

Royal Border Bridge and Niagra Falls are among the landmarks that will light up for NF Awareness Month this May. For more information on landmarks lighting up for NF, see page 3.



May is National NF Awareness Month and the Children's Tumor Foundation uses this occasion to put NF in the national spotlight, raising awareness in both the NF community and the general public, and providing numerous opportunities to raise money for groundbreaking NF research supported by the Children's Tumor Foundation.

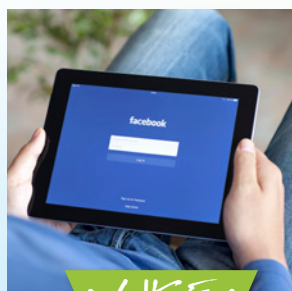
We want the world to know about neurofibromatosis and to see that those who are affected by it are the strongest people around. That's why our May Awareness Month campaign is called "**I KNOW A FIGHTER**" and focuses on actions to Fight NF!

Visit ctf.org/nfawareness to learn more about the following ways to take action and Fight NF:



• WEAR •

our exclusive "I Know A Fighter" T-Shirt available at ctf.org/store.



• LIKE •

Children's Tumor Foundation on Facebook.



• SHARE •

the many new May NF Awareness Month graphics we will be releasing all month long.

EVERY GIFT MATCHED

Generous Donors Establish Matching Gift Funds for All Three NF Types

Through the month of May and beyond, donations to the Children's Tumor Foundation will be matched dollar-for-dollar thanks to the generous Matching Gift Programs established by longtime and much appreciated supporters of the Foundation: **Jim Bob and Laurée Moffett** (NF1), **Carol Harrison** (NF2), and **Richard and Erica Horvitz** (schwannomatosis).

For the first time in the Foundation's history, three matching gift programs are at work at the same time. The dedication of these three donors is energizing the entire NF community as we come together to fight NF on all three fronts.

Double your donation at ctf.org/match.

YOUR GIFT TO FUND NF1: *Moffett Matched*

In October of 2014, the Children's Tumor Foundation announced that the Moffett family had created a \$2.5 million matching gift fund to raise donations toward NF1 research. Through this fund, CTF recently established Synodos for NF1, a multidisciplinary consortium of leading scientists from various backgrounds. With the help of many individual contributors, the Foundation has raised over \$1.3 million which will be matched dollar-for-dollar.

YOUR GIFT TO FUND NF2: *Harrison Matched*

The Children's Tumor Foundation launched Synodos for NF2 in March of 2014 and assembled a team of multidisciplinary scientists from twelve world-class labs to join together and develop effective new treatments to end NF2. Synodos for NF2 was CTF's first groundbreaking example

Continued on page 15

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LETTER FROM THE PRESIDENT

Annette Bakker, PhD



Spring is finally here, bursting forth with glorious beauty, tenacity, and strength! As we look forward to the warm days and blue skies this season offers, we also look forward to the launch of NF Awareness Month on May 1st. This year, the Children's Tumor Foundation (CTF) has chosen a theme reflecting the strength of those whose lives are affected by NF, "I Know A Fighter."

This month, the Children's Tumor Foundation, in partnership with you, ramps up our effort to inform the world that NF exists. NF is not fair, and as such we are all warriors in the fight against NF. So we invite the world to join us in this battle to End NF, because the more fighters we have, the faster the battle is won. We are certain that we all must join together—and collaborate—to conquer NF.

The battle against NF has made great advances in recent years: the number of scientific publications about NF, the number of NF-relevant animal models, and the number of drugs undergoing clinical testing have all greatly increased. CTF has transformed during this time from a funder of science to a partner in the research process. I want to assure you that, historically, the Foundation made the right investments. Seventy percent of the published data available today was funded or co-funded by CTF. Without the strong foundation of knowledge laid by CTF's early investments, NF research would be negligible.

Today, however, the Foundation's focus has evolved. We have teamed up with researchers, clinicians, and industry partners with only one goal in mind: to efficiently translate ALL new discoveries into solutions that benefit you, your families, and your friends. We are creating solutions that accelerate the drug discovery process. For example, data generation has become easier, faster, and cheaper. We want to guarantee that all this new data ends up in a central, usable place. So CTF partnered with a top data team (Sage Bionetworks) to ensure that all experts, regardless of lab or business affiliation, could access and learn from this data. We created solutions like Synodos and the Neurofibromatosis Therapeutic Consortium (NFTC) that are proving that collaboration and data sharing work!

There are several reasons we have been able to shift our strategy. Importantly, our work is attracting funds needed to drive research, thanks to the incredible matching gifts from Jim Bob and Laurée Moffett, Carol Harrison, and Richard and Erica Horovitz, as well as the ongoing generosity of Dan and Jennifer Gilbert, Cupid Charities, Inc. and so many amazing donors and participants in our fundraising programs. As donations increase, our ability to accelerate research grows exponentially. Another reason: we have brilliant minds working together to find solutions—researchers, clinicians, industry, Board members, and CTF's staff.

This May, let us burst forth together with tenacity and strength, further joining forces in the fight against NF!



• MAY IS •

≡ NF AWARENESS ≡

MONTH
ctf.org

May is NF Awareness Month *continued*



• WATCH •

our May Awareness Month Video.



• STAR •

in your own video by telling us how you Fight NF! "I WALK to Fight NF" or "I SMILE to Fight NF!" Send it to media@ctf.org.



• SUBSCRIBE •

to our YouTube channel to watch for your video!



• CHANGE •

your profile picture to one that celebrates NF Awareness.



• EDUCATE •

using facts sheets available at ctf.org/nfawareness.



• SHINE •

a Light in your community and add to the growing list of landmarks that will glow in CTF blue and green for NF Awareness Month.



• REGISTER •

in the NF Registry if you or your child have NF.



• DONATE •

and double your gift through the month of May at ctf.org/match.



• PARTICIPATE •

in an event in your community (see page 14 for a full list).



• COMMUNICATE •

Spread the Word and increase awareness about NF!

You may know people who are not familiar with neurofibromatosis, but can appreciate the strength and perseverance it takes to overcome obstacles and live a full life. Invite them to join us, we're stronger when we Fight Together!

And don't forget: May 17th is World NF Awareness Day!

SHINE A LIGHT ON NF

These landmarks will light up in Blue and Green this May to Raise Awareness of NF

As of publication

- May 1-31 City Hall Plaza, Manchester, NH
- May 2-3 PECO Crown Lights, Philadelphia, PA
- May 17 Niagara Falls, New York
- May 17 Bank of America Building, Dallas, TX
- May 17 Terminal Tower, Cleveland, OH
- May 17 Florida Hospital Ginsburg Tower, Orlando, FL
- May 17 Royal Border Bridge (connects England & Scotland)
- May 17 Tovrea Castle, Phoenix AZ
- May 17 Gardner Building, Boise ID
- May 17 Morrison Bridge, Portland, OR
- May 17-23 National Grid, Syracuse, NY

Visit ctf.org/nfawareness to take action!

NEW PARTNERSHIP



Children's Tumor Foundation and National Biomarker Development Alliance

Join Together to Address Critical Research Need

"This partnership will be the first and best effort in biomedicine to not just develop effective biomarkers for NF, but its emphasis on children's brain tumors will serve to underpin substantive strategies for precision medicine in these rare disease high-need populations," said Anna Barker, PhD, Director of the NBDA, Co-Director of Complex systems and Professor, Arizona State University.

The President and Chief Scientific Officer of the Children's Tumor Foundation, Annette Bakker, PhD, concurred, "This partnership will also serve to provide a rational basis for clinical trials and can overall become a model for other rare – and relatively rare – tumors in addition to NF."

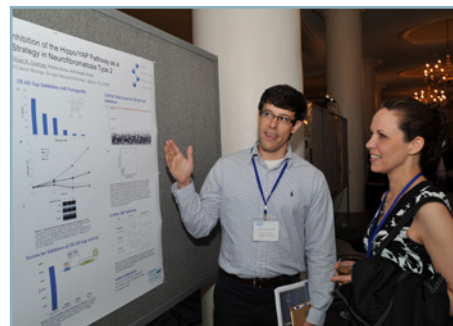
THE 2015 NF Conference

The best and the brightest in the NF field will convene once again in Monterey, CA, on June 6th to the 9th for the 2015 NF Conference. The meeting this year promises to be a stimulating, unique, and provocative program. In a departure from recent years, the Conference has been organized as a single rather than a dual track. Issues important to clinicians, basic scientists and those who straddle both disciplines will be the primary focus. All sessions will address aspects of Neurofibromatosis type 1 (NF1), Neurofibromatosis type 2 (NF2) and schwannomatosis across shared themes.

The Conference will kick off with an address on transformative healthcare and the development of new research models that leverage convergent knowledge, innovative teams, and novel funding approaches.

There are nine sessions in the core agenda covering all aspects in the therapeutic pathway pertinent to NF, from basic discovery through translational science to clinical trial design and implementation. The Conference will wrap up with an update of all things current in NF research, from clinical trials to the status of funded programs such as the Biobank, Synodos for NF2, and the REINS Initiative.

For more information visit ctf.org/NFConference.



New Deadlines for Key Awards Announced

To create a more streamlined process for applicants, the Children's Tumor Foundation has created new timeframes for two of the Foundation's awards programs.

The Clinical Research Award (CRA) program, launched in 2007, supports early stage pilot trials of candidate therapeutics and interventions for treatment of manifestations of NF1, NF2, and schwannomatosis. Additionally, the CRA award supports innovative clinical trial enabling studies. CTF supports a maximum of three CRA studies a year, each funding up to \$150,000, which includes overheads and indirect costs. The deadline for submitting a letter of intent is anticipated to be **June 15, 2015, with the full application due on August 17, 2015.**

The NF Clinic Network Award (NFCN) recognizes clinics that provide appropriate NF care through implementation of current guidelines for NF. Clinics in the network may apply for either or both of two annual NFCN Clinic Stipends. The first stipend must be used to benefit the clinic's local NF family community. The second stipend is a travel grant for the clinic coordinator or genetic counselor to attend the NF Clinics Meeting, which is held in conjunction with the annual NF Forum. The new deadline to apply for the NFCN award is **September 15, 2015.**

For more information on applying for either of these award programs, visit ctf.org/Funding.

2015 RESEARCH & GRANT DEADLINES:

Drug Discovery Awards (A)
Monday, April 20, 2015

Drug Discovery Awards (B)
Monday, August 3, 2015

Clinical Research Awards
Letter of Intent due
Monday June 15, 2015

Full Application due
Monday, August 17, 2015

NF Clinic Network
Tuesday, September 15, 2015

NF CLINIC NETWORK CONTINUES TO EXPAND

The Neurofibromatosis Clinic Network (NFCN) was established in 2007 to standardize and raise the level of NF clinical care nationally and integrate research into clinical care practices. The NFCN recognizes clinics that provide comprehensive medical care to individuals with NF, foster patient education, and encourage participation in clinical research trials.

The following four NF clinics were recently accepted into the NF Clinic Network (NFCN), bringing the total to 47 NFCN Affiliate Clinics in the United States.

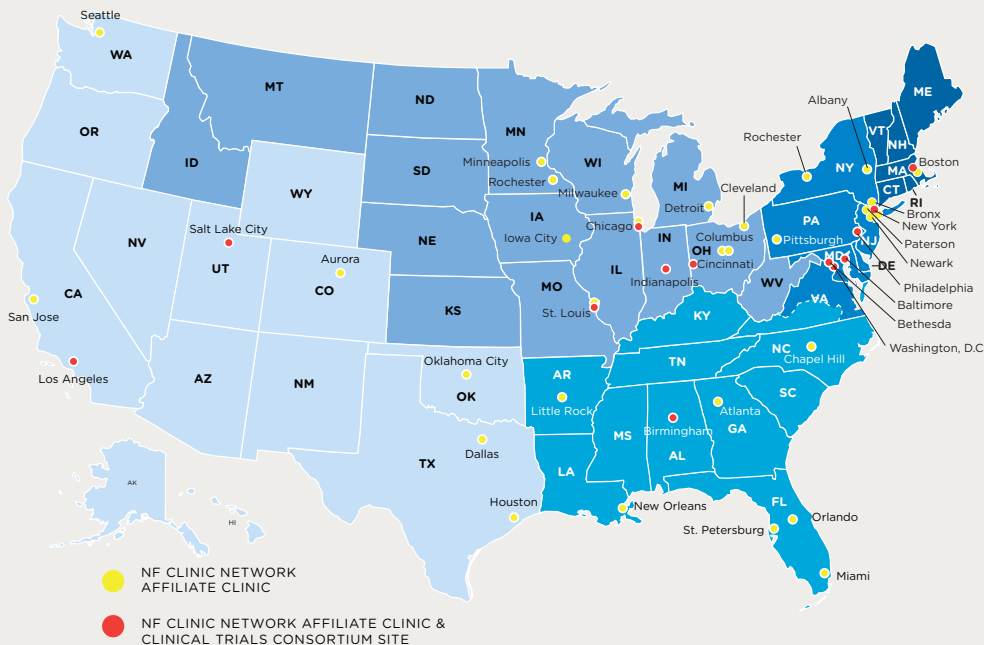
- **The Melodies Center for Childhood Cancer and Blood Disorders at the Children’s Hospital at Albany Medical Center in Albany, New York** with Director Lauren Weintraub, MD, Hematology/Oncology; case manager, Corinne Hunter, RN; and clinical care coordinator and nurse navigator Melissa Dupin, CNRN, RN. This clinic serves a 25-county region including

northeastern New York and western New England, providing a full range of treatments and services allowing children from the region to receive world-class treatment close to home.

- **Neurocutaneous Syndromes Clinic at Rainbow Babies & Children’s Hospital in Cleveland, Ohio** with Director Deborah Rukin Gold, MD, Neurology; and clinic coordinator Kelly Laschinger, CPNP, CPON. This clinic specializes in the multidisciplinary care of children, adolescents and young adults with NF. The clinic concentrates on the whole family and has special supports available for adolescents and young adults (AYA). Research in the clinic is focused on NF1-associated brain tumors and advanced neuro-imaging, especially optic pathway gliomas.
- **Neurocutaneous Disorders Clinic at All Children’s Hospital in St. Petersburg, Florida** with Director Stacie Stapleton, MD, Hematology/

Oncology; and clinic coordinator Sonja Steinbrueck, RN. All Children’s Hospital is a part of the Johns Hopkins Health System and is the first hospital outside of the Baltimore/Washington DC region to become integrated with Johns Hopkins Medicine. The NF team has developed a patient roadmap to provide the continuity of care that guides families through the clinic process.

- **URMC Neurofibromatosis Clinic at University of Rochester Medical Center in Rochester, New York** with Director Jennifer Mulbury, MD, neuro-oncologist; and clinic coordinator, Carolyn Dickinson, PNP. Dr. Mulbury has been enhancing the NF clinic for several years after taking an interest during her child neurology fellowship and furthering that commitment with a neuro-oncology fellowship. She and Carolyn work in conjunction with colleagues in hematology-oncology, neurosurgery, orthopedics, and ophthalmology to offer comprehensive care to NF patients.



CTF welcomes these newly appointed clinics. With the recent addition of Heather Radtke, MS, CGC as the NFCN clinic and symposium coordinator to strengthen clinic network collaborations and assist clinics with program development and symposium planning, the future is looking brighter than ever for NF clinics and NF families!

For further information contact **Heather Radtke** at hradtke@ctf.org or **646-738-8574**.

There are 47 clinics in the NF Clinic Network

NF REGISTRY AND NF BIOBANK: A Conversation with Mindell Seidlin

Mindell Seidlin is a physician with Board Certification in Internal Medicine and Infectious Diseases with vast experience in academic medicine as well as clinical development in the pharmaceutical industry. She began collaborating with the Children's Tumor Foundation on behalf of a donor in 2009 and has been a consultant to the Foundation since 2014.

Can you describe the nature of your work with the Children's Tumor Foundation?

The bulk of my work with the Foundation has been focused on creating a biorepository for tissues from people with NF. We recognized early on that this would be a critical resource for research into the mechanisms that drive the development of various disorders that people with NF experience. I've also been involved in creating and analyzing the data in the NF Registry.

How was CTF's NF Biobank created?

The first specimens were collected for the biobank in 2012, but the work began a couple of years before that. We worked hard to identify partners who could reliably manage both the variety of tissues of interest from NF patients and the clinical data and technical data about them. After that, we developed protocols for collecting the tissues and clinical data. Our first protocol involved collection of cutaneous neurofibromas from patients undergoing removal of multiple tumors in collaboration with Dr. Hubert Weinberg. The second protocol involves collection of tissues from recently deceased patients and is being conducted in collaboration with NDRI, the National Disease Research Interchange.

How would you like to expand the NF Biobank?

We would like to increase the variety of tumor and tissue types that are available in the biobank by developing protocols for collecting tumors when they are removed from patients for storage. We also plan to store cell lines that are developed from patient specimens so that we can make them available to investigators all over the world.

Tell me about the NF Registry. How is that data useful for researchers?

The NF Registry is a crucial resource in at least two different ways. The first is as a means of pinpointing key challenges identified by patients and caregivers over a broad range of ages, disease states and locations. When doctors look at their own patient populations,



they are often biased based on the location or type of practice that they have. A pediatrician sees only children, a surgeon only those requiring surgery, etc. The patient-entered registry can counter some of those biases and give a truer picture of the entire range of the NF experience. Furthermore, we will be able in the future to go back to people with particular issues to ask more detail about what works or doesn't, or what kinds of outcomes matter to them.

The second important use of the registry is a means for identifying patients who may be candidates to participate in clinical trials. One of the key challenges in conducting research on new treatments is to identify patients who are eligible to enroll in the trials. Companies are often unwilling to consider developing a treatment for a disorder if they don't think they can efficiently recruit patients for the trials. The availability of patient registries has been a big incentive for development of new treatments in other rare diseases such as cystic fibrosis and muscular dystrophy. We are hopeful that the NF Registry will similarly smooth the path to development of new drugs for our patients.

What have we learned from a preliminary look at the NF Registry data?

In our initial look at the registry data, we tried to determine how well the population is represented in terms of distribution of age, gender, ethnicity, and geography. We found that males are less likely to register than females and that the age distributions are somewhat different for NF1, NF2, and schwannomatosis. We also need to work harder to register a more ethnically diverse range of people. Currently the geographic distribution is similar to that of the NF Clinic Network, which is not surprising given that these have often been sites for recruitment for enrollment.

For more information visit www.nfregistry.org.

SPONSORSHIP SPOTLIGHT: ChemTreat



ChemTreat, a large industrial water treatment company headquartered in Richmond, VA, has provided charitable donations to the Children's Tumor Foundation since 2008, when two of their employees, Stephanie and Roy Arnette, learned that their two year old son, Cameron, had been diagnosed with NF1. The company has been very supportive of this couple, donating to all of their fundraising initiatives such as NF Endurance, Racing4Research, and, most recently, the NF Walk program. Stephanie Arnette joined the Walk program in 2012, and has raised \$90,000 for the Foundation in three short years, thanks to having a corporate sponsor like ChemTreat. ChemTreat continues to be a strong advocate for the NF Walk program, and has encouraged their employees to attend the Walk. They have even covered registration fees for employees as additional support. This company truly cares about their employees and families, and the NF Walk program would like to recognize ChemTreat for their ongoing sponsorship.



2015 WALK DATES

Scottsdale, AZ	April 19
Staten Island, NY	May 16
Kernersville, NC	May 16
Cincinnati, OH	May 17
Providence, RI	May 31
Boston, MA	June 14
St. Louis, MO	June 20
San Jose, CA	June 20
Philadelphia, PA	June 27
Concord, NH	July 11
Casper, WY	July 25
Portland, OR	July 26
Chicago, IL	August 1
Salt Lake City, UT	August 29
Idaho	September 12
Seattle, WA	September 12
Jacksonville, FL	September 19
Addison Oaks, MI	September 26
Denver, CO	September 26
Putnam, CT	September 26
Corbin, KY	September 26
Central NJ	September 26
Dallas, TX	October 3
Richmond, VA	October 3
Rochester, NY	October 3
Columbus, OH	October 4
Orlando, FL	October 10
Phoenix, AZ	October 11
Hoover, AL	October 18
Los Angeles, CA	October 25
Las Vegas, NV	November 1
Houston, TX	November 7

CONSIDER DOING AN **ADD-ON FUNDRAISER AT WORK**

Casual Day

Go casual for CTF! Have your employees or coworkers make a donation to the Children's Tumor Foundation in return for permission to wear jeans or shorts to work. Give them the opportunity to purchase a day pass, a monthly pass, or even a pass for the entire season! Employees receive a sticker, provided by CTF, for each day they purchase.

Lunch & Learn

Neurofibromatosis is hardly rare, but rarely talked about. Let a representative of the Children's Tumor Foundation visit your office and present a "Basics of NF" course to your employees or coworkers. We will provide information on neurofibromatosis, the Children's Tumor Foundation, and opportunities to get involved with the cause.

Create an NF Walk Team

Gather your coworkers, colleagues, friends, and family members and create a team for one of our local NF Walks! Choose from our current list of events at nfwalk.org.

Matching Gift

Help your employee participants double their fundraising goals and give each donation twice the impact! All funds can be matched by your corporation up to an amount of your choosing.



NFE Stops Traffic in Times Square

The NF Endurance Team took the Big Apple by storm on Sunday, March 15th at the United Airlines NYC Half Marathon! Eighteen NFE team members represented CTF, raising NF awareness and more than \$15,000 for NF research. Next up: the TCS New York City Marathon! You can join on November 1: run 5 bridges and all 5 boros with millions to cheer you on! For more information please contact Angela Dumadag at adumadag@ctf.org.



CHOOSE YOUR OWN EVENT

Who could ask for more in a brother? NF Hero Kate Cochran's older brother, Ben, currently in 8th grade, organized a 5K walk/run to honor his sister Kate. He called the event the 5Kate. He raised over \$3,000 for CTF and has decided to make this an annual event in his hometown of Springboro, OH. Thanks, Ben, for showing us that anything is possible!



Little Heroes of Georgia

On February 22nd in Gainesville, Georgia, over 300 participants kicked off the 3rd annual Little Heroes of Georgia 5K. Inspired by one of their hometown NF Heroes, Robert Owenby, this \$20,000 fundraising event was put together by Event Chairs Carolanne Owenby and Tara Rogers. Our Foundation President, Annette Bakker, joined in the festivities and met several families who participated in the event. If you are interested in starting your own Little Heroes 5K, please email at nfendurance@ctf.org.



We have your GUARANTEED IRONMAN Entry

IRONMAN Kona: Is racing in IRONMAN Kona on your bucket list? The NF Endurance team has one coveted entry available for the IRONMAN Kona World Championships being held in October of 2016. Those interested should email Emily Crabtree at ecrabtree@ctf.org. The athlete chosen must commit to raising \$40,000 for the Children's Tumor Foundation by September of 2016.

IRONMAN Florida: The Children's Tumor Foundation is the official charity partner for IRONMAN Florida. We have entries into the SOLD OUT event on November 7, 2015. If you've ever dreamed about completing an IRONMAN, we are here to help you every step of the way. Email Angela Earle at aearle@ctf.org for more information.

Athletes will receive...

- FREE entry into Ironman Florida 2015
- FREE coaching through South Shore Tri Coach
- CTF training shirt and tri kit
- Connection with an NF Hero to make your training and fundraising more meaningful
- Access to a fundraising website

Bank of America CHICAGO MARATHON

Andrea's road to the Chicago marathon began with a quick thought: "Last year I had the crazy idea to run the Bank of America Chicago Marathon. I wanted my run to have meaning, so I found the Children's Tumor Foundation. I have NF1, and I was excited to discover an organization committed to finding treatments and hopefully, one day, a cure for NF!"

Run with Andrea! Contact Lauren Walsh at LWalsh@ctf.org for more information.



RACING 4 RESEARCH

2015 R4R SCHEDULE

May 2 - Monterey, CA

May 16 - Bowmanville,
Ontario, Canada

June 27 - Elkhart Lake, WI

July 25 - Lime Rock, CT

August 1 - Lexington, OH

August 22 - Salt Lake City, UT

September 19 - Austin, TX

October 3 - Atlanta, GA

CTF LOGOS

Spruce Up the Racetrack

With the 2015 race season under way, the Children's Tumor Foundation logo is popping up all over the race paddock - on track, on television, in the garage, on pit lanes, on drivers' fire suits, on helmets, and on race cars! In fact, the CTF logo and our End NF logo are on eight race cars (and counting!) running in two race series that will crisscross North America over the next six months. Three of the cars feature all-new Jeffrey Owen Hanson artwork, continuing our Art Car program for a second consecutive year. In fact, the Art Car program continues to bring good luck to the team and has already garnered a podium this season! New Racing4Research driver Paul Holton finished second in Texas this March with our wonderful NF Heroes there cheering on the entire Compass360 Racing team.

New for 2015: We're excited to share that, beginning in May, the Children's Tumor Foundation logo will appear on the two Compass360 Racing rigs as they travel the roads in support of the team - talk about spreading the word!

Our Racing4Research program is open to all CTF families and friends - check out our upcoming schedule and join us at a track near you! Racing4Research offers NF families the chance to come out to the track and have a unique experience with the teams and corporate partners who have joined in our fight against NF. In addition to spending an afternoon with your fellow NF families, you'll meet the drivers and crew in person, have a chance to check out race cars throughout the paddock, and you may even have a chance to sit in a race car! Our partnerships within the racing community allow our NF Hero families to have an up-close, behind-the-scenes experience open to few others.

JOIN US and EXPERIENCE THE FUN! To sign-up for one of our upcoming events, please email Jill Beck at jbeck@ctf.org.



MEET THE STAFF

Monique Boucher



HOMETOWN:

Brooklyn, NY

CURRENT TOWN:

New York City

WHAT IS YOUR WORK WITH THE FOUNDATION?:

I'm the Database Supervisor. When gifts arrive at the Foundation, my staff and I enter them into our financial software, then I ensure that the funds are correctly allocated, meaning that they accurately reflect where the funds came from (Walk, Endurance, an individual, etc.) and I make sure that the restrictions on certain funds are in place. It requires great focus and attention to detail.

FAVORITE EXPERIENCE WITH THE FOUNDATION:

The day CTF took over NYC! Last summer we did a team-building exercise in which the CTF staff traversed the city on a scavenger hunt and put the CTF logo on everything. It was great, and an amazing way to get to know each other.

FAVORITE HOBBY: Spending time with my son and watching movies

FAVORITE MOTTO OR APHORISM: Live in the moment!

FAVORITE BREAKFAST FOOD: Ham, spinach, and tomato omelet or cinnamon French toast

IF YOU COULD HAVE ANY SUPERPOWER, WHAT WOULD IT BE? The ability to change my superpower!

GO TO KARAOKE SONG: I don't even like to do interviews, let alone karaoke.

WEIRDEST THING YOU'VE EVER EATEN: RABBIT - I did not like it.

MEET THE BOARD

Margaret (Peggy) Wallace, PhD



HOMETOWN: Crete, IL

CURRENT TOWN: Gainesville, FL

WORK WITH THE FOUNDATION: My work with the Foundation has spanned 27 years, beginning when I was a postdoctoral fellow and received a Young Investigator Award to work on NF1 gene discovery. The first NF Conference I attended was in 1988 and there were only about 25 people in the room! When I was a junior faculty member here at the University of Florida, I also received a small grant from the Foundation, which I used to hire the postdoctoral fellow who identified somatic NF1 deletions in some neurofibromas for the first time. In 1998, the Foundation invited me to be on the Research Advisory Board (RAB) for grant peer review, and I became Co-Chair of that group in 2004. In 2001, I had the privilege of being asked to Co-Chair the NF Conference (called International Consortium back then) with Dr. Rick Fehon, which was a lot of work but also a lot of fun. The conference was still in Aspen, CO at that point, but shortly after that year it moved to other locales due to the growing attendance. As RAB Co-Chair, I am also invited to attend the CTF Board of Directors and Medical Advisory Committee meetings as an ex-officio member.

FAVORITE EXPERIENCE WITH THE FOUNDATION: One experience that stands out was when the NF Conference dinner was held at the ranch of Mr. Rick Horvitz, a member of the Board of Directors. There was terrific music, camaraderie, and entertainment in the form of horseback riding and wildlife spotting.

FAVORITE HOBBY: Animals. I enjoy our two dogs and our pond full of turtles and fish, and the wildlife that comes into the yard.

FAVORITE MOTTO OR APHORISM: It is tied between two we use in the lab: "Murphy (as in Murphy's law) has smote you down" and "If you work on NF1, bang your head here" (representing the difficulty of this project at EVERY level).

NEW FACES AT THE CHILDREN'S TUMOR FOUNDATION

Welcome to the Foundation's newest staff members!



Erin Powers
Community Relations Assistant
epowers@ctf.org



Heather Radtke
NF Clinic and Symposium Coordinator
hradtke@ctf.org



Kate Kelts
Patient Support Coordinator
kkelts@ctf.org



Latisha Maxwell
Gift Processing Assistant
lm Maxwell@ctf.org

MEET AN NF HERO: *Henry Haag*

Henry was diagnosed with NF1 at age two. He has a tumor in the hypothalamus region of his brain and underwent a year of chemotherapy when he was three. Henry also has pseudoarthrosis of the fibula in his right leg, which has been a challenge. He's had a few unsuccessful bone graft surgeries and his family is currently trying to figure out what the next step for him should be.

His mother, Kristen, says, "Despite all of his health issues, this young boy is the most amazing human being! He is now seven and loves music, especially classic rock - he can name any tune! He also enjoys 'Friday Share Time' at school and often brings his musical instruments in to show the class. Henry lights up a room with his huge smile and he has an amazing memory; he knows every person we walk by, especially in the grocery store. He's my hero and I'm so proud to be his mother."

FIVE QUESTIONS FOR HENRY:

What is your idea of the perfect day?

"It has to be sunny for sure. When I wake up I'd go to my mom and dad's room and bring them coffee in bed. They love that. Then we'd get in the Jeep with the top down and go out to breakfast at a 'greasy spoon' diner. Then we'd take a ride, listening to AC/DC, and go to the park to swing. When we get home, I'd play with the dogs. Dinner would be either fried chicken or a rib-eye steak cooked medium rare with A1 Sauce. Then I'd get in the hot tub for a while, and later fall asleep watching School of Rock and eating a tub of popcorn. That would be the coolest day ever."

What is your favorite breakfast food? "Runny yoke eggs with thick sliced maple bacon. Or doughnuts, chocolate doughnuts!"



What sound or noise do you love?

"I love the sound of a Fender Stratocaster electric guitar, especially when played by Jimmy Page. So cool!"

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

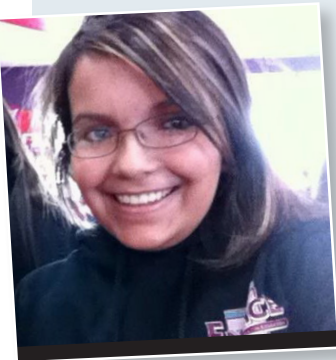
"I would like to be like Iron Man. Great suit. He rules!"

What was the last movie you saw?

"I watched *Little Miss Sunshine* last Sunday with my dad and older brother. I loved when she danced in the talent show at the end. That was awesome."

STORIES OF NF *Melissa Montoya*

"My name is Missy. I am 19 years old and live in Las Cruces, NM. I have NF1 and am the only one in my family who has it."



"There are five or six tumors on my back and three on my shoulder. When I was born, I had no motor skills and I have experienced learning problems throughout my life. I also have café au lait spots, scoliosis, and seizures. I had seven MRIs before I was three years old

and have had approximately 50 to date!

"Despite the challenges of living with this disorder, I try to focus on the positive. I am a freshman at Doña Anna Community College and enjoy singing, taking pictures, and hanging out with my friends. Having NF is not easy, but I know I am not alone in the fight against neurofibromatosis and that encourages me."

IN THE MEDIA



CTF Ambassador
Jeffrey Owen Hanson
was featured on
CBS Sunday Morning.

To view the segment go to
ctf.org/hanson

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.

WISCONSIN

Thank you to Elaine Pankow and Bonnie Wellnitz for hosting their annual Valentine's Tea at Watt's Tea Shop in Milwaukee. Although this event started in a basement, it now stretches over two weekends. The event raised over \$7,600 while bringing together the local community in a wonderful way.



ARKANSAS

The annual Wine and Art party held on Saturday, March 14th in Little Rock, AR raised over \$11,000. Guests had the opportunity to bid on art from local artists. Pictured are Vivian Griffith, Anne Trussell, and Belinda Woods, auctioning off Steve Griffith's artwork. Guests had the opportunity to pay \$5 to "make their mark" on it!



TEXAS

On Feb 7th, Gail and Paul LaBarge and the Antique Automobile Club of the Rio Grand Valley hosted a car show in Harlingen, TX to benefit CTF. Over 70 cars entered, CTF T-Shirts were sold, and approximately \$1500 was raised. Gail and Paul have a grand-nephew, Charlie Steenbergen of Warwick, RI, who has NF1.



CONNECTICUT

The 3rd Annual Craft Fair took place on Sunday, March 22th at the Knights of Columbus. Vendors ranged from Stella & Dot to hand-crafted birdhouses. The event, organized by Rhianna Curotto, raised \$1300 for the Putnam NF Walk. A special thank you to the Knights of Columbus, who donated \$300.

NEW JERSEY

The Children's Tumor Foundation would like to warmly thank Matthew Dichter and the Landis family for setting up a private basketball clinic with the Brooklyn Nets for our Tri-State NF Heroes. NBA star Darius Morris participated and helped make it a day to remember.





UTAH

Utah Grizzlies Hockey joined with 44 supporters of the Utah Chapter for the 2nd annual CTF/#EndNF with Travis night on March 6th. Utah NF Heroes Travis, Ryker, and Rylie participated in the ceremonial puck drop, in addition to the CTF-created human tunnel for the Utah Grizzlies hockey team.



ILLINOIS

Thanks for helping us Wine(d) Down!
On March 18th, the Illinois Chapter hosted their inaugural Wine(d) Down event. It was a casual after-work evening of drinks and laughter, with old faces and new brainstorming ways to get the word out about CTF and NF.



CALIFORNIA

On March 29th, the California chapter hosted its inaugural Fashion For NF: Heroes For A Cure event. Local NF Heroes strutted the runway in outfits graciously donated by several designers. The event was MC'd by Jonathan Sadowski who stars on the ABC Family TV show "Young & Hungry." The event raised over \$13,000.



NEVADA

Student Union and Event Services of UNLV hosted a pancake breakfast at Applebee's restaurant on Jan 24th in Las Vegas, NV. Families came from various parts of Las Vegas to take part in this fun-filled morning.

CALIFORNIA CHLA Neurofibromatosis Clinic Celebrates 10 Years

Children's Tumor Foundation co-sponsored the 10 Year Celebration of the Comprehensive Neurofibromatosis Clinic at Children's Hospital Los Angeles on March 12th at Desert Rose Restaurant in Los Angeles, CA. The event was well attended, with many doctors and members of the NF community present. A special thank you to the following attendees: Tena Rosser, MD, Linda Randolph, MD, Nathan Robison, MD, Girish Dhall, MD, Mark Krieger, MD, Erin Kiehna, MD, Benita Tamrazi, MD, Marvin Nelson, MD, Lisa Betesh, RN, BSN, CPN, Tina T. Liu, MS, LCGC, The Jaffa family (Rick, Amanda, Joe), Sharon O'Neil, PhD, Vanessa Guzman, and everyone else who was there to make this evening a wonderful event. We appreciate all that you do for the NF community.



COMMUNITY NEWS

NEW YORK

For a second year, the six offices of NY Physical Therapy & Wellness in Long Island, New York are celebrating NF Awareness Month throughout the month of May, with a special celebration on NF Awareness Day, May 17th. Owners Mark Diaz and Ronald Bredow became involved with the Foundation several years ago when Mark's niece, Kristina Diaz, was diagnosed with NF2. What a great way to bring NF awareness into the workplace!



COLORADO

The weather was perfect in downtown Denver for the March 14th St. Patrick's Day Parade. The Colorado Chapter was represented by 50 participants waving and handing out candy from their annual float. The chapter's leprechaun is always a favorite subject for selfies but this year's huge hit with everyone (including the media) was a leaping green morpher on running stilts!

• MAY IS •

NF AWARENESS

Community Events
ctf.org/calendar

• MONTH •

- 5/1 Cardinal Glennon Clinic Symposium, St. Louis, MO
- 5/2 4th Annual Woman's Day, Bountiful, UT
- 5/2 NF Guys Poker Night, Centennial, CO
- 5/2 Knights of Columbus - Las Vegas Night, Manhattan Beach, CA
- 5/3 Harvard Medical School NF Symposium, Boston, MA
- 5/4 Johns Hopkins NF Symposium, Baltimore, MD
- 5/7 Buffalo/Rochester NF Education, Rochester, NY
- 5/9 NF Mother's Day Tea, Denver, CO
- 5/9 UNLV Student Union Spring Celebration, Las Vegas, NV
- 5/15 CruisINForaCure, Lewisville, TX
- 5/16 Miami Children's Hospital Symposium and Family Day, Miami, FL
- 5/17 Spinathon to End NF, Fairfield, CT
- 5/17 NF Awareness Benefit Concert, Philadelphia, PA
- 5/30 #EndNF with Travis Charity Golf Tournament, Salt Lake City, UT

GET INVOLVED

Are you looking for a perfect outlet for your creative side, or a great way to use your budgeting skills for a good cause? We are always looking for volunteers to help us host awareness and fundraising events. Please contact your regional Community Relations Coordinator:

MIDWEST: Allison Cote (acote@ctf.org or 646-738-8575)

WEST: Kelly Mills (kmills@ctf.org or 310-216-9570)

SOUTHEAST: Kristin Stanley (kstanley@ctf.org or 404-861-2944)

TRI-STATE & MIDATLANTIC: Julie Pantoliano (jpantoliano@ctf.org or 646-738-8551)

NEW ENGLAND: Kristine Poirier (kpoirier@ctf.org or 617-456-4707).

EVERY GIFT MATCHED Continued from page 1

of our collaborative new research model. Carol Harrison and her family, through the B.F. Harrison Family Foundation, have agreed to set up a matching campaign for Synodos for NF2 up to \$250,000.

YOUR GIFT TO FUND SCHWANNOMATOSIS: *Horvitz Matched*

Richard Horvitz, Children's Tumor Foundation Board Member, and his wife, Erica, have agreed to match donations up to \$200,000 that support schwannomatosis research. Thanks to this funding, CTF will soon announce a Request for Proposals to a new Schwannomatosis Consortium. Over the past several years, CTF has convened a series of Schwannomatosis Workshops to identify priorities for better understanding this form of NF, and has funded schwannomatosis research totalling more than \$1.3 million since 2007.

For more information or to contribute to these campaigns, please visit ctf.org/match or contact:

Michael Divers at mdivers@ctf.org or 646-738-8546

John Heropoulos at jheropoulos@ctf.org or 617-456-4706

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 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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POKER TOURNAMENT

Thursday June 11th

For information contact Julie Pantoliano: jpantoliano@ctf.org

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JULY 11-17 OR
JULY 18-24

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