

# NF NEWS

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION  
FALL 2017

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

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## 2017 NF Conference

Greg Simon, President of the Biden Cancer Initiative, joined the 2017 NF Conference as the Keynote Speaker at the Welcome Dinner, held at the historic National Press Club in Washington, DC, on Saturday, June 10. Simon spoke on the important topics of research collaboration and breaking down barriers to research progress. His inspiring remarks were also personal; Simon is a cancer survivor, and has recently been successfully treated for chronic lymphocytic leukemia.

Greg Simon's relationship with the Children's Tumor Foundation (CTF) began when both he and CTF president Annette Bakker, PhD, attended the Cancer Moonshot Summit at the invitation of former Vice President Joe Biden. Simon was then serving as the Executive Director of the Cancer Moonshot Task Force.

Watch Greg Simon's complete speech online at [ctf.org/GregSimonSpeech](http://ctf.org/GregSimonSpeech).

*Greg Simon of the Biden Cancer Initiative addresses NF Conference attendees at the National Press Club in Washington, DC.*

THE NATIONAL  
PRESS CLUB

# FROM the President

Annette Bakker, PhD



by our community of donors, patients, and volunteers are working!

We are not only increasing the number of experts who are working toward a symptom-free future for those with NF, we are also increasing the variety. This NF Conference brought together the most diverse expertise in the world—oncologists, neurologists, geneticists, orthopedics—and the list goes on. There is no other opportunity for all of these diverse experts to meet and exchange ideas, and to do so in an environment that encourages and cultivates joint efforts. Bringing these experts together is very high on the Foundation’s priority list.

Our Conference attendees were especially inspired by the words of Greg Simon, President of the Biden Cancer Initiative, who spoke at our Welcome Dinner at the historic National Press Club. Greg and I met over a year ago at the Cancer Moonshot Task Force, where he was then the Executive Director of the Task Force. Greg is one of our nation’s great advocates for medical research, and a leader in the fight to get treatments to patients as quickly as possible.

Our Conference was an assembly of men and women who want to end NF suffering! These are scientists who care about NF Heroes, like Julie Adams and Sequoyah Daniel, both of whom you will read about in this newsletter. These scientists care about the teens with NF who gathered earlier this summer for NF Camp, and the families who are sending their children back

## Congratulations

Annette Bakker

*CTF President and Chief Scientific Officer Annette Bakker, PhD, has been announced as the recipient of a 2017 RARE Champion of Hope award for her notable contributions to science. The RARE Champion of Hope awards are presented by Global Genes, one of the leading rare disease patient advocacy organizations in the world.*

to school, worried about NF-related learning disabilities. It is because of that caring spirit that our Conference keeps growing. We are excited to share with you the highlights of the work that was presented, and the progress that continues throughout the year.

We have so many people to thank for this journey. Special thanks goes out to Beth and Jake Burke for their ongoing support and participation. This year, Beth passionately addressed NF Conference attendees from the all-important perspective of an NF parent. You, our donors, are funding more than NF research—you are instilling hope, creating dreams, and forging the path ahead. As individuals we can make a difference, but together—researchers, patients, clinicians, fundraisers, event planners, runners, bikers, walkers, and baseball players—we all play a part in the fight to end NF.

The arrival of autumn is a time of new beginnings. Children are heading back to school, and their parents are preparing for the winter ahead. In this season of reflection, I am reminded of the many years that the Children’s Tumor Foundation (CTF) has been committed to translating science into treatments for neurofibromatosis (NF). We are now seeing tremendous progress due to that commitment.

This progress was especially apparent this June as doctors, clinicians, patients, and researchers gathered in downtown Washington, DC for our annual NF Conference. This year almost 400 people were in attendance, which is approximately 25% more than last year, making it the largest NF Conference thus far. This tells me that the NF awareness efforts championed

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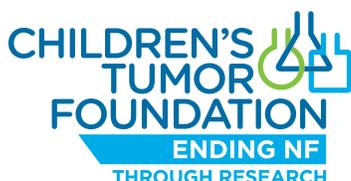
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## NF Registry Study Published

**T**he NF Registry has proven to be a valid and useful tool for both patients and researchers, according to an analysis published in the journal *PLOS ONE* in June 2017. Not only are thousands of patients from all over the world contributing their data to the NF Registry, the data is being actively used—and appreciated—by researchers working on all forms of NF.

With over 8,000 participants, the NF Registry is currently the largest reported cohort of people with NF, and the only one designed to be available to interested investigators. The analysis used a subset of data to examine how well patient-entered data matched the patterns seen in physician-entered data. Two overall conclusions emerged from the information: one, that patients are reliable in reporting their symptoms; and two, that researchers are eager to use this service. Over 18 different studies and clinical trials have used the NF Registry to notify individuals who fit certain trial or study criteria.

The publication was authored by CTF staff members along with outside experts, including a statistician and three prominent clinicians. To read more about this accomplishment, and to read the full publication go to [ctf.org/news](http://ctf.org/news), and to join the registry go to [nregistry.org](http://nregistry.org).



## Hackathon for NF2

The first Hackathon for NF2 took place in San Francisco, California over the weekend of June 23rd. Spearheaded by Onno Faber, an entrepreneur and NF2 patient, the event focused on analyzing genomic data and research publications using artificial intelligence and other computational methods.

Almost 150 attendees, including Clayton Mellina who also has NF2, worked for 48 hours on Onno's DNA sequence, scanned the web for useful data, and developed algorithms useful for cloud-based super-computers to run complex analyses. The high-energy gathering produced open source software products that researchers can use to assist their work in genomics. Specifically, this meeting produced valuable hypotheses and tools with which to analyze NF2 from a new perspective.

Marco Giovannini, MD, PhD, from University of California, Los Angeles, and Salvatore La Rosa, PhD, VP of Research and Development at CTF, acted as mentors and judges of the teams, providing useful medical and scientific insights about NF2 and drug discovery. For future Hackathons, CTF plans to actively collaborate with the organizing groups to evaluate next steps and probe into the kind of data needed for an even more powerful future event.

From left:  
Onno Faber,  
Salvatore La  
Rosa, PhD,  
and Clayton  
Mellina

## Synodos for Schwannomatosis Kickoff Meeting

An international consortium of clinicians and scientists from multiple disciplines met in Toronto, Canada on May 1st to officially launch Synodos for Schwannomatosis, another CTF consortium based on the successful Synodos model. Led by Gelareh Zadeh, MD, PhD from the University of Toronto, and Laura Papi, MD, PhD from the University of Florence, Italy, the project

will perform an extensive molecular analysis of schwannomatosis tumor samples to identify new therapeutic targets, and advance the understanding and management of the disease, with a special focus on pain.

To read more about this project go to [ctf.org/synodos](http://ctf.org/synodos).

“After the meeting today, I feel that we've assembled a total dream team of people who are highly dedicated to making something happen by working together.”

**RICHARD A. HORVITZ**  
CTF BOARD OF DIRECTORS CHAIR

## NF Conference Research Updates

With nearly 400 researchers and clinicians in attendance, the 2017 meeting was the largest NF Conference to date. Keynote Speaker **Elaine Fuchs, PhD**, a specialist in skin biology, skin stem cells, and associated genetic disorders, including cancers, kicked off the four-day event with a session on how understanding and influencing stem cell technology can be applied to NF1 skin manifestations.

### Screening for NF

Following the opening session, many groups reported results from newly established screening methodologies which were able to improve the prediction of NF in cell models and advanced animal models.

**The Synodos for NF2 team** presented a robust, genetically accurate system that can be used to identify drugs for NF2-associated tumors. The group is currently working to select one or more compounds to enter a human NF2 trial in the near future.

**The Synodos for NF1 Preclinical Acceleration Team** at the University of Minnesota presented their screening for NF1 using a pair of genetically identical cell lines. These cell lines only differ in their expression of the NF1 protein; this difference allows researchers to identify compounds that kill NF1-deficient cells, and spare normal cells. The team reported that 20 compounds have been identified as selective killers of NF1-deficient cells.

**Michaela Fenckova, PhD**, from Radboud University Medical Center in the Netherlands, reported on a highly sophisticated screen in the fruit fly *Drosophila*, which will open new avenues for improved translational research and treatment of cognitive and behavioral deficits in NF1 and other Rasopathies.



## AWARDS FOR OUTSTANDING SCIENCE



The 2017 **Friedrich von Recklinghausen Award** was presented at the NF Conference Welcome Dinner to **Karen Cichowski, PhD**, of Brigham and Women's Hospital/Harvard University, in recognition of her significant contributions to NF1 research, including her work to develop new therapies for the treatment of malignant peripheral nerve sheath tumors.



This year's **Excellence in Team Science Award** was presented to the Principal Investigators representing the 12 centers of excellence which comprise the Synodos for NF2 consortium. Established in 2014 as the first Synodos effort, it serves as the model for the Synodos for NF1 and Schwannomatosis consortia. To read more about Synodos for NF2 and all of the investigators, go to [ctf.org/synodos](http://ctf.org/synodos).

### Models of NF

Promising progress in the development of advanced models that recapitulate the various aspects of neurofibromatosis was reported by the **Synodos for NF1** team researcher working at Recombinetics, who shared that NF1-minipigs develop skin lesions over time that appear to resemble human dermal neurofibromas. Additionally, the team has observed tibial dysplasia and other manifestations that are typical of NF as observed in humans. The team is already beginning to test potential drug treatments.

Exciting news came from **Jeremie Vitte, PhD**, of the University of California, Los Angeles. He reported on a new mouse model that for the first time carries one of the underlying gene mutations that develop schwannomas of the same type as those found in schwannomatosis patients.

Researchers from the **University of Alabama at Birmingham** reported on the development of new reagents that will allow the insertion of different mutation classes into cells and mice, which will enable investigation of potential new treatment approaches to NF1.

### Treatment of NF

Researchers also presented evidence of new drug treatment options that are effective in animal models and could be readily brought to the clinic. Perhaps the most intriguing report came from **Thomas DeRaedt, PhD**, of Harvard Medical School, who showed the use of immunotherapy in MPNST (malignant peripheral nerve sheath tumors). Combining the use of a MEK inhibitor with a second drug, plus an antibody that triggers the immune system to recognize and attack tumor cells has shown incredible response in animal models. Researchers are now evaluating whether humans can tolerate this cocktail of drugs and are beginning to design a potential first clinical trial using immunotherapy.

**Filippo Giaccotti, MD, PhD**, from the MD Anderson Cancer Center showed a promising new combination of two drugs useful for NF2 tumors. Combining the drug MLN4924 (an NEDD8 activating enzyme inhibitor, NAE) with GDC-0980 (a PI3K/mTOR inhibitor) suppresses the growth of NF2-mutant

tumor cells in mouse models.

**Roberta Beauchamp** from Massachusetts General Hospital (MGH) reported the preliminary results on the efforts of her lab working with the Synodos NF2 group. Building from the results of the CTF program, the MGH group described that a novel combination of two drugs, ADZ-2014 (an mTOR inhibitor) with Dasatinib (a multi-kinase inhibitor) targets two independent pathways involved in the formation and development of NF2 meningioma tumors, showing synergistic effects in cells. Researchers are now moving to animal model studies to confirm the observation.

Finally, **Michel Kalamarides, MD, PhD**, of Hôpital de la Pitié-Salpêtrière in Paris, identified a specific mutation in SMO, a signaling pathway occurring in 3-5% of patients' meningiomas. Evidence of efficacy on the use of the specific SMO-inhibitor Sonidegib in cell models of NF2 meningioma warrants further investigation to prove whether or not this treatment strategy could be useful for NF2 patients.

The exciting findings of the 2017 Conference represent new ideas that will hopefully translate into new treatment options for patients. The researchers and clinicians in attendance returned home with new knowledge and relationships as a solid foundation for future, fruitful collaborations.



The 2018 Joint Global NF Conference will be held November 2-6 at the Maison de la Chimie in Paris, France. Visit [ctf.org/nfconference](http://ctf.org/nfconference) for updates.

### More on MEK for NF1

More evidence on MEK as a useful target for NF1 treatment was reported in two additional clinical trials for plexiform neurofibroma and NF1-driven low-grade glioma, building on the confidence of the selumetinib registration trial, in which significant tumor shrinkage is being found in patients with plexiform neurofibroma.

**Brian Weiss, MD**, of Cincinnati Children's Hospital Medical Center, reported results on a Phase 2 NF-Consortium Trial of the MEK inhibitor PD-0325901 in adolescents and adults with NF1-related plexiform neurofibromas. The study demonstrated that PD-0325901 causes plexiform shrinkage in 42%

of adolescent and adult subjects with NF-related plexiform neurofibromas, and that treatment is well tolerated at the dose tested.

**Roger Packer, MD**, from the Children's National Health System, Washington, DC reported on Jason R. Fangusaro's publication, "A Phase II Prospective Study of Selumetinib in Children with Recurrent or Refractory NF1-Associated Low-Grade Glioma (LGG): A Pediatric Brain Tumor Consortium (PBTC) Study." It was reported that selumetinib was effective in treating children with NF1-associated recurrent and progressive LGG. Larger prospective studies specifically incorporating validated outcomes are necessary to determine the specific role of this agent in treatment in the future.

Last year's Dancing With Our Stars event raised \$35,000 toward sending young people to NF Camp this summer! Thank you to Lesley Oslica, her fellow organizers, and the generous donors who make the Arkansas event such a success each year. Because of you, these teens will treasure their experience at NF Camp.



## Friendship and Fun at NF Camp

Over 100 youth attended the 21st annual NF Camp, which expanded from two to three sessions this July. NF Camp is held at the beautiful Camp Kostopulos in Emigration Canyon, Utah. Campers enjoyed horseback riding, rope courses, "Survivor" day, and day trips to local theme parks. At NF Camp, often for the first time, campers can talk freely about NF, share their experiences, and make lasting friendships.

## UPCOMING GALAS & CHARITABLE EVENTS

to benefit the Children's Tumor Foundation

**Dancing With Our Stars, Arkansas**  
September 7

**New England Gala, Massachusetts**  
September 16

**Cocktails for a Cure, New York**  
October 21

**New York City Gala, New York**  
November 9

**The beNeFit V, Michigan**  
November 18

Learn more at [ctf.org](http://ctf.org)



## NYC Poker Night

The 2017 New York City Poker Tournament was held on June 7th and hosted over 135 players. The annual event brought in more than \$100,000 to support NF research. We extend a huge thank you to the planning committee for all of their hard work and dedication, and a hearty congratulations to Brad Johnson, our winner of the night!

*2017 Poker Committee Dan Wilpon, Jon Tolpin, Corey Altman, CTF Board Member Dan Altman, and Brandon Maymudes*

## Julia Adams

We noticed that Julia had café au lait spots at eight months of age. At ten months old we saw a neurologist for the first time. NF1 was suspected but there was no family history. Julia had an MRI at 15 months old and it was then that they saw areas of hyperintensity in the brain. Diagnosis was confirmed at that point.



Julia has multiple café au lait spots, freckling, and Lisch nodules. Although physically her symptoms have been mild, Julia has had many of the behavioral manifestations seen with NF1. She has been diagnosed with ADHD, obsessive compulsive personality, sensory concerns, fine motor issues, and gross motor issues. She does well in school but struggles with maintaining focus. She has a huge heart and tries so hard to make others happy. She loves everything having to do with baking and wants to own her own bakery one day.

Julia is a sweet, caring, and funny 2nd grader. On weekends, she loves playing outside on playgrounds near our house. When Julia was younger, going to the doctor was a struggle, but now she walks up to the nurse for blood pressure readings like a champ. She has become her own advocate, letting people know that she doesn't like the feeling of hugs or the taste of certain foods. She does not understand all the aspects of NF1 yet, but she knows that it is a part of who she is and that it makes her stronger inside and out.

—Hillary Adams, Julia's mom

“The NF group is such an inspiration. To know that you are not the only one, even when you feel that way sometimes, is a real encouragement. I'm now moving forward with a clear mind while being positive and knowing that NF2 will not define me.”

—SEQUOYAH DANIEL

## Sequoyah Daniel

I was diagnosed with NF2 in June 2015 after having a seizure. I was devastated. My dad has NF2, but was told that I didn't have it as a child. I found out that the tumor actually started growing when I was 15. I'm now coping with it day by day. Some days are great but other days my body and head feel terrible, especially during rainy days. I still want to have children and if they end up having NF2, I'm glad that I can tell them that this does not define them!

When I found out that I had NF2, it actually brought my dad and me closer. He helps and encourages me when I have severe headaches and constant tingling and numbness. It definitely felt good when I told

my boyfriend I had NF2. He immediately began researching and came with me to the clinic symposium at NYU last year. The NF group is such an inspiration. To know that you are not the only one, even when you feel that way sometimes, is a real encouragement. I'm now moving forward with a clear mind while being positive and knowing that NF2 will not define me and the goals I want to achieve.

I am a photographer. Traveling makes me so happy; I've been traveling the world since I was four years old. After I had surgery to remove my meningioma in July of 2015, my mom and I made plans to go to Iceland. I was ecstatic the day the doctor cleared me to go!



# Awareness Month HIGHLIGHTS

The annual NF Awareness Month campaign raises awareness about neurofibromatosis in a plethora of ways big and small, near and far, through numerous events held during the month of May.

The Shine a Light on NF initiative continues to cast a blue and green glow on buildings, bridges, and monuments around the country and around the globe, bringing this year's total to 159 landmarks spanning 9 countries.

Special thanks to our corporate partners, including Bedrock Management, Dan Gilbert, Craig Realty Outlets, Reagan Outdoor Advertising, and Adams Outdoor Advertising. We are also grateful to the NF organizations who partner with us, including The Neuro Foundation, CureNFwithJack, Texas Neurofibromatosis Foundation, NF Kinder, the British Columbia Tumour Foundation, and NF Ontario.



Woodmen Building, Omaha, Nebraska

The “Where in the World do you End NF” photo contest showed that the NF community’s drive for spreading awareness knows no limits or bounds!



PHOTO CONTEST WINNER

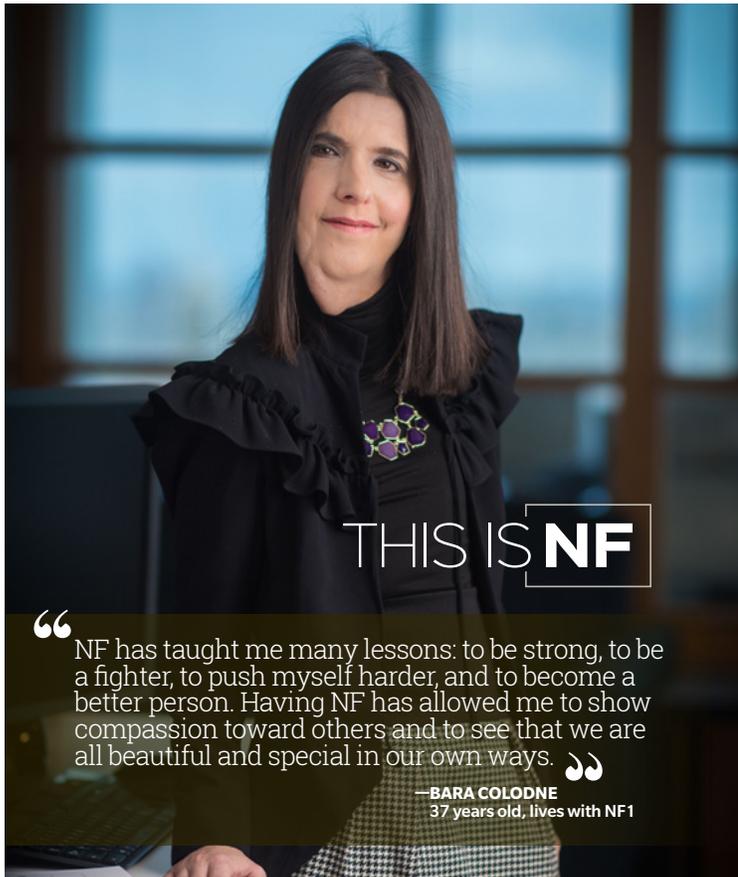
“Averhy had two surgeries with one week separating them ... This photo was taken mere weeks after leaving the hospital. She promised everyone that she would roar louder than a lion... and she did!”

**ANNA**

MOM TO AVERHY, WHO LIVES WITH NF

With the “This is NF” photo series, we told a side of the NF story that isn’t often told—that of the passion that those living with NF bring to their daily lives. Eleven adults shared a side of their story that often goes unnoticed, demonstrating that living with NF doesn’t mean letting NF define your life.

Read all the profiles at [ctf.org/thisisnf](http://ctf.org/thisisnf).



THIS IS **NF**

“NF has taught me many lessons: to be strong, to be a fighter, to push myself harder, and to become a better person. Having NF has allowed me to show compassion toward others and to see that we are all beautiful and special in our own ways.”

—BARA COLODNE  
37 years old, lives with NF1



Arkansas Governor Asa Hutchinson presented a proclamation declaring May as NF Awareness Month at the Arkansas Travelers baseball game.

Proclamations were issued in 26 state houses and 30 city halls across the country recognizing NF awareness month! Special thanks to all the volunteers who engaged their local leaders and helped ensure more people in office know about NF and how it affects their constituents.

“With all the unknowns that I’m afraid of for my 10-year-old daughter with NF, it gives me hope [to read about]... adults with NF who have successful and challenging careers. Thanks to all the NF warriors for sharing your stories with us. I see you and admire you and am hopeful.”

—LAURA WHITE MERELLO, VIA FACEBOOK

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



## Extraordinary Spirit / IAN DESMOND

**W**hen baseball player Ian Desmond was playing for the Washington Nationals in 2012, he befriended South Carolina native

Ethan Brown, who had been diagnosed with neurofibromatosis. Ian began interacting with Ethan via Twitter and invited him to a game in Atlanta later that year. Since then, the two have continued to correspond and Ian, who now plays for the Colorado Rockies, has become a champion for NF awareness and the Children's Tumor Foundation.

Ethan's condition worsened as tumors developed on his brain stem, spine, and hands, surfacing inside and outside his body. In a show of support, Ian and Ethan created a tattoo design that they both agreed to have inked on their body, which includes the CTF motto: End NF. Both now have this tattoo on their forearms.

Ian has continued his relationship with Ethan and the NF fight. In 2014, he created an Indiegogo campaign that raised over \$30,000 for NF research. Always ready to use his platform

to raise awareness, Ian frequently gives media appearances on our behalf, and often provides free baseball tickets to NF families, and meets up with them all around the country.

In 2016, Ian and his family pledged to donate \$1,000 to the Children's Tumor Foundation for every run he hit during the month of May for NF Awareness Month, resulting in a \$20,000 donation.

This May, Ian released a special edition T-shirt featuring his profile and our End NF message, with the proceeds from sales coming to CTF. In June, nearly 200 members of the CTF community from Colorado watched the Rockies play at the third annual NF Night at the Rockies, which aims to raise funds for CTF and gather local NF families together to enjoy a great evening of baseball. The Desmond family presented a check for \$16,000 to CTF which represented \$1,000 for every run he scored in May.

We are especially grateful to Ian and Chelsey Desmond for being so passionate and generous in their continued efforts to help find a cure for NF.



In the NF community, they have this thing where it's 'I know a fighter.' ... It's awesome to see how these families and these individuals who are affected by neurofibromatosis are so optimistic, and my family and I draw strength from that.

**IAN DESMOND**

AS REPORTED IN MILE HIGH SPORTS





**2017 United Airlines NYC Half**

On March 19th over 40 NF Endurance athletes gathered in New York City for the United Airlines NYC Half Marathon, raising more than \$85,000 for NF research. NFE runners and fundraisers included CTF Board Members Tracy Galloway, Bruce Korf, Gabriel Groisman, and former Board Member Lesley Oslica.

The three-day event weekend was also the first NF Endurance Alumni Reunion Weekend. Team members and alumna enjoyed team camaraderie, as well as words of motivation from many in the NF community, including 2017 Children's Tumor Foundation Ambassador Sarah Rodbell. The next NF Endurance Alumni Reunion weekend will take place at the 2018 Rock 'n' Roll Las Vegas Marathon.

**Congratulations to CTF Board Member Tracy Galloway for completing her first half marathon!**



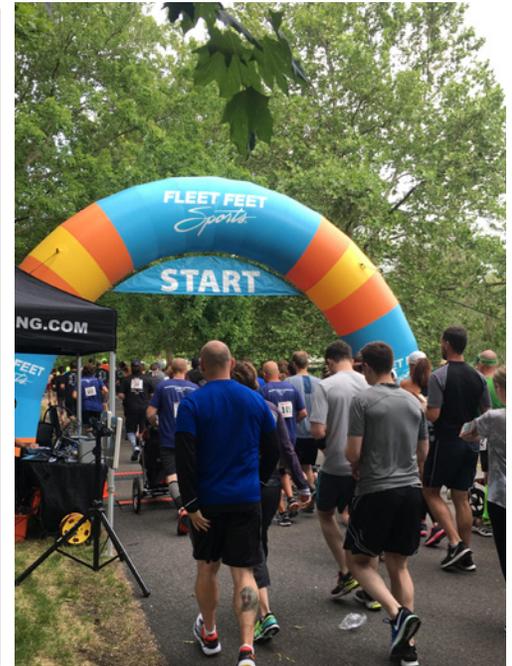
**TD Five Boro Bike Tour**

On Sunday May 7th, over 50 NF Endurance cyclists joined 32,000 from around the world to roll through every borough of New York City at the TD Five Boro Bike Tour. This is the second year the NF Endurance team has participated in the 40-mile event, and this year raised more than \$64,000 to support CTF. The top fundraising team, Team COLBECK, led by Jason Colodne, collectively raised more than \$38,000.

On June 16th the 5th annual Summer Solstice 10K and Kids Fun Run took place in Spokane, Washington. Nearly 200 registrants raised more than \$10,000 this year, and almost \$60,000 over the past five years thanks to the amazing sponsors, volunteers, and participants.

**“My daughter Grace, a fun loving 15-year-old, has NF1 and is my reason for helping to organize this super fun event.”**

—JANET CARNEY, EVENT CHAIR



I am so thankful to everyone who donated to help our NYC Half Marathon team raise almost \$90,000 for NF Research! They help me recognize what we can do when we join together in a mission—a mission to end NF!

—LESLEY OSLICA, ENDURANCE ATHLETE AND FORMER CTF BOARD MEMBER



## UPCOMING WALKS

Sep 9, 2017  
Rochester, NY

Sep 16, 2017  
Idaho  
Iowa  
Maine  
New Jersey

Sep 17, 2017  
Addison Oaks, MI  
Moorhead, MN

Sep 23, 2017  
Chicago, IL  
Kansas City, KC  
Las Vegas, NV  
Seattle, WA  
Washington, DC

Sep 24, 2017  
New York City

Sep 30, 2017  
Augusta, GA  
Nashville, TN  
Putnam, CT  
Houston, TX

Oct 1, 2017  
Columbus, OH

Oct 7, 2017  
Jacksonville, FL  
Phoenix, AZ

Oct 14, 2017  
San Antonio, TX

Oct 21, 2017  
Dallas, TX

Oct 22, 2017  
Long Island, NY

Oct 28, 2017  
Los Angeles, CA

Nov 5, 2017  
Birmingham, AL

Nov 11, 2017  
San Diego, TX

Nov 12, 2017  
Atlanta, GA

Dec 3, 2017  
Boca Raton, FL

Sign up today at  
[nfwalk.org](http://nfwalk.org)

## The 7th Annual Cincinnati Walk

More than 500 Ohioans came together for the 7th annual Cincinnati NF Walk. Featuring superheroes, face painting, and ENDNF cookies, this wonderful event raised more than \$63,000 for the mission of the Children's Tumor Foundation.



Gavin and Ally Downing at the Cincinnati Walk

## BOSTON WALK

The 2017 Boston NF Walk was held on June 24th in Boston, Massachusetts. Organized by NF Moms Vanessa Dangoia, Amie Lee, and Erin Ward, even heavy rain couldn't wash out the Walk! With the Boston skyline behind them, over 140 family and friends walked along the water and raised over \$28,000 for NF research. Walkers enjoyed children's games, arts and crafts, and a Hero Dash that kicked off the day. Team JP took home top fundraising team honors and Karen Perella was the day's top fundraiser.



Wren Lilly Strachan, and NF Hero Brady Ward at the Boston Walk.

## PROVIDENCE WALK

The 2017 Providence NF Walk was held on May 21st in Providence, Rhode Island.

Walter and Priscilla Steenbergen, longtime supporters and active CTF volunteers, hosted the event in honor of their son Charlie. More than 75 family and friends walked along Blackstone Boulevard Park's tree-lined walkway and afterwards enjoyed music, children's activities, and gourmet wrestling-themed grilled cheese sandwiches from Championship Melt. The event raised nearly \$10,000 for NF research, with Team Mighty Max taking home top fundraising-team honors and NF Hero Christopher daCunha named the day's top fundraiser.



Mitchell, Walt, Priscilla, and NF Hero Charlie Steenbergen at the Providence Walk

# Regional NEWS

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](http://www.ctf.org).



Barbara White and her family at Family Fun Day.

## NEW YORK

### Staten Island Family Fun Day

With a band, carnival games, pony rides, and tons of food, the Staten Island Family Fun Day

was a huge success! The Staten Island community came out in a show of support for people with NF. Thank you to Barbara White, Susan Gullisano, Christina Christophersen, and Lydia Parker for all of your hard work and commitment.

“It was such an inspiration to see so many children running for CTF and embracing my son with NF1. They welcomed him like a superhero and in the end the kids raised over \$4,000. I was so overwhelmed with the love and support. It's humbling.

—DIANE OWENS, NF MOM

## CONNECTICUT

### Pomperaug Elementary School Kid's Hero Dash

In support of Pomperaug Elementary School's mission of tolerance and embracing differences, students and teachers participated in a Kid's Hero Run on May 31st during the school's Field Day in support of the Children's Tumor Foundation. Encouraged by cheers from the crowd, NF Hero Alex Owens and his older brother Justy led the run, followed by their classmates as they helped spread NF awareness and raised over \$4,000 to fund NF research.



## UTAH

### 4th Annual #EndNF with Travis Classic Golf Tournament

The 4th Annual #EndNF with Travis Classic Golf Tournament was held on Saturday, May 20th at The Ridge Golf Club in Salt Lake City, Utah. The event has continued to grow, drawing 129 golfers this year, and raising nearly \$10,000 for NF research. Prizes were awarded to first and second place teams, and the overall last place team also walked away with prizes, including some brightly colored golf balls. NF Hero Travis was active throughout the event, tracking down each golfer on the course to provide a mystery envelope containing a gift card or other donated items from area businesses. Everyone involved walked away a winner and had a great day!





## CALIFORNIA

### Ryder's Rainbows

Special thank you to Karlie, Bryan, Tyson, Ryder, and Sydney Savage for being a part of the Health Wellness and Beauty Social in Huntington Beach, California. The event was a fun time for all! Ryder, Tyson, and Sydney decided to paint some paintings to sell for donations. Special thanks to Anitra Ackerman for inviting CTF to be a part of the event.



## UTAH

### Utah Women's Day

The Women's Day annual gathering in Utah was held on Saturday, June 3rd at the home of Andrea Davis. Several NF moms attended this gathering for the first time and everyone appreciated the community of support within Utah. Many topics were discussed and shared as the commonality of NF concerns arose. The news of current NF research progress inspired hope to all in attendance.

## ILLINOIS

### Stand Up To NF

Nearly 100 people came out on May 15th for a night of comedy, and laughed it up for a very good cause. FanBags Cornhole sponsored the hilarious Chicago event and raffled off a CTF cornhole set.



## WYOMING

### Paint with a Purpose

Casper, Wyoming's Paint With a Purpose fundraiser was a huge success! Twenty-two participants showed up to paint their masterpieces, and bid on amazing silent auction items. The creative event raised more than \$900 toward the Casper NF Walk, and all those in attendance had a wonderful time.



## The NF Parent Guidebook:

*How to Help Children With Learning Challenges Associated With Neurofibromatosis Type 1*

**A**s children and teens head back to school this fall, we are proud to release our newest educational resource, The NF Parent Guidebook. This home-based, 160-page guidebook is designed to provide support and education to families, and help guide you through your journey with NF and associated learning, behavioral, or social deficits. The NF Parent Guidebook is a place to find ideas, strategies, and suggestions that will help you understand and meet the needs of your family and child.

Each of the Guidebook's 13 sections covers an important topic related to NF and learning challenges. Topics include:

- The Impact of Neurofibromatosis on the Family
- Talking With Your Pediatrician
- Executive Function Difficulties in People with Neurofibromatosis
- Strengthening Family Relationships
- Social Skills Deficits
- Bridging the Gap between Home and School
- Educational Rights for Your Child

- Resilience, Transition to Adulthood, and Future Success

We would also like to introduce you to our new CTF mascots, Moxie and Sparx, who are helping CTF connect with families to end NF. Each section of the NF Parent Guidebook ends with an activity for children featuring Moxie and Sparx. Parents can share these activities with their child, such as a coloring page for younger children, or conversation starters for older children and teens.

The NF Parent Guidebook is the product of a multi-year CTF research grant given to Maria Acosta, MD, of the Children's National Health System. Other contributors to the Guidebook include Beth Kaplanek, RN, BSN, and Karin Walsh, PsyD.

The NF Parent Guidebook is available for download at no charge at [ctf.org](http://ctf.org).



Meet Sparx and Moxie, CTF's new EndNF Mascots!

NF

## Q&A

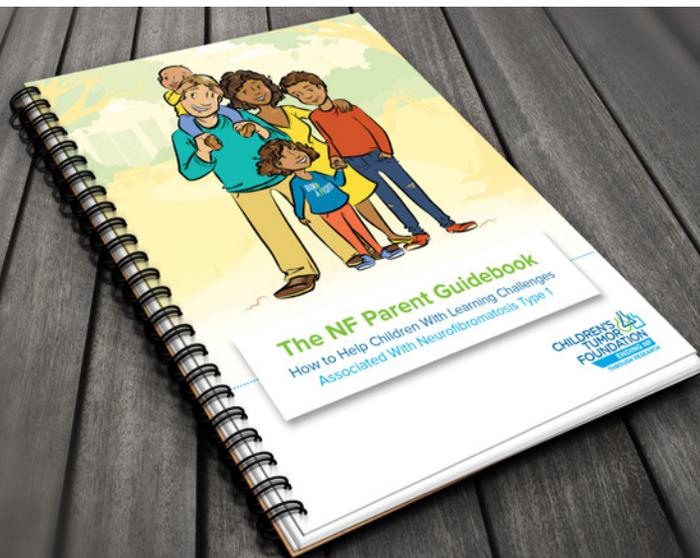
Have a question about NF? We're here to help!

**Q:** How can I get prepared to help my child with NF succeed in school?

**A:** When it comes to helping your child succeed in school, I recommend getting a neuropsychological evaluation by a trained neuropsychologist. The school may also perform an evaluation of your child's needs, but a neuropsychologist will assess a broader range of areas, giving you (and your child's school) a more complete picture of how to capitalize on their strengths and support any weaknesses.

If you would like more information on what a neuropsychological evaluation involves, and other things you can do, contact Kate Kelts at [kkelts@ctf.org](mailto:kkelts@ctf.org).

*Kate Kelts, the Children's Tumor Foundation's Patient Support Coordinator, is a registered nurse with 11 years working with the NF community.*



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



**JOANNE PASTEL**  
Minneapolis, MN  
Daughter Jacqueline lives with NF1

“I joined the registry because...

**I want to  
End NF.”**

[www.nfregistry.org](http://www.nfregistry.org)

## save the date **2018 NF FORUM**



### **CHILDREN'S TUMOR FOUNDATION**

**NF Patient-Centered Outcomes Research (NF-PCOR) Forum**

**MAY 4-6, 2018, ATLANTA, GEORGIA**

- Patient training and education
- Patient participation in research
- Shared knowledge through partnership

TO LEARN MORE CONTACT **Traceann Rose**, [trrose@ctf.org](mailto:trrose@ctf.org)

## New Faces at the Children's Tumor Foundation



**Katie Bloom**  
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**Channell Hogan**  
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*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 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 funding and driving innovative research that will result in 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, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and cancer. NF affects 1 in every 3,000 births across all populations equally. There is no cure yet – but the Children's Tumor Foundation mission of driving research, expanding knowledge, and advancing care for the NF community fosters our vision of one day ending NF. For more information, please visit [www.ctf.org](http://www.ctf.org).

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If you'd like to save the Foundation the cost of printing and mailing this newsletter to you, please visit [ctf.org/newsletter-unsubscribe](http://ctf.org/newsletter-unsubscribe) and let us know. We'll email you the newsletter going forward.



Join the NF Registry [nfregistry.org](http://nfregistry.org)

Donate [ctf.org/donate](http://ctf.org/donate)

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