

## PLAYFUL AND ELEGANT GALA SEASON:

Detroit's Playdate to End NF raises an unsurpassed \$5 million

Laurée Moffett  
at the New  
York Gala



A playful time was had by more than 1,500 attendees at the third annual Detroit beNeFit, "A Playdate to End NF." Hosted by esteemed CTF patrons Jennifer and Dan Gilbert, "The beNeFit" was held on Saturday, November 7th, at the Cobo Center in Detroit, Michigan. The event raised an unsurpassed \$5 million for the Children's Tumor Foundation (CTF) and our mission to fund research that will lead to treatments and, one day, a cure for neurofibromatosis (NF).

The numerous supporters who came out to play were invited to "wear your dress-up clothes" and enjoy a night of "drinks, dinner, and afterglow." Presented amid giant toy dinosaurs and a cartoon cityscape, the evening's entertainment included silent and live auctions, with an afterglow party following the event. Among those in attendance were LeBron James and most of the Cleveland Cavaliers basketball players.

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Dan Gilbert  
at the Detroit  
beNeFit

2016 Ambassador,  
Corinne Moffet, stands with  
her parents, Jim Bob and  
Laurée Moffett, as they  
accept the Children's  
Humanitarian Award



## BE THE ONE *This Holiday*

### CHILDREN'S TUMOR FOUNDATION

This holiday you can BE THE ONE to play a vital part in our mission to end NF. Whether it's making a donation, or joining the registry, or wearing an End NF T-shirt, every action—and every dollar—counts!

For more information about  
**BE THE ONE**, please visit [ctf.org/betheone](http://ctf.org/betheone).



"You can never get too comfortable with NF. Although Maddox's condition has stabilized, he is now blind in one eye and his tumor has expanded to his jaw area. But every day his amazing spirit keeps us going. He shows me what it means to be brave and strong ... how important it is to be thoughtful and kind ... and to appreciate every good day."

— NICOLE STEINERT  
mom to Maddox, who lives with NF

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## LETTER FROM THE PRESIDENT

*Annette Bakker, PhD*



COLLABORATION has been the guiding principle for 2015 at the Children's Tumor Foundation (CTF), both in spirit and in action. Clinicians, scientists, patients, family members, volunteers, donors, fundraisers, industry members, and advocates—we are UNITED in the fight for a cure for neurofibromatosis (NF).

As we approach the holiday season, it seems natural to reflect upon the many achievements these partnerships have produced, both within NF research and in the broader NF community. Nowhere were these accomplishments more palpable than at this year's annual benefit galas.

Our unceasing appreciation goes out to Jennifer and Dan Gilbert, our partners in this fight, who continuously extend their tremendous support. This year was the third annual Detroit "beNeFit," and it took my breath away! The commitment and trust the Gilbert family shares with CTF is unparalleled.

We are also deeply grateful for Jim Bob and Laurée Moffett, who were honored with the Children's Humanitarian Award at the New York Gala. The Moffett's matching-gift fund has enabled the launch of three separate multi-million dollar collaborations under the umbrella of Synodos for NF1.

NF patients are at the center of everything we do, which is why the Children's Humanitarian Medical Award went to Tena Rosser, MD. Dr. Rosser knows that the knowledge we gain from our initiatives in the lab is not enough; we learn the most from the NF patients who share not only their personal information and tissue samples for the NF Registry and the biobank, but also the challenges they face and the triumphs they achieve.

As I stood on the gala stage with Corinne Moffett, our 2016 Ambassador, her remarkable and inspiring energy stirred within me a feeling of continuity with all of our NF Heroes—heroes like Brianna Worden, who was presented with the Strength and Honor Award at the Detroit beNeFit, and who, like Corinne, lives courageously with NF.

Our collaborations extend beyond our research efforts. Earlier this year, we met with the White House Office of Science and Technology Policy in Washington, DC, to advocate for funding of neurofibromatosis research throughout the country. We are also thrilled to have a relationship with many other terrific NF organizations. Above all, we applaud the thousands who come together at events throughout the year. Our Community Relations, NF Walk, NF Endurance, and Racing4Research programs are bursting at the seams.

We can only win this fight if we join together. So we thank you for your collaboration, your passion, and your love. Together we will end NF!

Gratefully,

Annette Bakker, PhD

## A DIFFERENT KIND OF NF HERO

*Brad Johnson is certainly an NF Hero, but of a different kind. Here, he shares his experience with living with NF1, and what led to his decision to donate his body to NF research.*

Growing up in the Detroit suburbs, Brad Johnson did not know why he was “sickly,” or why he had pain and physical problems. Not until he was 14, and in the hospital recovering from a dirt bike accident, did he learn that he had NF. “I passed a doctor in the hallway, and he stopped me, and the doctor said, ‘I know what you’ve got!’” From then on, Brad had a name for his condition, but discovered there was no treatment.



“I just ignored it and kept going,” says Johnson. He spent 40 years earning a living as a concessionaire at shows and carnivals until his worsening health caused him to retire. Now living in Florida with his wife, Johnson copes with severe pain from spinal tumors and pseudarthrosis.

He first started thinking about donating his body for NF research not long after he noticed a young child with NF. “No child should have to go through what I’ve gone through,” he decided. “Doing this [tissue donation], knowing it could help kids, for me it’s the greatest thing I could do.”

When Johnson, 55, called CTF and learned that the Foundation was developing a tissue donation program, he was relieved.

“I feel at peace that my body’s going to go to research to help people with NF1. That makes me extremely happy. I’m a working man and can’t afford to donate money, so this is the only gift I can give.”

To learn more about the tissue donation program, contact the Foundation’s Clinical Program Director, Pamela Knight, at 212-344-6633 or [pknight@ctf.org](mailto:pknight@ctf.org).

## IMPORTANT 2016 DATES FOR NF RESEARCHERS

January 11	Young Investigator Award pre-application deadline
April 18	Drug Discovery Awards (A) application deadline
June 18-21	NF Conference, Austin, Texas
June 20	Clinical Research Awards Letter of Intent due
September 26	Drug Discovery Initiative (B) application deadline

## NY GALA RESEARCH ANNOUNCEMENT: Synodos for NF1 launched!

The New York Gala served as another important launching pad: the announcement of not one, but three new Synodos collaborations! Synodos researchers gathered for a pre-gala celebration, where they were greeted by Synodos for NF1 champions and Children’s Humanitarian Awardees Jim Bob and Laurée Moffett.

As established in the collaborative research model Synodos for NF2, numerous investigators from a host of multidisciplinary institutions will collaborate, sharing their data in real time. Synodos for NF1 is comprised of three distinct collaborations: one **NF1 Low Grade Glioma Synodos** will focus on low grade gliomas, and two **NF1 Preclinical Acceleration Synodos** will focus on the development of a swine model, with the goal of accelerating the path to a cure.

These three consortia will bring together twenty-four investigators from ten leading institutions.

Please look for more about Synodos for NF1 in our upcoming newsletters and at [ctf.org](http://ctf.org).



David Gutmann, MD, PhD, and Michael Fisher, MD, co-leaders of the NF1 Low Grade Glioma Synodos.

## A Discussion with Principal Investigator **LUDWINE MESSIAEN, PHD**, *University of Alabama at Birmingham*

Ludwine Messiaen, PhD, is the recipient of CTF's **Isaac and Sadie Fuchs Genotype-Phenotype Grant**, which will greatly facilitate the discovery of additional NF1 genotype-phenotype correlations over the next three years.

### What is your background?

I obtained my PhD from the University of Ghent, Belgium, in 1990, and thereafter started a Laboratory of Molecular Diagnostics at the University Hospital in Ghent. At that time, only a few genes causing hereditary disorders had been cloned, and the laboratory initially started by offering a limited number of tests.

### How did you get involved in the study of neurofibromatosis?

The NF1 gene was cloned by two independent research groups in 1990. It was clear from the beginning that the NF1 gene was complex and large, so the development of a sensitive and specific genetic test would be a major challenge. I decided at that point in my career to focus on the development of a comprehensive genetic testing approach for this gene.

In 2003, I was recruited to the University of Alabama at Birmingham by Prof. Bruce Korf, Chairman of the Department of Genetics, where I started a new laboratory that I have directed over the last 12 years: the UAB Medical Genomics Laboratory.

We are currently offering clinical genetic testing for a broad array of genetic disorders, however the specific focus and vast majority of our clinical testing and associated research involves the neurofibromatoses. From the beginning, we requested referring physicians to complete a phenotypic checklist upon submission of a sample for NF1 genetic analysis. This has increased our understanding and awareness of the complexity and variability of the NF1-associated signs and helped with the identification of potential genotype-phenotype correlations.

**Definition:** *The genotype of an organism is the genetic code in its cells. The phenotype is the visible or expressed trait, such as café au lait spots. The phenotype depends upon the genotype but can also be influenced by environmental factors.*

### What is it about NF1 that makes a genotype-phenotype study so important?

Very few clinically significant NF1 genotype-phenotype correlations are known today, which does not definitively mean there aren't more that need to be discovered. So far, few indicators can predict the severity of the disorder over time, and this uncertainty can put a heavy load on the quality of life of the patients and their families. It is important that clinicians involved in the care of NF1 patients are aware of the emerging genotype-phenotype correlations.

We expect additional clinically useful genotype-phenotype correlations to exist, and our future work will focus with priority on the discovery of additional correlations that lead to a significantly reduced tumor burden, as these have an immediate impact on the quality of life of these patients. On the contrary, some mutations are associated with a more severe phenotype, including an increased tumor burden, and their characterization is equally important. Their identification may guide efforts to design mutation-specific cell and animal models necessary to develop targeted therapies.

### How can individuals with NF1 and/or their families help?

Individuals with NF1 can help by closely collaborating with the NF1 scientific community and patient organizations. It would also be helpful for them to register with CTF's NF Registry at [nfregistry.org](http://nfregistry.org). Furthermore, as classification of the pathogenicity of many NF1 variants is still a huge challenge, clinical and genetic evaluation of relatives sometimes is essential for the interpretation of an unclassified mutation found in the proband (the first affected member) of a family. The UAB Medical Genomics Laboratory offers free-of-charge genetic testing in these scenarios to all relevant relatives. When an unclassified mutation is encountered in your family, you can help by working closely with your physician: this can speed up the correct classification of the mutation, which is helpful for your own family, of course, but also for all other patients eventually identified as carrying the same mutation.



## Synodos for NF2: Results

The Synodos for NF2 steering committee reviewed results of this collaborative team's ongoing experiments in early November. Principal Investigators from eight institutions presented the findings of their work from the first year of this three-year, three-million-dollar collaboration.

Analysis of the results show that promising new drug combinations as potential treatments for NF2 are emerging from the data. These combinations will soon be tested in cells and in animal models.

The 2016 schedule of experiments and milestones is in progress. Please look to our upcoming newsletters for updates from Synodos for NF2.



## INTERNATIONAL SCHWANNOMATOSIS DATABASE receives additional funding

In our efforts to expand and encourage research in schwannomatosis, CTF is extending the funding of the International Schwannomatosis Database (ISD) program for three more years. This program, which is headquartered at Johns Hopkins University and led by Allan Belzberg, MD, will be aimed at increasing awareness of the ISD in both the scientific and lay communities through a focused marketing campaign; increasing the enrollment of patients worldwide by expanding the number of sites participating, both in the US and internationally; and actively coordinating all participating sites and investigators. Going forward, the broad focus of the ISD will serve to increase the amount of schwannomatosis research being performed in labs around the world.

## CTF collaborators awarded \$12M National Cancer Institute grant: NF IS AT THE HEART OF THIS PROJECT

The Indiana University School of Medicine has been selected to lead a five-year, \$12 million national research project. The grant, one of the highly competitive projects funded by the National Cancer Institute's Specialized Programs of Research Excellence (SPORE) initiative, is the first such SPORE grant to focus on pediatric cancers, life-threatening tumors, and other developmental disorders, mainly in children.

This national multi-institutional collaborative effort harnesses the expertise of researchers from nine leading academic institutions. The overall goal is to implement effective new targeted treatments for tumors characterized by mutations of the *NF1* tumor suppressor gene.

*"The Children's Tumor Foundation's early adoption and support of the collaborative research model, from NFPC and now the NFTC, was instrumental in providing the initial funding that is at the heart of this research, and a research group infrastructure to develop key preliminary data. This certainly provides proof that a multi-institutional group can be tremendously effective, for which the Foundation has been a key proponent."* —D. Wade Clapp, MD

The Children's Tumor Foundation is providing infrastructure support for the bioinformatics component of the grant through our collaborator Sage Bionetworks. In addition, Foundation President and Chief Scientific Officer Annette Bakker, PhD, will serve on the consortium's external advisory board.

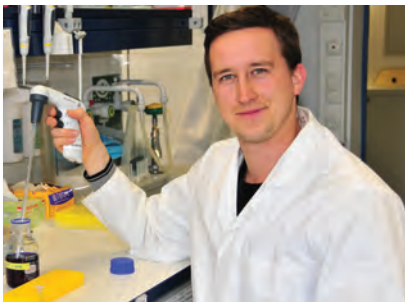
Our hearty congratulations to Principal Investigators D. Wade Clapp, MD, of the University of Indiana, and Kevin Shannon, MD, of the University of California, San Francisco for securing this very important source of funding, to continue research that has its roots in CTF programs!



## 2015 DRUG DISCOVERY INITIATIVE AWARDEES:

CTF awarded five Drug Discovery Initiative (DDI) awards in its first of two calls for applications in 2015. Two of the awards will target novel therapies for NF1-related tumors, specifically malignant peripheral nerve sheath tumors (MPNSTs), and three for NF2-related tumor therapies. We are enthused to be able to fund these exciting projects!

**Alexander Schulz, MD, PhD, of Leibniz Institute for Age Research, Germany,** received an \$85,000 *in vivo* award for his proposed study, ***“Establishing a protein replacement therapy for the treatment of Schwann cell-derived nerve sheath tumors.”***

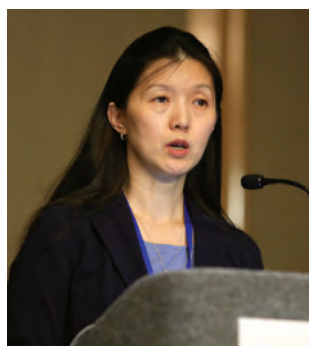


This proposal aims to establish an innovative approach using recombinant proteins to prevent schwannoma development by altering the interaction of Schwann cells and axons (long nerve cell protrusions).

**Andrea McClatchey, PhD, of Massachusetts General Hospital/Harvard University,** received a \$40,000 award allowing her to continue to work on her 2014 project, ***“Expanded testing of centrosome-unclustering drugs in NF2-mutant tumors.”***



Centrosomes are so-called cellular organelles that are essential for normal cell division, and their overduplication is a feature in tumor cells. The goal in this expanded study is to investigate the sensitivity of other NF2-mutant tumor cells, particularly meningioma, to centrosome targeting drugs and to test an expanded panel of these drugs that act in different ways on all NF2 tumor types.



**Lei Xu, MD, PhD, of Massachusetts General Hospital,** received an \$85,000 award for her proposed study ***“Combining immunotherapy and antiangiogenic therapy in an NF2 schwannoma model.”***

The use of bevacizumab, a so-called antiangiogenic

drug, in the treatment of NF2 vestibular schwannomas has shown an ability to improve hearing in some patients. The proposed study will combine the use of bevacizumab with immunotherapy, and if the results are superior to either treatment alone, Dr. Scott Plotkin of MGH will use the results to design a clinical trial for NF2 patients.

**Jeffrey Field, PhD, of University of Pennsylvania,** received a \$40,000 *in vitro* award for his proposal ***“MPNST profiling and screening: an experiment in research-based education.”***



This project will create the first ever college course in drug screening, and will specifically screen for drugs for NF1 MPNSTs. Students will screen drugs, both known and novel, against NF tumor cell models, primarily cancer models. The known drugs will serve as a starting point for comparison with other screening efforts.



**Steven Lewis Carroll, MD, PhD, of the Medical University of South Carolina,** received an \$85,000 *in vivo* award for his proposed study ***“Combinatorial therapy with receptor tyrosine kinase inhibitors for MPNST.”*** This study will identify three drugs (all currently in clinical use or clinical trials for other cancer types) that effectively inhibit MPNST proliferation. These drugs will be tested in various combinations in hopes of generating sufficient data to attract follow-on funding from the NIH or DOD to expand testing of RTK therapies for the difficult-to-treat MPNSTs.

## THANK YOU for helping NF Walk raise more than \$1 million in 2015!

Thank you to the incredible donors, organizers, and participants who, as of November 2015, have helped NF Walk exceed \$1 million for the Children's Tumor Foundation! More than 80 percent of every dollar goes directly to NF research and programs, in the hope that one day we can put an end to NF.

Please visit [nfwalk.org](http://nfwalk.org) for a complete list of individuals, teams, and donors who have helped us exceed our fundraising goal of \$1 million in 2015! Special thanks to these incredible \$10K-plus donors and teams:



Cincinnati Walk



Philadelphia Walk



Central Jersey Walk



Milwaukee Walk



Idaho Walk



Addison Oaks Walk

### \$10K + DONORS AND TEAMS

- |   |                     |
|---|---------------------|
| Firstronic LLC                          | Addison Oaks Walk   |
| Go Get Em Gracie                        | Addison Oaks Walk   |
| Team Moss                               | Alabama Walk        |
| Team Waldrop                            | Alabama Walk        |
| Gertrude & William C. Wardlaw Fund      | Atlanta Walk        |
| Team Taub                               | Boca Raton Walk     |
| All*tech Carpentry Contractors          | Central Jersey Walk |
| Nomadic Expeditions                     | Central Jersey Walk |
| Team Alex                               | Central Jersey Walk |
| Trek4Tati                               | Central Jersey Walk |
| Donald Baltzer                          | Cincinnati Walk     |
| Kendall Samblanet                       | Cincinnati Walk     |
| Kendall's Crew                          | Cincinnati Walk     |
| Ellen Carpenter                         | Denver Walk         |
| Dreaming for Danielle                   | Houston Walk        |
| Team Parker                             | Houston Walk        |
| Andrew and Frances Kallman              | Los Angeles Walk    |
| Frances Kallman                         | Los Angeles Walk    |
| Maddox is Strong                        | Los Angeles Walk    |
| Michael and Kelly Peterson              | Los Angeles Walk    |
| Michael Peterson                        | Los Angeles Walk    |
| Team Blake                              | Los Angeles Walk    |
| Team Sammy                              | Los Angeles Walk    |
| TeamCureNF                              | Los Angeles Walk    |
| Team Iz                                 | Milwaukee Walk      |
| Team Max                                | Moorhead Walk       |
| The A Team                              | Philadelphia Walk   |
| Inspired by Ryan                        | Putnam Walk         |
| Mariah, Faith, Gabriel, Jay, and Joelle | Richmond Walk       |
| Team Cameron                            | Richmond Walk       |
| Team Isla                               | Seattle Walk        |
| The Sheridan Family                     | Seattle Walk        |
| Matt Riley                              | Seattle Walk        |



*"Team Garrett has given me a sense of purpose..."*  
 —Terry Owens

### Terry Owens

Terry Owens has been the captain of Team Garrett for three consecutive years on our Choose Your Own Event platform. Team Garrett ran America's Finest City Half Marathon/5K in San Diego with 100 members for 3 years, raising about \$75,000 in honor of Garrett Baumann, who is living with NF2. To say that Terry is humble would be an understatement. The amount of work he has done for Team Garrett and the Baumann family is beyond measure, and the Endurance Team is grateful to have him as one of our star volunteers and participants.



*"We fundraise in hopes that, one day, the money we raise will help find a cure for Natalie."*  
 —Joe and Linda Keller

### Joe and Linda Keller

Joe and Linda Keller of Chicago, Illinois, have been dedicated to the Children's Tumor Foundation since 2012, when they ran their first NF Endurance event together at the Rock 'n' Roll Chicago Half Marathon. Since then, they have participated in Cupid's Undie Run, the Bank of America Chicago Marathon, and the Chicago Flywheel event. Joe just completed his sixth Chicago Marathon with the NF Endurance Team in October of this year. The Kellers do all of this in honor of their little girl, Natalie, who is living with NF1.



*"Robert and my son, Will, are the best of buds. These two have fun being little boys, with Ninja Turtles and Legos ranking high on their list of toys! Everything we do for the Children's Tumor Foundation brings us one step closer to finding a cure for Robert."* —Tara Rogers

### Carolanne Owenby and Tara Rogers

The NF Endurance Team will be launching a new nationwide Little Heroes 5K program in 2016, thanks to the dedication of our volunteer chairs, Carolanne Owenby and Tara Rogers. These two have been involved with the NF Endurance Team since 2012, when Carolanne's son, Robert, was diagnosed with NF1. They turned their personal fundraising efforts into a community-wide initiative by creating a Little Heroes of North Georgia year-round fundraising program. They also participated on our team for the Philadelphia Marathon, Chicago Marathon, and Big Sur Marathon and have raised more than \$100,000 for the Children's Tumor Foundation.

**JOIN OUR TEAM!** Get your early entry into these 2016 events:

- Little Rock Marathon - March 6, 2016
- New York City Half Marathon - March 20, 2016
- Big Sur Marathon - April 24, 2016
- London Marathon - April 24, 2016
- IRONMAN Hawaii 70.3 - June 4, 2016
- IRONMAN Florida - November 5, 2016

[nfendurance.org](http://nfendurance.org)



# RACING 4 RESEARCH

Racing4Research is a familiar sight within the motorsports community, thanks to our amazing NF Hero families who join us rain or shine, to cheer on the drivers and teams that support the Children's Tumor Foundation. The 2015 race season was our biggest yet with the Foundation logo carried on 17 race cars in 2 race series. More than 500 NF families joined us at the track, wearing the blue CTF T-shirts and enjoying incredible VIP access throughout the paddock. THANK YOU to every family that joined us in 2015. YOU make Racing4Research unique and special. If you haven't yet joined CTF at the track, the 2016 schedule will be published soon. Sign up and find out for yourself what everyone is talking about!

**As a team, we will end NF.**

[Racing4Research.org](http://Racing4Research.org)



## Special Reader's Issue

# RUNNER'S WORLD

How To...

- ▶ Get Stronger
- ▶ Snack Smarter
- ▶ Beat Injuries
- ▶ Stay Motivated
- ▶ Love Your RBF

& Be **Awesome!**

9 Seasonal Superfoods

GEAR OF THE YEAR  
Hot Shoes, Cool Clothes & Other  
Runner-Tested Gift Ideas



Congratulations to Bobby Gill, of Cupid's Undie Run, who won the Runner's World Cover Search!

JOIN CUPID'S UNDIE RUN IN FEBRUARY 2016  
[CupidsUndieRun.com](http://CupidsUndieRun.com)



# SHOP TO END NF

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

**The Children's Tumor Foundation Official Store**  
Whether it's an End NF T-Shirt or a Children's Tumor Foundation baseball cap, you'll look great and spread awareness. Buy for your friends as well! [ctf.org/store](http://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](http://goodshop.com)

**AmazonSmile** You shop. Amazon gives. Amazon will donate a percentage of your purchases to Children's Tumor Foundation. [smile.amazon.com](http://smile.amazon.com)



## Welcome Reid Horovitz, Chief Operating Officer

Please join us in welcoming Reid Horovitz, who recently joined the Children’s Tumor Foundation as Chief Operating Officer. In this role, Reid oversees the functioning of many important aspects of the Foundation, including Finance, Operations, Legal, Fundraising/Development, Human Resources, and Community Relations.

Reid previously worked at the global law firm Orrick, Herrington and Sutcliffe, LLP, where he held several senior executive positions including Chief

of Staff and Strategic Alignment and, most recently, Chief Operating Officer.

He has a wealth of experience in Operational Leadership, Strategic Planning and Implementation, CEO and Board Support, and Human Resources. Reid holds an MBA from Columbia University, a law degree from Boston University, and a BS in Industrial Management from Carnegie Mellon University.

Reid lives in Tenafly, New Jersey with his wife (Marlene) and 11-year-old twins (Aryn and Dean).

## MEET THE STAFF

**Hyerim Lee, PhD**



**HOMETOWN:**

Seoul, Korea

**CURRENT TOWN:**

Manhattan, New York

**EDUCATION:**

BA in Chemistry from Hunter College, and PhD in Biophysical Chemistry from Columbia University.

**WORK WITH THE FOUNDATION:**

I manage the NF Therapeutic Consortium (NFTC) and our newest initiative, Synodos for NF1. In this capacity, I oversee multiple work streams and projects to ensure on-time project delivery and facilitate open and regular communication among all project stakeholders. I also oversee other translational science projects that CTF supports.

**FAVORITE EXPERIENCE WITH THE FOUNDATION:**

I participated in the Central New Jersey NF walk organized by CTF last year with my husband and 11-year-old daughter. It was my first experience meeting children affected by NF and their families and it touched my heart so deeply. In fact, my daughter has become an advocate for NF through this experience. She campaigned to make CTF the charity recipient of her school’s annual Penny Harvest fundraiser this year, and they collected more than \$200 in pennies for CTF.

**FAVORITE HOBBY:** I am a new hiker and love hiking with my husband and daughter.

## MEET THE BOARD

**Brendan Hanrahan, PhD**



**HOMETOWN:** Lilburn, Georgia

**CURRENT TOWN:** Silver Spring, Maryland

**EDUCATION:** I studied Materials Engineering (aka making stuff) at Clemson University and continued through graduate school at the University of Maryland.

**WORK WITH THE FOUNDATION:** I do research for a living and I know that it’s hard, it’s expensive, and significant progress requires courage and persistence. My role on the board for CTF and the organization I co-founded, Cupid Charities, is to come up with creative fundraising that keeps the research machine moving.

At Cupid Charities we like to say Cupid’s Undie Run puts the “fun” in fundraising. To date, Cupid has contributed almost \$8 million to CTF-directed research efforts to end NF. Since Valentine’s season is around the corner, I encourage everyone in the CTF community to support the event!

**FAVORITE EXPERIENCE WITH THE FOUNDATION:** My favorite experience with the Foundation was watching Dr. Bakker’s opening remarks at the recent NF Conference in Monterey, California. She invigorated and inspired a roomful of researchers and clinicians from all around the world with the goal of ending NF.

**FAVORITE HOBBY:** My wife would say it’s torturing her with at-home science experiments, but I would say tennis.

**FAVORITE MOTTO OR APHORISM:** “It’s better to run slowly than to walk.”

**FAVORITE BREAKFAST FOOD:** Breakfast burritos

## MEET AN NF HERO: *Gianna Neely*

My daughter, Gianna, or Gigi as we call her, is the strongest little girl I know. At nine months old she was diagnosed with neurofibromatosis type 1. She was born with about ten café au lait spots, but it wasn't until she developed her first fibroma, on her wrist, that I become concerned.

Now, with Gigi at age four, NF1 brings many challenges to our life. Gigi has a growing number of café au lait spots, some bone deformation, three iris Lisch nodules in each eye,

and more than 80 fibromas. She has endured yearly MRIs and countless exams, specialist visits, and doctor appointments, all while remaining positive and brave.

Gianna loves being outside, animals, chocolate brownies, playing with her dolls and cars, and reading.

As her mother, I am committed to increasing NF advocacy and awareness. Our family participated in both the Orlando NF Walk and the Boca Raton NF Walk. We enjoy spending time with

others in the NF community and raising money to help end neurofibromatosis—for our little hero and for the millions worldwide affected by this disorder.

### **What advice do you have for others facing similar challenges?**

Join social networking groups, do your homework, become an advocate for your NF hero, and always find the bright side of things.

### **What's a success or accomplishment you're really proud of that happened this year?**

My daughter started pre-K this year knowing all letters, numbers, sounds, colors, and a

few sight words! Yay!

### **What are you most looking forward to in 2016?**

Working more with the Children's Tumor Foundation.

### **What's one song you will never skip on your playlist?**

Gospel songs. They keep us motivated and encouraged, especially "I Am God" by Donald Lawrence and "No Weapon" by Fred Hammond.

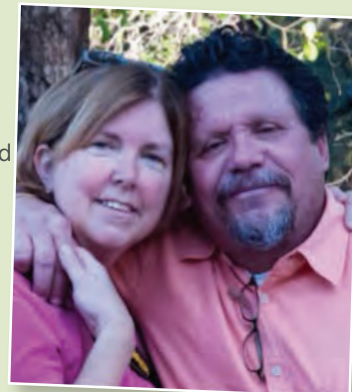
—Jessica Daniels, Gianna's mother



## STORIES OF NF: *Michael Michailov*

My husband, Michael, is an amazing guy. He is 58 and was diagnosed with NF1 at age 7.

His mother also had neurofibromatosis. He was in special education classes and suffered constant bullying as a teen, but he loves everybody and greets the world with a smile every day.



Michael attended Glendale College and California State University, Los Angeles. He became a teacher and taught special education for 17 years. In recent years, he mainly taught as a substitute in middle-school grades.

We met in 2011, married in 2014, and, along with his daughter, who is now 25, became a family.

Michael loves to paint and make sculptures from repurposed items. We want to donate some art to the Children's Tumor Foundation one day. He loves caring for our pets, Teddy, the Havanese dog, and Bea, our ragdoll cat, and he enjoys cooking.

Michael gives his heart unconditionally as a wonderful father and spouse. He is my hero, and I am so grateful to share my life with him.

### **What advice do you have for others facing similar challenges?**

I have only been with my husband for 5 of his 58 years. The bullying, isolation, and horrible experiences he had to endure when he was a child and teenager should never happen to anyone. My advice is to help others to feel included, to be kind, and to bring awareness of NF and its struggles to others, so they know how to be of help.

—Ellen O'Donohue Michailov, Michael's wife

## NEW FACES AT THE CHILDREN'S TUMOR FOUNDATION

Welcome to the Foundation's newest staff member!

### **Vidya Dhote, PhD**

Basic Science Manager, [vdhote@ctf.org](mailto:vdhote@ctf.org)



# COMMUNITY NEWS

## Great Events from Across the NF Community

The Foundation has a presence across the United States and facilitates local patient support groups, medical symposia, and fundraising events. Learn more about the Children's Tumor Foundation in your area by visiting [www.ctf.org/communityrelations](http://www.ctf.org/communityrelations).

### MISSOURI

A big thank you to Justin Cordy, who "star-tended" at Joannie's Pizzeria in St. Louis, Missouri. He donated his tips and, along with a matching donation from Joannie's, raised \$1,200 in the fight against NF. Thanks, Justin!



### FLORIDA

On September 13th, the Tampa Bay Rays hosted Children's Tumor Foundation Day and had more than 45 NF Heroes and their families out at the ballpark. It was a day of fun and awareness, as volunteers sported their CTF and "I Know a Fighter" T-shirts to raise NF awareness.

### INDIANA

Thank you to Matt and Stephanie Reeve for hosting a cocktail party at their home with the proceeds going to the Children's Tumor Foundation. More than 30 people were in attendance and raised more than \$5,000 to help end NF. What a great way to spend an evening; friends, food, and cocktails, all for a good cause!



### RHODE ISLAND

On September 12th, PFD (Pretty Fun Day) for NF was launched at Brewer's Marina in Warwick, Rhode Island. Families enjoyed a Jeopardy-style game featuring questions about NF, along with clam cakes and chowder from Chelo's Waterfront Restaurant. NF Heroes were at the steering wheel on boat rides donated by the Freedom Boat Club of Rhode Island.

### COLORADO

Thank you to all those who attended our NF Picnic in Broomfield, Colorado, on July 18th! More than 50 attended and enjoyed a storyteller, lunch, and even Mickey Mouse!





## MINNESOTA

A perfect location, a beautiful day, and more than 150 people combined to make the make first-ever Moorhead NF Walk a rousing success. Huge thanks to Tina Lien and her sister-in-law Brittany Lien for chairing this event. This Walk raised more than \$20,000, increased NF awareness, and brought NF Heroes from Minnesota, North Dakota, and South Dakota together.

## MAINE

Now in its fourth year, the Biddeford Walk took place on September 12th on the Eastern Trail and featured great food, face painting, and a Kid's Fun Run! Seventy people attended and raised more than \$13,000 for CTF. Thanks to all those who volunteered their time on Walk day, and to Tricia Ricker and Samantha Canane for organizing this wonderful event.



## CALIFORNIA

Loco Cycle of Rancho Santa Margarita, California, sponsored two charity rides for Team Maddox in support of the LA Walk and CTF. They raised \$1,275 to fight NF. Loco Cycle then asked if the Children's Tumor Foundation would be their charity for the month of May! Huge thanks to Monica and Chuck Gray, the owners of Loco Cycle, and the charity ride instructors for their generosity and support.

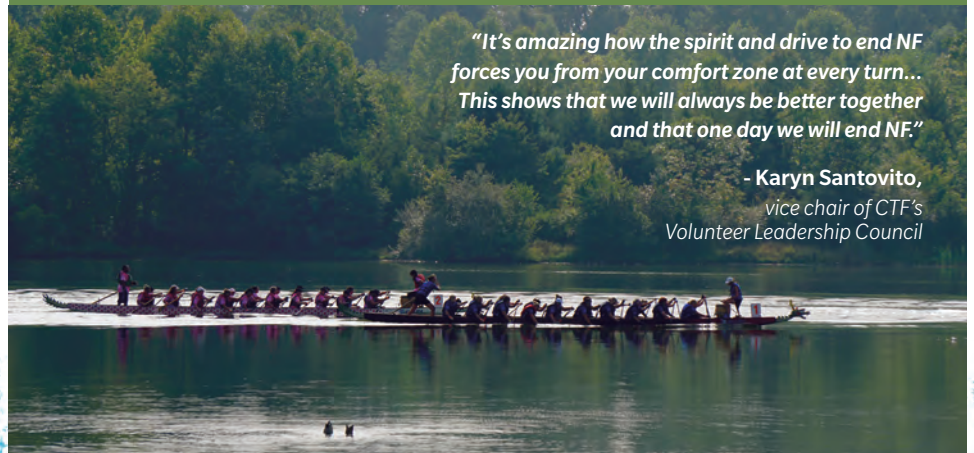


## GEORGIA & ALABAMA

On September 12th, three Kendra Scott stores across Alabama and Georgia participated in the Kendra Gives Back Day, where 20 percent of the proceeds from sales were donated to CTF. Thanks to this generosity, more than \$1,200 was raised to help end NF.

## PENNSYLVANIA

Special thanks to Gwen Coverdale who coached the "CTF Dragons" to victory this September at the Bucks County Dragon Boat Festival in Langhorne, Pennsylvania. The CTF Dragons may have been largely comprised of dragon boat novices, but this 21-member crew proved that it didn't need experience to get the job done. The team beat out more than 35 other teams to capture the bronze medal in the Community Mixed Division A Championship.



*"It's amazing how the spirit and drive to end NF forces you from your comfort zone at every turn... This shows that we will always be better together and that one day we will end NF."*

- Karyn Santovito,  
vice chair of CTF's  
Volunteer Leadership Council

## FORUM NEWS

### Save the Date 2016 NF FORUM

The NF Forum is a patient and family gathering that features:

- NF clinical and research updates
- Sessions on the personal and social challenges of living with NF
- Interactive Q&A sessions with NF specialists
- Fun activities, meals, and social time with new friends and old

[ctf.org/nfforum](http://ctf.org/nfforum)



**JUNE 17-19 JW MARRIOTT AUSTIN, TEXAS**

“Focus on what you can, not what you can’t.

For me, I can’t listen to a live band, you know, at a bar; I’m not able to really pick up anything that’s happening because of all the noise. So I could really get down about that. But I can hear my kids say, “I love you, Dad.” And I’ll take that over a bar band any day. And the ABI gave me that.”

— **MATT HAY, CTF Board Member**

on his ABI (Auditory Brainstem Implant) during his presentation on “Coping with Hearing Loss” at the 2015 NF Forum



*Brianna Worden, Strength and Honor recipient, congratulated by host Jennifer Gilbert at the Detroit beNeFit*



*CTF President and Chief Scientific Officer, Annette Bakker, PhD, with Children’s Humanitarian Medical Award recipient, Tena Rosser, MD, at the New York Gala*

### PLAYFUL AND ELEGANT GALA SEASON *Continued from cover*

**Brianna Worden**, Miss Teen New York International 2013, was presented with the Children’s Tumor Foundation Strength and Honor Award. Brianna lives a remarkable and courageous life with NF. This award celebrates her indefatigable spirit, and honors her work to raise awareness about NF and the Children’s Tumor Foundation.

The previous week, the **New York Gala**, “A Night to Fight NF,” was an elegant evening that honored and celebrated exceptional individuals who are leading the fight against NF. The annual gala took place in

the Cipriani Wall Street ballroom in New York City on October 29th, and raised more than \$900,000 for the Children’s Tumor Foundation.

**Jim Bob and Laurée Moffett** were awarded the Children’s Humanitarian Award for their remarkable contribution and commitment to CTF. In 2014 the Moffetts pledged a \$2.5 million matching-fund gift that has set in motion three new Synodos collaborations for NF1.

**Tena Rosser, MD**, of Children’s Hospital Los Angeles was the

recipient of the Children's Humanitarian Medical Award for her dedication to those living with NF, and her longtime work in furthering the Foundation's mission.

**Corinne Moffett** was named the Foundation's Ambassador for 2016, a distinct honor bestowed upon a young person with NF to recognize her fortitude in overcoming the challenges of the disorder as well as her efforts to further the Foundation's goals of research, public awareness, and patient support. In an inspiring moment during the live auction, our 2015 Ambassador, Jeffrey Owen Hanson, joined Corinne at the podium, followed by 2014 Ambassador, Bailey Gribben, and 2007 Ambassador, Kenneth Rudd.

In addition to the benefit galas in New York and Detroit, this year's gala season included events around the country. More than 200 guests gathered at the **New England Gala** in Boston, Massachusetts, on October 24th and raised more than \$90,000. The evening honored those in the NF Community who are making a difference. **Brad Welling, PhD**, was the Excellence in Science Honoree and the two Volunteer Honorees were **Lindsey Norse** of Cupid's Undie Run — Boston, and the **Massachusetts State Council Knights of Columbus**.

The annual **Dancing With Our Stars** event, hosted by toe-tapping CTF board member Lesley Oslica, hit an all-time record for attendance and support. This annual dance benefit was enjoyed by more than 400 guests in Little Rock, Arkansas. Together they raised more than \$170,000, with more than \$30,000 raised in the "Send a Kid to NF Camp" campaign. NF Hero **Myleigh Marshall** and her family were honored with the NF Courage Award for their efforts in fundraising and heightening NF awareness in the community.

The Children's Tumor Foundation is extremely grateful for such a successful gala season. We humbly extend our thanks to the attendees, donors, honorees, and organizers who support



**Dancing With Our Stars:** (from left) Sarah Wengel, Nick Copas, Natalie Rockefeller, Dr. Clea Hupp, Kirk Bradshaw, and Matt Mershon

our Foundation with such remarkable fervor. Whether elegant, playful, graceful, or lively, these events bring the NF Community together in our shared goal of advancing research that will end NF.

To view the awardee videos presented at these events, go to [ctf.org/2015GalaVideos](http://ctf.org/2015GalaVideos).

**CTF Ambassadors at the New York Gala:** (from left) Kenneth Rudd (2007), Bailey Gribben (2014), Jeffrey Owen Hanson (2015), Annette Bakker (CTF President), and Corinne Moffett (2016)



**NF News** is the official publication of the Children's Tumor Foundation. All issues are available on our website at [www.ctf.org](http://www.ctf.org). Please direct any questions to [info@ctf.org](mailto: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, deafness, bone abnormalities, learning disabilities, disabling pain, and cancer. 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.

#### FOUNDATION STAFF

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**Reid Horovitz**, Chief Operating Officer

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**Maria Carela**, Grant Manager  
**Vidya Dhote, PhD**, Basic Science Manager  
**Kate Kelts**, Patient Support Coordinator  
**Pamela Knight**, Clinical Program Director  
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**Patrice Pancza**, Program Director, Research  
**Heather Radtke**, NF Clinic and Symposium Coordinator  
**Sarah Rosenberg**, Executive Assistant

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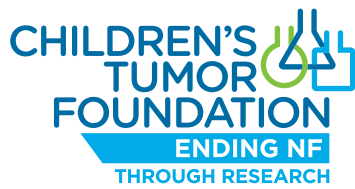
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**Jessica Beckerman**, NF Walk Manager  
**Maggie Converse**, NF Endurance Coordinator  
**Allison Cote**, Community Relations Coordinator  
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**Angela Dumadag**, NF Endurance Manager  
**Angela Earle**, NF Endurance Mgr, Community & Youth Events  
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**Julie Pantoliano**, Community Relations Manager  
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**JASON COLE**

-Son Owen Lives with NF1

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