

**KEYNOTE  
ADDRESS:**

## Texas Governor Speaks at Joint Gathering of NF Patients and Researchers



*Laurée Moffett, Cecilia Abbott, Governor Greg Abbott, and Jim Bob Moffett at the 2016 NF Forum and NF Conference Joint Dinner*

FATHER'S DAY WEEKEND was quite an occasion for the entire neurofibromatosis (NF) community, as a worldwide gathering of clinicians, researchers, clinic coordinators, patients, families, and patient advocacy groups took over the JW Marriott in Austin, Texas, for the Children's Tumor Foundation (CTF) annual NF Conference and NF Forum. With over 600 people in attendance, the two groups came together on Saturday, June 18, for a special dinner event featuring Texas Governor Greg Abbott as the keynote speaker.

"We are moving closer to treatments for all forms of neurofibromatosis because of the work of the Children's Tumor Foundation. It takes passionate volunteers, strong families, generous donors, and dedicated scientists working together to detect, diagnose, treat, and defeat diseases like NF."

— Governor Greg Abbott to the attendees of the NF Forum and NF Conference joint dinner

After remarks by 2016 CTF Ambassador Corinne Moffett, and an introduction by her mother, Laurée Moffett, the Governor outlined the initiatives that the State of Texas is implementing into disease research. No stranger to personal struggles himself, the Governor uses a wheelchair due to being paralyzed from an accident many years ago. A personal friend of Jim Bob and Laurée Moffett, Governor Abbott is well acquainted with NF and the challenges it presents, and he provided words of encouragement and hope to the patients and their families in the audience.

The Governor's complete keynote address can be viewed at [ctf.org/TexasGovernor](http://ctf.org/TexasGovernor).

## Richard A. Horvitz and Erica Hartman-Horvitz Donate \$1 Million to Launch Synodos for Schwannomatosis

The Children's Tumor Foundation (CTF) is preparing to launch its newest consortium, Synodos for Schwannomatosis, thanks to a generous \$1 million donation from Honorary Board Member Richard A. Horvitz and his wife Erica Hartman-Horvitz. Mr. Horvitz is a dedicated neurofibromatosis (NF) advocate, and was a longtime caregiver to his late wife, a schwannomatosis patient.

The new Synodos for Schwannomatosis initiative will be a multi-tiered project that will bring together basic, translational, and clinical researchers toward an end goal of developing effective treatments for schwannomatosis pain. This consortium will be based on the Foundation's current Synodos consortia models for NF1 and NF2, in which leading scientists from across scientific disciplines come together to collaborate closely and share their NF data in the hopes of shortening the time it takes to develop drug treatments.

Schwannomatosis is the rarest and least studied form of neurofibromatosis. Schwannomatosis patients may develop multiple benign schwannomas and may suffer from debilitating pain. Incomplete understanding of the molecular basis of the disease, and the absence of well-characterized preclinical tools, have been the primary roadblocks to therapeutic advancements. The astounding \$1 million gift from Richard and Erica will enable a team of collaborators to work toward specific solutions to these problems.

Mr. Horvitz's long-standing involvement with the Children's Tumor Foundation demonstrates his passion and unwavering commitment to



*Richard A. Horvitz and Erica Hartman-Horvitz*

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## LETTER FROM THE PRESIDENT

### Annette Bakker, PhD

As the summer season comes to a close, I want to take a moment to acknowledge the NF community that keeps us moving toward our greatest goal—finding effective treatments for neurofibromatosis and delivering them to our patients. This movement was especially apparent this past June in Austin, Texas. NF patients and their families gathered at the NF Forum while NF doctors, clinicians, and researchers met for the NF Conference. The shared energy was fantastic, and watching our families and volunteers meet and engage with our scientific community reinforced our purpose.

This year, the Forum hosted an Adults with NF meet-up, giving adults living with NF the opportunity to connect with one another. I was so thrilled to meet with these fighters, who not only live every day with NF, but also live to the fullest!

At the combined NF Forum and NF Conference dinner, Texas Governor Greg Abbott gave an inspiring speech that further strengthened and solidified the bonds we have made as a community. With each day that passes, we work to give NF a voice and to make that voice heard.

The Forum and Conference taking place side by side is no coincidence, as the Foundation prides itself on its collaborative approach to both science and community. This year, the Foundation presented the Excellence in Team Science Award to a group of researchers making breakthroughs in NF science in a collaborative setting.

Dr. David Viskochil received the prestigious Friedrich von Recklinghausen Award in recognition of his three decades of contributions to NF1 research, his dedication to NF patients as an outstanding clinician, and his long-standing involvement with the Foundation. From his yearly Q&A's at the NF Camp in Utah to his dedication to NF research in the lab, Dr. Viskochil is clearly a leading member of the NF family!

At this year's Conference, and for the first time in NF history, two unpublished datasets were released: one is the set generated by the Synodos for NF2 group and the other is a very comprehensive dermal neurofibroma dataset that was outsourced by CTF to HudsonAlpha. The Synodos teams are committed to making their data openly available to the world.

This is all possible because of the financial support that our donors provide. Our dedicated and much appreciated Board Member Richard Horvitz and his wife Erica Hartman-Horvitz have committed \$1 million to Synodos for Schwannomatosis, an initiative that is sure to impact those living with the disorder. This is just the beginning of our journey toward finding a treatment, which would not be possible without this kind of commitment and generosity. Thank you, Rick and Erica!

Individually, we all make a difference for those living with NF, but together, we can end NF. Let us keep going—there is so much to do—but as a community, I know we will get there!



## 2016 YOUNG INVESTIGATOR AWARDEES

We are pleased to announce the 2016 Young Investigator Awardees, which include one pre-doctoral student and three post-doctoral individuals.

### **JOHN ELLIOTT ROBINSON, MD, PHD**

California Institute of Technology  
**“Utilizing CLARITY, optogenetics, and novel viral vectors to deconstruct and reverse ADHD-like phenotypes associated with neurofibromatosis type 1”**



This project will use technologically advanced methods for brain mapping to discover how abnormal development of circuits involved in decision-making and motivated behaviors produces cognitive symptoms in NF1, including learning disabilities, ADHD, etc., which affect up to 80% of individuals with NF1. Through the use of CLARITY on the whole brain (a tissue clearing method allowing individual neurons to be mapped across long distances), and optogenetics (a technique precisely controlling neuronal activity with pulses of blue light), the project will take important steps toward determining the NF1 connectome (a kind of “wiring diagram”), and fill in important gaps in understanding how abnormalities in specific brain circuits produce symptoms of NF1.

### **STEPHANIE BOULEY**

Dartmouth University  
**“Targeting tumors with NF1 loss via modulation of autophagy”**



Plexiform neurofibromas, a common NF1-specific tumor type, have the ability to develop into the more aggressive tumor type malignant peripheral nerve sheath tumors (MPNSTs), for which there are few treatment options. Loss of *NF1* has been shown to be important in the development of a number of cancer types, including MPNSTs, due to its role as a tumor suppressor. While the loss of tumor suppressing genes like *NF1* can help cancer cells survive, they can also introduce vulnerabilities into a cell. This lab has developed a novel way to identify the Achilles heel of cancer cells that have lost *NF1*, and has identified at least one drug that potentially can target tumors with *NF1* loss, such as MPNSTs. The focus of this proposal is to identify how this drug works in cancer cells with *NF1* loss and to determine if it could be a useful drug against tumors with *NF1* loss.

### **IONICA MASGRAS, PHD**

University of Padua  
**“TRAPping the metabolic adaptations of NF1-associated tumors”**



The overall focus of this research will be on an unexplored aspect of NF: the unprecedented possibility that NF1-associated tumors develop as a result of their metabolic changes. The goal is to shed light on a new mechanism by which loss of neurofibromin function in NF1 patients leads to cancer onset and on a possible therapeutic strategy involving the inhibition of molecules such as TRAP1, a protein that plays a key role in uncontrolled growth of cells, potentially reversing these tumor metabolic adaptations.

### **JEAN-PHILIPPE BROUSSEAU, PHD**

University of Texas Southwestern Medical Center  
**“Fibroblasts: the missing gap in NF”**



This project plans to explain the contributions of fibroblasts, which are connective tissue cells required for tumor formation, to the development of neurofibromas. Anti-fibrosis and anti-cancer drugs that reduce the number of fibroblasts significantly enhance patient survival. This proposal intends to transfer this knowledge in the context of neurofibromas, opening the door to a wide array of clinically approved drugs already effectively targeting fibroblasts in classic organ fibrosis and cancer.

## NF Conference Highlights

More than 300 individuals from the NF research and clinical communities, representing 14 countries and more than 30 states, were joined by representatives from industry, government, and other allied patient groups at the annual NF Conference. The core agenda of this four-day event is to present the latest findings in NF basic research, clinical research, and clinical care. Additionally, multiple satellite meetings are organized to take advantage of the broad attendance at the event, demonstrating that this CTF-sponsored gathering is clearly the most significant date on the NF clinical and research calendar.



Co-chaired by Michael J. Fisher, MD, of Children's Hospital of Philadelphia, and Eduard Serra, PhD, of the Institute of Predictive and Personalized Medicine of Cancer (IPPMC), Barcelona, Spain, this year's Conference endeavored to take a "bench to bedside" perspective. The topics covered included genetics, oncology, surgery, NF1 and NF2 therapeutics, imaging, biopsychosocial aspects of the neurofibromatoses, cell pathophysiology, stem cell research, and the latest in animal model development.

Attendees were also given updates on the various CTF-supported consortia initiatives, including Synodos for NF1 and NF2, the NF Therapeutic Consortium (NFTC), and the Response Evaluation in Neurofibromatosis and Schwannomatosis initiative (REiNS).

Of note in the Synodos for NF2 update was the release of data generated by two years of research prior to publication in a peer-reviewed journal, as promised by CTF. This is particularly noteworthy, as it is rare for data to be shared with the public prior to publication, and it was done so in the spirit of collaboration focused on speeding up the discovery process.



Eduard Serra, PhD



Michael J. Fisher, MD

Satellite meetings included the educational symposium, meetings of all CTF consortia, the NF Clinics meeting, the International Neurofibromatosis Autism Consortium Team symposium, the International Schwannomatosis Database meeting, and a REiNS meeting. Many opportunities were presented for mentoring and networking,

including a lunch dedicated to multiple NF experts sharing their knowledge with young investigators.

The Children's Tumor Foundation was pleased to be able to offer CME (Continuing Medical Education) credits this year to attendees, a large number of whom took advantage of this opportunity.

Though it was a demanding four days, much was accomplished, and planning has already begun for the 2017 NF Conference, which will be held at the Renaissance Washington, DC, Downtown Hotel from June 10-13, 2017.



2016

## Von Recklinghausen Award

The NF Conference also served to honor key members of the NF research and clinical communities. Among them, David Viskochil, MD, PhD, was presented with the annual von Recklinghausen Award in recognition of lifelong efforts on behalf of NF research and patient care. Dr. Viskochil has, for more than three decades, dedicated himself to every aspect of the neurofibromatoses, from the lab, to the clinic, to academia. He was recognized for his research accomplishments, which include helping to identify the *NF1* gene; his mentoring skills; his administration of national and regional programs; and, most important, his role as a caring and unwavering advocate of the NF patient. And we can't forget "Dr. Dave's" personal involvement with the NF Camp from its inception, which has been and continues to be a transformative experience for so many teens and young adults struggling with NF. All these qualities and contributions define Dr. Viskochil as most worthy of this prestigious award.



Von Recklinghausen awardee, David Viskochil, PhD



Annette Bakker, PhD, presents Nancy Ratner, PhD, with a Team Science Award

## 2016 EXCELLENCE IN TEAM SCIENCE AWARD

In recognition of the value and impact of CTF's growing portfolio of team science initiatives, the Foundation launched the inaugural Excellence in Team Science Award at this year's NF Conference.

In 2008, the Foundation initiated its first consortia-based program, the NF Preclinical Consortium (NFPC), which concluded in 2013. To continue the work of the NFPC, and building on its infrastructure and collaborations, the NF Therapeutic Consortium (NFTC) was created and has been co-funded by CTF and the Neurofibromatosis Therapeutic Acceleration Program (NTAP).

The existence of the NFPC/NFTC has changed the NF clinical trials landscape. The work of these two groups provided the first proof of concept on MEK in NF, which led to other organization's later development of Selumetinib, the first NF drug to be in a registration trial. The work of the NFPC/NFTC also led to a \$12 million National Cancer Institute Specialized Program of Research Excellence (NCI SPORE) grant, with the goal of developing better treatments for tumors in patients with NF1. CTF's investment was instrumental in providing initial funding and a collaborative research group infrastructure to develop key preliminary data.

The 2016 Excellence in Team Science Award was presented to each of the four labs that comprise the NFTC:

### **Karen Cichowski Lab**

*Brigham and Women's Hospital, Harvard Medical School*

### **D. Wade Clapp Lab**

*Indiana University School of Medicine*

### **Nancy Ratner Lab**

*Cincinnati Children's Hospital Medical Center*

### **Kevin Shannon and Benjamin Braun Lab**

*University of California, San Francisco*

# 2016 NF FORUM

YOU'VE GOT THE  
**POWER**  
TO END NF

More than 200 patients, caregivers, families, volunteers, and medical experts gathered in Austin, Texas, from June 17-19 for the much-anticipated eighth annual NF Forum. It was an action-packed weekend! Highlights included an Adults with NF Meet Up, volunteer awards that recognized the outstanding efforts of CTF volunteers, and informative presentations from NF experts from all over the world. Photos from the event can be viewed in the NF Forum 2016 album at [ctf.org/photos](http://ctf.org/photos).

"I recently attended the Children's Tumor Foundation's NF Forum that was held in Austin, Texas. I think there is a misconception among many of the adults with NF that we do not matter when it comes to research and clinical trials. This NF Forum proved that to be wrong! By attending the different breakout sessions that were offered, I learned a great deal of information about the research that is being conducted that not only benefits the children with NF but the adults as well... The best part of the NF Forum is the hope it gave me for the future and hope for the end of NF."

—Tera Wilhelm, who attended the 2016 NF Forum

NF Forum co-Chairs  
Rosalie Ferner, MD,  
Karin Walsh, PsyD, and  
Gareth Evans, MD



Forum participants  
enjoy a walking tour  
of Austin



## VOLUNTEER LEADERSHIP COUNCIL

The Volunteer Leadership Council, a group of about 90 CTF volunteers and their families, enjoyed an amazing barbecue held by Jim Bob and Laurée Moffett at their lovely home. The next day, they met to discuss the ongoing work of the Council. For the first time, top volunteers making significant strides in advocacy, fundraising, and much more were given Volunteer Recognition Awards. The highlight of the ceremony was the presentation of the Volunteer of the Year Award.

Annette Bakker, PhD, President and Chief Scientific Officer of the Children's Tumor Foundation, recognized Renie Moss of Birmingham, Alabama, as CTF's Volunteer of the Year.

For a full list of VLC awardees, visit [ctf.org/blog](http://ctf.org/blog).



Annette Bakker, PhD,  
and Renie Moss

# FOUNDATION NEWS

## Awareness Month Highlights

CTF celebrated NF Awareness Month with its annual month-long campaign to raise awareness about neurofibromatosis. Through numerous community and online events held during the month of May, NF Awareness Month and its “I Know a Fighter” and “Born a Fighter” themes drew attention to the inspirational stories of those living with NF.

Highlights of this year’s awareness month included the following:

- **Shine a Light on NF:** One hundred and forty-six buildings, bridges, and monuments around the world (including Niagara Falls!) lit up blue and green. This year, CTF aligned efforts with the Neuro Foundation, an national NF charity in the UK, to extend our reach globally. Special thanks go to Bedrock Management, Dan Gilbert, Coastal Outdoor Advertising, Craig Realty Outlets, Reagan Outdoor Advertising, and so many others who participated.
- **Baseball player Ian Desmond**, of the Texas Rangers, brought attention to NF by pledging to donate \$1,000 for each run he scored during the month of May. A huge thanks to him and his family for raising NF awareness, offering NF families tickets to games, and for a \$20,000 donation!
- **Shopping carts embellished with NF awareness messages** were seen in more than 4,000 supermarkets across the country, donated by News America Marketing.
- **CTF launched a Twibbon campaign**, in which more than 17,000 people changed their social media profile photo to one that spread the “End NF” message.
- **The family of Sherri Silesky pledged a matching gift**, to fund NF clinic initiatives up to \$75,000. Thanks to the Silesky family and the generosity of many individual donors, the match was met!
- **The Picture a World Without NF photo contest!** Individuals submitted photos that showed that no matter where you are or what you’re doing, you’re fighting for a world without neurofibromatosis.
- **Proclamations were issued** in dozens of state houses and town halls across the country recognizing NF Awareness. Special thanks to CTF Board Member Gabriel Groisman for securing a number of these proclamations, and to Cindy Hahn and the Texas NF Foundation for participating in several proclamation events.



Baseball player, Ian Desmond, with two of his fans



City of San Marcos Proclamation



Peace Bridge, Buffalo, New York



### Photo Contest Winner

*“Ryker, age nine, is enjoying his day outside at our house in Midlothian, Texas, with our dog, Molly. He’s fighting NF by showing the world that even though he has struggles because of NF1, he doesn’t let it stop him from enjoying life.”*

—Celeste, mom to Ryker, who lives with NF

Please visit [ctf.org/photos](http://ctf.org/photos) to view all the NF Awareness Month photos.

## FOUNDATION NEWS

### Richard A. Horvitz and Erica Hartman-Horvitz Donate \$1 Million to Launch Synodos for Schwannomatosis *Continued from cover*

finding treatments and cures for all forms of neurofibromatosis. He first became involved with CTF (then called the National Neurofibromatosis Foundation) shortly after his first wife, Marcy, picked up a Foundation brochure after surgery at University Hospitals Case Medical Center in Cleveland in the early 1990s for a tumor of unknown cause. Suspecting from the reading material that she might have some form of these disorders, they reached out to then President Peter Bellerman for information which promptly

personally funded numerous NF research awards.

Mr. Horvitz received the Foundation's highest honor, the Humanitarian Award, for his work with the Children's Tumor Foundation, presented to him at the 2012 Gala in New York City. Upon receiving it, he remarked, "The wonderful thing about

"I've dedicated myself to doing anything I can to cure this, to help treat this disorder for my family, for my friends, for people I don't know. This I view as my life mission...as long as it takes, whatever it takes. I'm in it forever."

—Richard A. Horvitz, Synodos for Schwannomatosis benefactor

led to Horvitz's involvement with the Foundation.

In 1996, he was asked to join CTF's Board of Directors, and in 2002 he became its Chairman and was later named Chairman Emeritus. Never eager for public acclaim, Mr. Horvitz championed the work of the Children's Tumor Foundation's advocacy efforts, work that benefits the entire NF research field. His efforts were instrumental in helping secure increased federal funding for NF research. In 2003, he convened the first conference on schwannomatosis, and he has

the Foundation is it gives you a way to act. It gives you a way to take that helplessness, this helpless feeling you have, and turn it into positive action. And say, 'I'm gonna do everything I can to move things forward.'"

In addition to his work with the Children's Tumor Foundation, Mr. Horvitz serves as an officer and trustee of the Jewish Federation of Cleveland; as a Life Trustee of the Board of University School (an independent country day school in Cleveland), where he also serves on the Investment Committee; and as a member

of the University Hospitals Emeritus Leadership Council, after having served for 17 years on the Board of Directors of University Hospitals Case Medical Center. Mr. Horvitz is also a life member of the Board of Visitors of Duke University School of Law.

Mr. Horvitz is married to Erica Hartman-Horvitz, who is also active with the Foundation and has given her time and treasure to advance its mission. He has two children, Danielle and Matthew, from his marriage to his late wife, Marcy Rochelle Horvitz, a stepdaughter, Ashley, and a granddaughter, Arabella Juliet. ■



### Annette Bakker Invited to National Cancer Moonshot Summit

As top scientific leaders convened this June in Washington, DC, at the invitation of Vice President Joseph Biden, among them was Children's Tumor Foundation President and Chief Scientific Officer Annette Bakker, PhD. The effort, called the National Cancer Moonshot Summit, was dedicated to shortening the length of time it takes to develop effective treatments for cancer in particular, and disease in general. The first-of-its-kind summit was focused on promoting collaboration among researchers, industry, and patients, and to breaking down the barriers that hamper progress. "It's an honor

to be here at the Cancer Moonshot Summit at the invitation of the Vice President," said **Annette Bakker, President and Chief Scientific Officer of the Children's Tumor Foundation.** "And it's an inspiration to see everyone come together—academia, industry, government, and patients—all with one common goal: to find a cure for disease in our lifetime."







**Boston NF Walk**

On June 26th, on a warm and breezy day at Boston's Carson Beach, nearly 160 NF Heroes, families, and friends walked to raise more than \$28,000 for NF research supported by CTF. With many new faces, as well as Walk veterans, the day was filled with Star Wars characters, ice cream, and a lot of support for the Boston NF community.



**Philadelphia NF Walk and 5K**

On June 25th, more than 500 people joined together in Doylestown's Central Park at the fifth annual Philadelphia NF Walk and 5K! The Joker and Harley Quinn interrupted the day of fun, but luckily all the kids had superhero training, and together with Batman, Spider-Man, and other superheroes, they saved the day and celebrated with a superhero parade! More than \$60,000 was raised at this exciting annual Walk!



**Providence NF Walk**

On May 22nd, nearly 100 NF Heroes, families, and friends braved inclement weather and walked to raise nearly \$14,000 for NF research supported by CTF. With music blasting and generous food prepared by Paco's Taco's Taco Truck, the day was one of community and support, bringing together the Providence NF community.

**Staten Island NF Walk**

More than 150 people came out on May 14th for a beautiful day of fun at the Staten Island NF Walk. They enjoyed music by Joan Caddell, magic by Steve the Magician, Lisa Loo the Clown, Scooter from the Staten Island Yankees, and a rock wall courtesy of the NYPD. Nearly \$20,000 was raised to support NF research.



**UPCOMING WALK DATES**

Meridian, ID	9/10
Richmond, VA	9/10
Rochester, NY	9/10
Moorhead, MN	9/11
Seattle, WA	9/11
Saco, ME	9/17
Hamilton Twp, NJ	9/17
Concord, NH	9/17
Kansas City, KS	9/17
Addison Oaks, MI	9/18
Putnam, CT	9/24
New York, NY	9/24
Jacksonville, FL	10/1
Milwaukee, WI	10/1
Houston, TX	10/1
Washington DC	10/1
Columbus, OH	10/2
Dallas, TX	10/15
San Antonio, TX	10/15
Nashville, TN	10/15
Hoover, AL	10/16
Los Angeles, CA	10/22
Long Island, NY	10/22
Phoenix, AZ	10/23
Augusta, GA	11/12
Las Vegas, NV	11/13
Atlanta, GA	11/13
Boca Raton, FL	12/4

For more information, visit [nfwalk.org](http://nfwalk.org).



### NYC ALUMNI REUNION RACE

In March 2017, all NF Endurance alumni are invited to reconnect over the New York City Half Marathon race weekend and paint the town blue with a message to end NF! Runners can join in the lottery and try to gain entrance on their own, or they can take a spot from the Children's Tumor Foundation and commit to raising \$1,250 to receive free race entry. Sign up at [join.ctf.org/nfereunionrace2017](http://join.ctf.org/nfereunionrace2017).

### NYC TRIATHLON

This summer, 20 athletes took part in the New York City Triathlon and raised more than \$96,000 for the Children's Tumor Foundation. Fundraising was led by Team Raphael, which alone raised more than \$70,000. Team Raphael is captained by an amazing woman named Lara Levine-Lipof, who raced along with her husband, Ron, in honor of their brave boy, Raphael.



### TURKEY TROT

Join the NF Endurance team for the 3rd Annual Virtual Turkey Trot in November! Choose any race, any pace, any place, as long as it's a Turkey Trot. Registration for the NF Endurance team is free!

Join a Turkey Trot at [join.ctf.org/nfeturkeytrot2016](http://join.ctf.org/nfeturkeytrot2016)

### TOUGH MUDDER

Sports have played a huge role Drew Pounds' life since grade school. He was trying to find a way to give back to his family and his community, when the perfect opportunity arose with Tough Mudder!

*"I wanted to volunteer with CTF, in some form or fashion, because of my nephew, Vance. Vance was diagnosed with NF five years ago when he was three. Although he is doing well, NF affects him every day; in how he learns, grows, plays, behaves, etc. I discovered the NF Endurance Team and found out I could represent CTF through fundraising efforts at the 2016 Tough Mudder Atlanta event. I am finally at a place in my life where I can help, in my own way, to fight back against NF."*



Think you've got what it takes to follow in Drew's footsteps? MAKE MUD MATTER with NF Endurance and join our Tough Mudder team today. For more information, please go to [nfendurance.org/toughmudder](http://nfendurance.org/toughmudder).

### Upcoming Events

- 10/9 **Bank of America Chicago Marathon**  
Chicago, IL
- 10/22 **IRONMAN North Carolina**  
Wilmington, NC
- 11/5 **IRONMAN Florida**  
Panama City Beach, FL
- 11/6 **TCS New York City Marathon**  
New York, NY
- 12/11 **Honolulu Marathon**  
Honolulu, HI

For more information visit [nfendurance.org](http://nfendurance.org).



## R4R Across the Country

Springtime marked the green flag on the Racing4Research 2016 race season. All across the United States, Racing4Research welcomed NF families from Northern California to upstate New York, and from Birmingham, Alabama, to western Connecticut. NF Hero families enjoyed private tours of the racing paddock and a few even enjoyed hot laps around the track, courtesy of Compass360 Racing and Audi USA. The race season kicked into full swing this summer with events in Lexington, Ohio; Elkhart Lake, Wisconsin; Salt Lake City, Utah; and Austin, Texas on the schedule.

Please contact Program Director Jill Beck at [jbeck@ctf.org](mailto:jbeck@ctf.org) to participate in a Racing4Research event.

## A Tea Party for NF

Looking for a way to help CTF but worried about the time commitment of planning a fundraiser? Consider hosting a virtual fundraiser like “Tea Party for NF!” Simply order invitations from our website, mail them to your friends and family, and take pride in doing your part to help us raise money to end NF! No need to find a location or clean your home—this event is all online!

Visit [join.ctf.org/nftea2016](http://join.ctf.org/nftea2016) to find out more or to order invitations.



## Ongoing Study Seeks Participants

There is an ongoing study at the National Cancer Institute evaluating an intervention to help people with plexiform neurofibromas to cope with chronic pain. To be eligible, you must be between 16 and 34 years of age, have one or more plexiform neurofibromas, and have chronic pain for at least the past three months. To learn more, go to [ctf.org/NIHstudy](http://ctf.org/NIHstudy).

## NF CAMP

Happy 20th anniversary, NF Camp! With each passing year, the NF Camp program grows, maintaining its status as the place to be for teens and young adults to escape the daily challenges of living with NF, engage in fun activities with their peers, and simply be themselves, amid the scenic landscape of beautiful Utah. At Camp, the energy is always high, and the campers are always in good spirits. From the waterpark and amusement park to the ropes courses and Survivor Day competition, our Heroes are immersed in day-to-day activities that foster community and friendship, all while having the time of their lives. Here's to another 20 years of NF Camp!



“NF Camp was truly one of the greatest experiences of my life. Beforehand, I was always afraid of talking about my NF, since no one around me understood the condition. But at Camp, talking with my new friends and counselors felt so welcoming and comfortable that we did it every day.”  
—Paige, an NF Hero who attended the 2016 NF Camp

## 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).

### NORTH CAROLINA

For their 50th anniversary, Charles and Carolyn Peterson of New Bern, North Carolina, asked their friends and family to make donations to CTF instead of gifts or cards. More than \$9,000 was raised as part of that celebration. This is the third time New Bern Cares to Cure NF has had a fundraiser in support of the Petersons' granddaughter Natalie. Special thanks to Allstate Insurance, Renee and Bill Elworthy, and Natalie's great aunt Nancy for their \$1,000 contributions. Over the last five years, New Bern Cares to Cure NF has raised more than \$50,000. As in past years, Kelly and Michael Peterson pledge to match all money raised by New Bern Cares to Cure in honor of their daughter Natalie.



### COLORADO/MONTANA

A Midwest heat wave couldn't stop the Iron Butt riders from putting more than 1,000 miles on their motorcycles in one day to raise awareness for NF, and more than \$1,000 for NF research. Groups of riders left from Colorado and Montana early on the morning of July 22nd and set off for a 21-hour ride to Sycamore, Illinois. Along the way they were joined by eight more riders, becoming nearly 30 bikes strong when they rolled into DeKalb Harley-Davidson in DeKalb, Illinois. This is the third year of the Iron Butt ride, which is organized by Heather and Shaun Nepl, and the Smokin' Guns Motorcycle Club.

### CONNECTICUT

On June 17th, the Haddam Killingworth Youth Lacrosse Association hosted a Hero Dash during the league's end-of-year picnic. The teams were inspired to organize this event in support of a local fourth-grader, Emma Becker, who lives with NF. Ten-year-old Emma has completed several rounds of chemotherapy to treat two tumors in her brain and two cysts that continue to grow. In addition to going to school, Emma still finds time to help other sick children by hosting lemonade stands, and making cards. The event raised more than \$2,400 for NF research.





## ALBAMA

More than 80 Alabama NF families and friends gathered on Saturday, May 21st, at Birmingham's Regions Field to cheer on the Birmingham Barons for Blue Out NF with the Barons. Julie Ann Camp and Renie Porter Moss of Birmingham, Alabama, hosted an NF awareness table at the entrance to the baseball stadium. The Birmingham Barons lit up the well-known Regions Field Birmingham sign in blue in support of the Shine a Light on NF campaign.



## CALIFORNIA

On May 22, the 2nd Annual Kids Fashion For NF: Heroes For a Cure event took place at the Federal Bar in North Hollywood. The event included a champagne brunch, silent and live auction, kid's artwork, a candy bar, and of course, the fashion show. Local NF Heroes strutted the runway in clothing donated by various vendors. The models expressed happiness and confidence, and a good time was had by all. Actors Jonthan Sadowski from *Young and Hungry*, and Chiara Aurelia from *Pretty Little Liars*, emceed the event, which raised \$19,541 for NF research!



## CALIFORNIA

The Studio City Chamber of Commerce and CBS graciously invited CTF to be the charity recipient for the 18th annual CBS and Studio City Chamber of Commerce Fourth of July Fireworks Festival. NF Heroes Blake Robinson and Ryder Savage were there to help sell raffle tickets. This is the fourth year that CTF was chosen as the charity recipient for this festival which raised more than \$32,000 and spread NF awareness to almost 4,000 attendees.

## NEW YORK

The New York City Annual Poker Tournament Committee went ALL IN planning the big event this year. More than 135 guests attended on Thursday, June 16th, and raised more than \$115,000! Texas Hold'em-style poker was played, as a new champion came forth. Congratulations Brian Neugeboren for winning a seat at the World Series of Poker! Also in attendance were Brian Behrens, Jason Colodne, Ken Rudd, Scott Gottlieb, Billy Lerner, and Dan Altman, who was honored with a trophy for his dedication and continuous support.



## COLORADO

This past May, the Denver, Colorado, NF Mother's Day Tea was a wonderful event during which the NF Hero for this year's NF Walk was announced—Cailin Hubbard! Claire Honl filled the room with her harp music while fresh scones, treats, fruit, and tea were served. Speakers, massages, and giveaways were enjoyed by some 50 guests.



## MEET AN NF HERO:

**Kaetlynn Newland**

My daughter, Kaetlynn, just graduated from Jimtown High School in Elkhart, Indiana, and has plans to take classes at Animal Behavioral College online in order to become a Veterinary Assistant. She loves God and her country with all her heart; growing up as a military kid, she has the utmost respect for our troops and for her father who is a retired Marine.

We live in Indiana now, but while her dad was on active duty (he did ten deployments),

we lived in Twentynine Palms, California, for eight years; at Marine Corps Base Camp Pendleton in Oceanside, California, for three years; and on a military base in Hawaii for two years.



Kaetlynn was diagnosed with NF1 as a toddler. Kaet has many “birthmarks” (café au lait spots) and is now beginning to notice some bumps, though she is the only one that can tell where they are at present. She used to have yearly MRIs on her head and optic nerves, but we’ve been told that she no longer needs them.

Within the last year, a grapefruit-sized nerve sheath tumor was discovered on the back of her right leg, just above the knee on her sciatic nerve. It is benign, and we are scheduling surgery to have it removed.

Kaetlynn is a wonderful young woman with a bright future. She fights neurofibromatosis head on, and had a wonderful time attending the Children’s Tumor Foundation’s NF Camp in Salt Lake City, Utah, this summer. We love her very much, and she makes us proud every day.

—Tracey Newland, Kaetlynn’s mother

## STORIES OF NF: *Candice Patterson*

I was diagnosed with NF2 at birth, but I don’t think about it on a daily basis. I’m just doing my job as a nurse and caring for others, but my scars reveal that I carry much more with me. When I do feel NF-related anxiety, I try to lower my stress level through laughter, biking, and encouraging others to live fully.

In July of 2010, I had an article published in *More* magazine, which included an excerpt from my autobiography, *Candice Patterson, NF Survivor*:

“I am beautiful. There is a world full of people trying to convince me that I am not. I feel it when I walk into a room; I see it in their eyes and their expressions, and then I hear it in their words. But I am still beautiful. For 40 years I have lived with a facial deformity caused by neurofibromatosis and for 40 years the best surgeons in the world have taken me apart and reassembled me.

“I am not my disease. I have spent my life as a patient undergoing 24 surgeries to remove tumors caused by NF and repairing the damage that they have caused. Every summer of my youth began with surgery and my head wrapped tightly in gauze and pressure dressings, unable to see the new cuts on my face and the new scars that I would have to befriend. I was trapped in a hot, sound-muffled prison of my own pain. Then the bandages would be removed to reveal a face that I did not recognize; a face beaten, bruised, bloody, and damaged, all in the name of beauty. I would have to learn this new face, accept this new face, love this new face in all aspects of its healing. At times I would hide during this process, to avoid frightening children and hearing the cruelty of the world. In my cocoon, silently, I would heal.

“My face has been broken so many times that I have suffered every disability of senses known to man. My vision would be taken away because my eyes were sewn shut in order to heal, but I never lost sight. My ability to speak was taken away when they shattered my jaw into pieces, but I never lost my voice. I’ve walked feeling the walls of my home and using my feet to sense floor changes in order to find my way to the kitchen, in an effort to be independent and pour myself a glass of juice. I’ve survived breathing through a pinky sized opening in my mouth because my face swelled so badly.

“I have thought that I would die, and sometimes I wished for death in order to be released from the pain. But I always reminded myself that life was just too beautiful, that eventually the pain would leave, and that a beautiful butterfly would emerge once again.

“I’ve run 5K’s, swam for miles, and danced my way into preparing my body for battle and healing. My future will be spent raising NF awareness and funds for research so that those born after me will not suffer as I have. That is why I live the way I do.

“I am beautiful. I am not my disease. I am a powerful woman. I am a tri-athlete. I am a healer. I am a friend. I am a lover. I am a fighter!”

— Candice Patterson, an NF Hero



## MEET THE STAFF

**Sarah Bourne**, Director of Finance



**HOMETOWN:** Ormond Beach, Florida

**CURRENT TOWN:** Milwaukee, Wisconsin

**EDUCATION:** Bachelors in Accounting from North Park University, Chicago, Illinois

**WORK WITH THE FOUNDATION:** I started working for the Foundation in 2009 as the Junior Accountant. Shortly after that, I was promoted to Accountant, and in April of this year I was promoted to Director of Finance. I've seen the Foundation go from an \$8 million budget to a budget of more than \$15 million! It's very exciting!

**FAVORITE EXPERIENCE WITH THE FOUNDATION:** As the accountant working behind the scenes, I don't often get to interact with the families affected by NF. Anytime I get a chance to be a part of any of our events (whether it's a Walk, a

Tea Party, or gala) I jump at it because getting to know the families that we help every day is what it's all about, and is what makes my job meaningful.

**FAVORITE HOBBY:** Reading. When I lived in New York, my long commute allowed me the chance to read for at least an hour a day. Now that I have no commute, and a child, reading has become a luxury! I love reading anything I can get my hands on, but popular fiction is my go-to (think *The Da Vinci Code*, *Gone Girl*, etc.).

**FAVORITE MOTTO OR APHORISM:** If you don't like something, change it. If you can't change it, change your attitude.

### New Patient Brochures Available

Visit [ctf.org/brochures](http://ctf.org/brochures) to peruse our list of new and updated brochures, many of them available in multiple languages.



### NEW FACES AT THE CHILDREN'S TUMOR FOUNDATION

Welcome to the Foundation's newest staff member!



**Adam Gracia**  
Regional Development Manager, New England  
[agracia@ctf.org](mailto:agracia@ctf.org)

### PLEASE HELP US MAKE NF NEWS EVEN BETTER!

Fill out our newsletter survey at [ctf.org/survey](http://ctf.org/survey) for a chance to win a CTF bag of goodies.

*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](http://www.ctf.org). Please direct any questions or feedback 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 causes 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](http://www.ctf.org).

#### FOUNDATION STAFF

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**Reid Horowitz**, Chief Operating Officer and Chief Financial Officer

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**Kate Kelts**, Patient Support Coordinator  
**Pamela Knight**, Clinical Program Director  
**Hyerim Lee, PhD**, Translational Science Project Director  
**Patrice Pancza**, Program Director, Research  
**Heather Radtke**, NF Clinic and Symposium Coordinator  
**Sarah Rosenberg**, Executive Assistant

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**Traceann Rose**, Director, Community Building & Patient Engagement  
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CHILDREN'S  
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THROUGH RESEARCH

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AN AQUATIC AFFAIR TO END NF

**NOVEMBER 19, 2016**  
Cobo Center Grand Ballroom  
1 Washington Boulevard  
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