhD, Scientist

Development and Community Relations

John Heropoulos, Vice President, Community Building & Advocacy

Michael Divers, Vice President of Major Gifts and Major Events

Jill Beck, Program Director, Racing4Research

Jessica Beckerman, NF Walk Coordinator

Carolyn Castellano, Program Director, Major Events

Allison Cote, Community Relations Coordinator

Emily Crabtree, Program Director, NF Endurance

Angela Dumadag, NF Endurance Manager, New York

Angela Earle, NF Endurance Mgr, Community & Youth Events

Garrett Gleeson, Program Director, Major Gifts

Kelly Mills, Community Relations Regional Manager

Julie Pantoliano, Community Relations Coordinator

Kristine Poirier, Director, Community Relations

Traceann Rose, Program Director, NF Walk

Kristin Stanley, Community Relations Coordinator

Mary Vetting, Prospect Coordinator

Lauren Walsh, NF Endurance Manager, Chicago

Jennifer White, NF Walk Coordinator

Public Education and Communications

Simon Vukelj, Vice President, Communications

Alissa Marks, Marketing Manager

Susanne Preinfalk, Design Director

Katherine Sanderlin, Writer

Rebecca Silver, Public Relations Manager

Vanessa Younger, Communications Manager

Human Resources

Catherine Blessing, Human Resources Manager

Finance and Administration

David Webber, Vice President of Finance and Operations

Mohamed Amin, Database Assistant

Monique Boucher, Database Supervisor

Danielle Meyer, Technical Support, National Programs

Carey Milligan, Accountant

Rosa Amelia Perez, Project Administrator

FRIDAY, APRIL 17 - SUNDAY, APRIL 19

JOIN US FOR THE 2015 NF FORUM



REGISTER TODAY!
www.ctf.org/nfforum