

Galas TO END NF:



2017 CTF
Ambassador
Sarah Rodbell with
2016 Ambassador
Corinne Moffett

Evenings to Remember in New York, Detroit, and across the Country!

New York business leaders, friends, and families gathered to "Imagine a World without NF" at the annual Children's Tumor Foundation (CTF) New York Gala. The event took place at Current at New York City's Pier 59 on October 19, 2016. To illuminate the evening's theme, a giant planet Earth hung from the ceiling with the room lit in blue, giving guests an "outer space" feeling. Adorning the tables were paper lanterns decorated to look like planets, carefully created by NF Heroes from across the country.

Sarah Rodbell was named the 2017 Children's Tumor Foundation Ambassador, an honor passed down to her from last year's ambassador, Corinne Moffett. The night's research auction filled the room with excitement thanks to a lively auctioneer, actor Jonathon Sadowski of Freeform TV's *Young and Hungry*, and brought the event's entire proceeds to over \$1 million.

Continued on page 6

Believe

WE CAN END NF

This holiday season, we believe that together we can find an end to NF! Whether it's making a donation, joining the NF registry, or spreading awareness about NF, your every action inspires hope!

For more information
please visit ctf.org/believe



*"Miracle! You all are our
miracle workers."*

— RENIE MOSS

Read more about the
Moss Family on page 8

New Strategies for a New Year

The Children's Tumor Foundation (CTF) is committed to revisiting its research strategies on an ongoing basis. In order to evaluate the Foundation's goals and priorities, a strategic planning retreat was held at the Airlie Conference Center in Virginia on September 19-21, 2016. With CTF's mission to "drive research, expand knowledge, and advance care for the NF community" firmly in mind, a number of important assessments were made.

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


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LETTER FROM THE PRESIDENT



Annette Bakker, PhD

2016 has been a defining year for the Children's Tumor Foundation (CTF). We believe now more than ever that we must work with, and not just for, the NF (neurofibromatosis) patients who make this community as strong as it is. With patients in mind, the Foundation continues to contribute to the advances being made in NF research. At the 2016 NF Conference, we were proud to showcase some of the advances being made in diagnosing NF with state-of-the-art tools now available to clinicians, leading to improved care for the NF patient.

These advances could not be made without your unwavering fundraising efforts. In the last few months of the year, our annual benefit galas highlight these advances and their importance during celebratory evenings that we will never forget—especially emphasizing the patients who make it all possible, and the exceptional people fighting beside them.

First, I must thank Dan and Jennifer Gilbert, who ceaselessly provide this Foundation with the utmost support and a partnership that continues to amaze me. This year is the Gilbert's fourth annual Detroit "beNeFit," an event that grows each year. I am continuously grateful for their energy, commitment, and dedication to the Foundation.

We are also very thankful for Billy Lerner and Brigitte Widemann, MD, who were honored with the Children's Humanitarian Awards at the New York Gala this year. Mr. Lerner is an exceptional example of a donor who not only gives back to his community, but gives back with a genuine spirit and kindness that directly affects the lives of those around him.

Dr. Widemann's understanding of NF patients and their needs has moved us in so many ways. From her trailblazing efforts to bring clinical trials to patients, to her unwavering commitment to partnering with the Foundation to collaboratively end NF, Dr. Widemann is revolutionizing this field.

I also thank our 2017 NF Ambassador, Sarah Rodbell, and our outgoing Ambassador, Corinne Moffett. These young women are a testament to all of those with NF living their lives so beautifully and so bravely every day. I could not have been more proud to stand next to them at the New York Gala this year.

Lastly, to those who attend CTF events each year, and also to those who help make them a success through fundraising, volunteering, and planning, I thank you. To those who donate or advocate on behalf of CTF, I thank you. To our patients and those who support you each and every day—we thank you, and will continue to stand with you in 2017 and beyond.

Gratefully,

Annette Bakker, PhD

New Strategies for a New Year *Continued from cover*

Strategic plans for the Foundation's research goals were previously formulated in 2006 and again in 2011. These plans have been instrumental in guiding CTF research initiatives over the past decade. The NF research landscape has evolved significantly since the last plan was formulated, with numerous technological advances made. Additional groups, in particular, the pharmaceutical industry, are now interested in funding NF research.

Given these changes, and the need to periodically re-evaluate the CTF research portfolio, the strategic planning retreat was instrumental in evaluating CTF's research goals. In attendance were key opinion leaders from the NF research and clinical communities, as well as representatives from the government, the pharmaceutical industry, venture capital, and other NF organizations. Members of CTF's Board of Directors contributed along with staff and patient representatives.

The report generated by the participants made the following assessments:

CTF Is Uniquely Suited To:

1. Catalyze and support collaborative, cutting-edge research initiatives.
2. Develop transformative therapies in partnership with government entities, research funders, and industry.
3. Integrate communities with an interest in NF, including patients, clinicians, researchers, and funders.
4. Attract and retain outstanding investigators to focus on NF.

Neurofibromatosis Research Needs:

1. Identification of New Therapeutic Targets.

A better understanding of the cause of the loss of function of the NF genes and the resulting symptoms of NF will identify additional therapeutic targets.

2. Development of Innovative Therapeutic Approaches.

There is a need for increased capacity for robust preclinical studies of individual drugs and combinations of therapeutic agents. Innovative approaches will be needed to expand the capacity of both preclinical testing and clinical trials.

3. Development of Approaches to Early Diagnosis and Prediction of Specific Manifestations.

Best practices for patient care need to be established to enable appropriate and efficient diagnostic testing and initiation of treatment. The validation of biomarkers, studies of patient outcomes, and analysis of tissue specimens are essential for advancing individualized patient care.

CTF Research Opportunity

CTF will continuously monitor the NF research landscape and be responsive to change and pressing needs, seeking funding partners where appropriate.

Funding priorities are:

- The global NF Conference and NF-related workshops as flagship events for



the exchange of ideas and consensus-building.

- Promising early-stage investigators.
- Synodos model of team science.
- Preclinical Consortium and pursuit of opportunities for collaboration with pharmaceutical companies to provide a pipeline for clinical trials.
- Enable and enrich clinical trials.
- Engage partners to:
 - support tissue collection and biobanking initiatives.
 - develop biomarkers for manifestations of NF.
- Develop innovative approaches to grow the NF Registry, and promote patient engagement.
- Implement and fund a two-tier system to support NF centers of excellence and grow the number of NF clinics nationwide that support the CTF mission.

This preliminary assessment is currently under review by the Foundation's Board of Directors and Medical Advisory Committee. The official 2017 – 2022 Strategic Plan will be finalized and presented in early 2017.

NF Conference Highlights

Many advances are being made to further understand neurofibromatosis, leading the way to better diagnostic criteria, earlier diagnoses, and improved clinical care. At CTF's NF Conference in June, the following presentations demonstrated how state-of-the-art tools are advancing our knowledge and ability to care for the NF patient.

A Better Technique to Analyze Optic Nerve, Chiasm, and Tract to Predict Vision Loss in OPG Development

This 38-patient study presented by Robert Avery, DO, of the Children's Hospital of Philadelphia, examined whether the size of an optic pathway glioma (OPG) influences vision in children with NF1-related OPG's, in addition to the location of the tumor. Recent advancements in magnetic resonance imaging techniques (MRI) allowed it to be used as a tool to measure the entire anterior visual pathway (AVP), and beyond. The team hypothesized that children with a larger AVP are more likely to have thickened retinal nerve fibers, which is a measure of axonal loss (axons are signal transmitters). This establishes AVP measurement as a biomarker of visual impairment. The study results affirmed that MRI analysis may become a critical tool to accurately determine vision loss from NF1-OPGs.

A New Technique Called MRF (Magnetic Resonance Fingerprint) That Can Distinguish Between Real Tumors and White Matter

In this study, led by Peter de Blank, MD, of Rainbow and Babies' Children's Hospital, traditional diagnostic methods for childhood brain tumors using MRI were compared to that of Magnetic Resonance Fingerprint (MRF), a new technique. The study demonstrated that the data received from MRF is far more accurate than the data generated through a traditional MRI. MRF proved to more directly measure tissue properties that can improve diagnosis or therapeutic assessment. This approach may be an important diagnostic tool in differentiating real tumors from images that mimic tumors, thereby avoiding a treatment regimen which might cause complications.

Novel Methods for Genotype-Phenotype Correlation in Schwannomatosis

Justin Jordan, MD, of Massachusetts General Hospital presented a study on pain in schwannomatosis patients, where the authors tried to establish a correlation between pain and mutated genes. This study used a novel gene capturing technique with next-generation sequencing (NGS) and whole body MRI to search for genotype-phenotype correlation in 37 patients with schwannomatosis. An *LZTR1* mutation was identified in 8 patients, while 17 presented a *SMARCB1* mutation. The *LZTR1* group had fewer and smaller tumors, compared to the *SMARCB1* group which showed more and larger tumors. Pain, however, measured significantly higher in the *LZTR1*-mutation patients with the smaller tumors, compared to the *SMARCB1* cohort. From this study, it appears that pain and tumor size do not correlate.

Update on Next Generation Sequencing (NGS) for Diagnosing NF1 and NF2

Early diagnosis and clinical care of the neurofibromatoses is extremely difficult due to the diversity and variability of symptoms. NF can easily be misdiagnosed as other similar diseases, like Legius or Noonan syndrome. Even molecular genetic analysis performed on NF patients can sometimes return false results. However, a presentation by Beatrice Parfait, PhD, of Hopitaux Universitaires Paris Central, demonstrated how a new technology called next generation sequencing is being used. This technology has shown to be more accurate and is able to distinguish between overlapping syndromes. It will provide more accurate diagnosis for all NF and non-NF patients, allowing for confirmation of clinical diagnosis and more precise and effective clinical management for patients.

Malignant Peripheral Nerve Sheath Tumor (MPNST) Consensus Meeting

CTF is proud to have co-sponsored the 2016 NF1-associated MPNST Consensus Meeting along with the Center for Cancer Research and the Division of Cancer Epidemiology and Genetics of the National Cancer Institute (NCI). Held October 6-7, 2016 at the National Institutes of Health (NIH) in Bethesda, Maryland, this meeting was the first consensus meeting on malignant peripheral nerve sheath tumors (MPNST) since 2002.

The organizing committee (Drs. Karlyne Reilly, Brigitte Widemann, Aerang Kim, Doug Stewart, and Dave Viskochil) gathered an impressive multidisciplinary group of more than 60 international clinicians and researchers with expert knowledge in MPNST. Before the workshop, the committee submitted a publication summarizing the current MPNST landscape. The Children's Tumor Foundation's Clinical Care Advisory Board chair Dave Viskochil opened the workshop with a presentation reviewing the current body of knowledge about these tumors.

The goal of the meeting was three-fold:

- 1) to discuss the current challenges in MPNST clinical diagnosis, treatment, and management, and preclinical models for translational research
- 2) to develop guidelines and consensus for clinical and pathological diagnosis, imaging, and medical treatment
- 3) to brainstorm about a strategy to accelerate MPNST research and clinics for the next 5-10 years

The participants shared both published and unpublished data. They were then divided up into smaller working groups to discuss the challenges and obstacles in the field that need to be overcome, and to identify the most pressing research questions for MPNST.

In order to analyze the volumes of MPNST data available, CTF President and Chief Scientific Officer Annette Bakker was eager to explore an approach modeled after a "hackathon," an event in which a group of people gather to engage in collaborative computer programming. Big data expert Shasha Jumbe, PhD, Senior Program Officer, Quantitative Sciences,

from the Bill and Melinda Gates Foundation, served as a keynote speaker. Dr. Jumbe was willing to help explore a hackathon approach as a potential method of solving MPNST questions.

Collaborative research as well as a data-driven approach was promoted to facilitate knowledge exchange and resource transfer.

David Miller, MD, PhD, of Boston Children's Hospital announced that he is able to launch a new MPNST-focused program thanks to an anonymous donor. We were honored to learn that he would like to model his new collaborative effort on the CTF Synodos and the CTF-NTAP (Neurofibromatosis Therapeutic Acceleration Program) collaborations—an amazing validation of our team science approach.

The summary of this consensus meeting will be presented at the upcoming CTF-sponsored NF Conference in 2017, and the proposed guidelines and research priorities will be published and disseminated in the broader scientific community.



Galas TO END NF: Continued from cover

This year Brigitte C. Widemann, MD, of the National Cancer Institute at the National Institutes of Health (NIH) was given the Children's Humanitarian Medical Award. Dr. Widemann's commitment to supporting NF patients and their families is exemplified in the MEK inhibitor selumetinib clinical trial, of which she is principal investigator, and, in which many patients have had a decrease in the volume of their tumors.

The Children's Humanitarian Award was given to entrepreneur and philanthropist Bill Lerner of iPark and Billy4Kids. In addition to his own philanthropic organization, Bill Lerner is a remarkable supporter of the Children's Tumor Foundation.



From left: Dan Altman, Bill Lerner, Stuart Match Suna, and Randall Stanicky at the New York Gala



Brigitte C. Widemann at the NY Gala

The Gilberts presented artist Jeffrey Owen Hanson with the Children's Tumor Foundation Strength and Honor Award. Jeff is a 22-year-old philanthropic artist who has painted and donated more than \$2 million in acrylic canvases to more than 150 charitable causes since 2006.

The hugely successful Detroit beNeFit is a highlight of the year. At the time of publication, the event's proceeds had not yet been finalized. To read more about the Detroit beNeFit, visit ctf.org/news.



Dan and Jennifer Gilbert, hosts of the Detroit beNeFit IV



CTF Strength and Honor Awardee Jeff Hanson

In Arkansas, **Dancing With Our Stars** was held at the Little Rock Marriott on September 8, 2016, and it was a big hit! Local stars spent months rehearsing to perform at the event and competed to win the coveted championship trophy. This year's winner was philanthropist and volunteer Susan Hickingbotham, and the best performance trophy went to Win Rockefeller. The whole night was a win for the fight against NF, with \$227,000 raised for NF research.

Serving as Master of Ceremonies, Paula Faris, of ABC News and *The View*, brought warmth and humor to a night that was out of this world!

The fourth annual **Detroit beNeFit** was "An Aquatic Affair to End NF," held at the Cobo Center in downtown Detroit, Michigan on November 19th. Sporting an aquatic theme, the evening was hosted by cherished CTF patrons Jennifer and Dan Gilbert. The evening's entertainment included silent and live auctions, with an underwater afterglow party.

Over 200 guests came together in Cambridge, Massachusetts to try their luck at the **New England Gala's "Vegas Night."** Bets were placed and prizes were won, as guests took part in blackjack, poker, roulette, and craps, a live and silent auction, and a raffle. The evening brought in more than \$75,000, thanks to a wonderful committee, some of whom have been involved with this event for over 30 years!



Paula Faris, of ABC's *The View*, served as the New York Gala's Master of Ceremonies, and actor Jonathan Sadowski of Freeform TV's *Young and Hungry* was a lively auctioneer



Rob Brainin and Nicola Kean at the New England Vegas Night Gala

New Executive Officers of the Children's Tumor Foundation Board of Directors

The Children's Tumor Foundation is pleased to announce newly elected executive officers of the Board of Directors. These exemplary individuals will help guide the Foundation toward our goals for 2017 and beyond.

Richard Horvitz will serve as the new Chair of the Board of Directors. Mr. Horvitz is currently the Chairman of Moreland Management Company, a closely-held private family investment office based in Ohio. He has been involved with the Foundation since 1996, and previously served as Chair from 2002-2006.

Tracy Galloway will fulfill the role of Vice Chair. Mrs. Galloway has been a member of the Board since 2011. She is an avid supporter of the Synodos model, and has specifically backed the Synodos for NF2 initiative since its inception in 2014.

Gabriel Groisman will serve as the new Secretary of the Board. Mr. Groisman is a Shareholder at the Miami-based law firm, Coffey Burlington, P.L., where he specializes in trademark law and complex commercial litigation. He became a member of the Board in June 2016.

Randall Stanicky will continue his role as Treasurer for a second term. Mr. Stanicky currently serves as Managing Director of Global Equity Research at RBC Capital Markets, focusing on the specialty pharmaceuticals sector. He has served on the Board since 2015, and brings both his financial background and knowledge of the healthcare sector to the Foundation.

To read more, please visit ctf.org/news.

Cocktails for a Cure was held on October 22, 2016 at the Brookville Country Club in Long Island, New York. It was a beautiful evening with passed hor d'oeuvres and flowing champagne. The event was hosted by Laura Perfetti, Cristina Spoto, Jill Hannity, and Lisa Arena. More than \$80,000 was raised to support the mission of the Foundation thanks to a silent auction, raffle, diamond dig, and a live auction for two pumpkins decorated by our very own NF Heroes, Julia Perfetti and Charlotte Spoto.

The Children's Tumor Foundation humbly extends our thanks to the attendees, donors, honorees, and organizers who support our Foundation with such remarkable fervor. Whether in space, under water, in a casino, or on the dance floor, these exciting events bring the NF Community closer to our vision to advance research that will end NF.



Julia Perfetti and Charlotte Spoto pose with their pumpkins next to Stuart Acker at Cocktails for a Cure



CTF Board of Directors officers Tracy Galloway, Vice Chair, and Richard Horvitz, Chair



Foundation President Annette Bakker with new BOD Secretary, Gabriel Groisman



Local Arkansas celebs, including big winners Susan Hickingbotham and Win Rockefeller, pose with Dancing with Our Stars organizer, Lesley Oslica

STORIES OF NF: *Leticia Leano*

When I was 27 years old, I became a single mother, and I fell in love with my baby the moment I saw him.

Two weeks after I gave birth to my son, I developed a limp and was having difficulty walking. I decided to see my doctor and, after a quick exam, she sent me to the emergency room. A few hours later, as my mom was bringing my baby boy to see me, the doctor said that I would be admitted to the hospital for further tests and evaluation. I held my son and cried. At that point, they had no idea what was wrong but wanted to rule out multiple sclerosis (MS) among other things.

Within a couple of days, I could no longer walk. I was missing my baby and just wanted to be with him. Finally I had a full body MRI and that's when I first heard the term neurofibromatosis (NF). I had a large tumor in my spine that was causing the paralysis. The doctors said that they would remove it but they were not sure that it would reverse the situation. Well, I was blessed and the surgery was not only a success, but with a little physical therapy I walked again and eventually ran!

When I crossed the finish line of my first marathon I cried!

I continue to run but my fight with NF is not over. I have several tumors in my spine that need to be monitored with MRIs, I suffer from

frequent headaches and pain, and running has become a little more difficult. But I will not give up. I will continue to run, not only for me but to show my two boys who also have NF that we need to keep fighting.

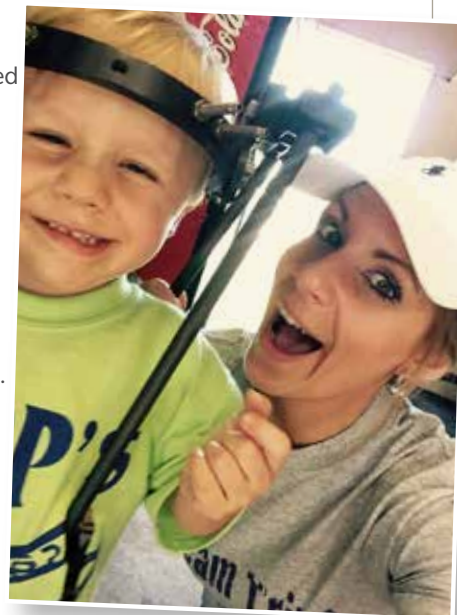
I have been a stay-at-home mom for more than 20 years and raised four amazing sons. I will soon be sending my youngest child to college and my husband and I will be empty nesters. I don't know what my future holds or what my boys will have to face, but we will not give up. We will continue to do all that we can to increase NF awareness, raise funds for neurofibromatosis research, and help find a cure!

— Leticia Leano, an NF Hero



STORIES OF NF: *Tripp Moreau*

Tripp is a lively three-year-old boy who was diagnosed with NF1 at eight months old. We first noticed small brown spots on his legs, but we ignored them thinking they were just birthmarks. Then more and more began appearing all over his skin. We brought him to our pediatrician who counted and measured many of the spots, which we learned were called café au lait marks. We were referred to Children's Hospital of New Orleans to see a neurologist and a geneticist.



After seeing these specialists, Tripp was diagnosed with neurofibromatosis type 1. We did not know what NF was. The doctors explained it to us and said that from now on Tripp would have to be closely monitored by a team of doctors.

After a CT scan, the doctor noticed that the tip of Tripp's cervical spine was kyphotic (a forward rounding of the back) and suggested further x-rays. Upon seeing those images, we were immediately referred to a spinal surgeon because Tripp had a 48 degree curve in his cervical spine due to NF. This all happened very quickly and was quite a shock!

By age two, the curve in Tripp's cervical spine was almost 100 degrees, so in March of this year he was placed in an 11-pound halo traction device for 15 days. A team of doctors placed a strut graft in his cervical spine. After the ten hour surgery, Tripp was placed in an upper body cast with halo attached until the site was stable. Upon discharge from the hospital, the curve in Tripp's spine was around 60 degrees.

Tripp has been such a little trooper throughout this entire ordeal! We were so afraid that he would lose his vibrant personality but it has been just the opposite! He is a fun, loving, always on-the-go, happy, little boy. He's always smiling, he loves being outside, and he absolutely adores the television show Peppa Pig. Tripp has taught us the meaning of the word strength and he will always be our hero!

— Laura Winn, Tripp's mother

Believe

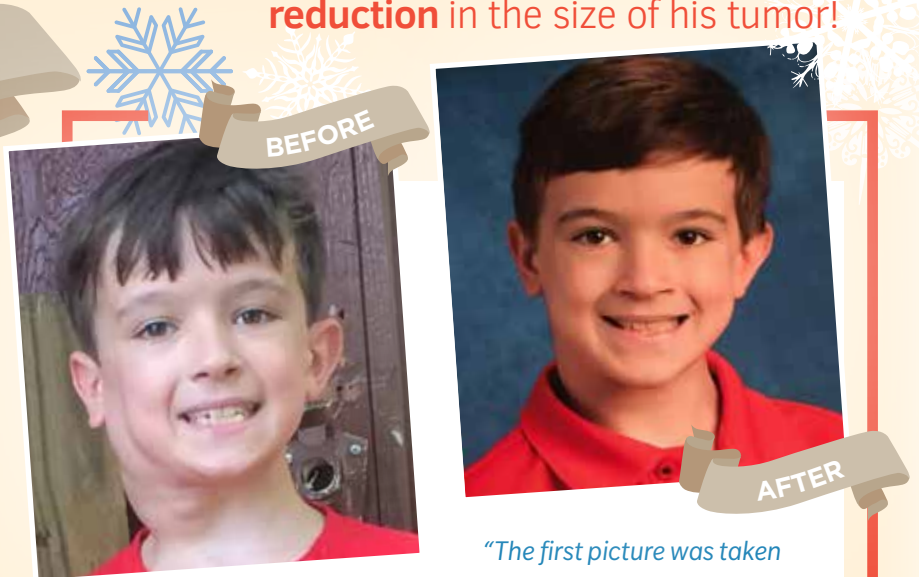
WE CAN END NF

Clinical trial results show a **36% reduction** in the size of his tumor!

Here at the Children's Tumor Foundation, we champion a team approach to ending neurofibromatosis. And you are a vital part of our team. Together we are transforming lives and building brighter futures for millions of people like Philip Moss and his family. Read about the Moss family below, and join us in celebrating the tremendous success they have seen since Philip's enrollment in a clinical trial of the MEK inhibitor selumetinib (AZD6244 hydrogen sulfate) at the National Institutes of Health.

This highly successful clinical trial is the result of a major investment of the Children's Tumor Foundation NF Preclinical Consortium, in which it was demonstrated that MEK inhibitors (MEKi) have a massive result on tumor volume. The 2017 CTF Children's Humanitarian Medical Awardee Brigette C. Widemann, MD is the principal investigator of this promising clinical trial. Significant decreases in the volume of plexiform neurofibroma (PN) tumor growth have been found in 50% of the study participants. In Philip, it has resulted in an astounding 36% reduction in the size of his tumor—see the photos to the right!

This significant clinical progress in the development of effective treatment for NF1 is incredibly exciting. We believe that more and more clinical trials such as these are on the horizon, and will lead us to a future in which there is an end to NF.



"The first picture was taken in June of 2015, two months after Philip was discontinued from [the drug] Gleevec after eight months of tumor growth. We were sent home with no other option. When I asked his oncologist about other chemotherapies, she shook her head, took my hand and said, 'We are not going to treat your son like a pin cushion.' We walked out of her office with no hope, facing an uncertain future. The second picture is from September 2016, after a year on selumetinib (AZD6244).

MIRACLE! *You all are our miracle workers.*" — **Renie Moss, mom to Philip, who lives with NF**

THE MOSS FAMILY

The Moss family has been busy living life to the fullest at their home in Birmingham, Alabama. Renie Moss is an active CTF volunteer, and recently organized the third Birmingham NF Walk. Her husband "Big Philip" is finishing work on his doctoral dissertation to complete his EdD in Higher Education Administration. Their son "Little Philip" enjoys varsity level chess and is finishing his cub scout journey as a Webelos II this year. His sister Helen is head over heels in love with playing soccer, and enjoys anything high energy, artistic, and creative.

"Little Philip continues to be enrolled in the AZD6244 MEK trial through the National Institutes of Health. This drug has been the answer to many prayers for us. At the one year mark since enrolling, Philip's tumor is now 36% smaller. We rarely hear children ask Philip what is wrong with his neck anymore. The drug does make Philip fatigued and that can be difficult for an eleven-year-old boy with peers that are active in sports and the outdoors. He takes this in stride and continues to amaze us with his resiliency. He keeps us motivated to fight for a cure." — **Renie Moss**

With your continued financial support,
this is only the beginning.

Donate today to the
"Believe We Can End NF"
campaign.

ctf.org/believe



IRONMAN Mont-Tremblant

Gary Rodbell trained for the 2016 IRONMAN Mont-Tremblant on behalf of his niece Sarah Rodbell, who is the 2017 Children's Tumor Foundation NF Ambassador. Sarah is a junior in high school and has been fundraising for CTF since she was 11 years old. Together, Sarah and Gary raised more than \$18,000 for CTF. Just prior to the race, Gary sensed some pain in his chest and decided to visit the doctor instead of racing; he had immediate surgery and received two stents in his heart. Gary

is now on the mend, and he and Sarah plan to team up again together in 2018 for the IRONMAN Hawaii 70.3!



IRONMAN Kona

On October 8th, four Children's Tumor Foundation athletes participated in the IRONMAN World Championships in Kona—the Superbowl of IRONMAN races! Congratulations to John Joseph, Steve Mount, Conor Bell, and Mitch Zelman for competing in this once-in-a-lifetime experience. Together, these four athletes, none of whom have a direct connection to NF, raised over \$180,000 for the Children's Tumor Foundation.

IRONMAN Kona 2017

Is racing in the IRONMAN World Championships on your bucket list? If you or someone you know is interested, please email us at nfendurance@ctf.org.



"Thank you for the privilege of fundraising for CTF! It was such an amazing experience, one I will cherish and never forget." —Keena Hutchinson, CTF staff member and athlete

TD Five Boro Bike Tour athlete spotlight

Keena Hutchinson has been a CTF staff member since April 2015, working with the Gifts Processing Team to receive and enter donations raised by our committed supporters. But in her role, Keena doesn't often interact with those volunteers and fundraisers, nor have an opportunity to participate in a CTF event—until one day when a friend told her about the TD Five Boro Bike Tour. Keena joined the 24-member team and helped to raise over \$15,000! To join Keena and the NF Endurance Team for the 2017 TD Five Boro Bike Tour, go to join.ctf.org/NFEtdbike2017.



Congratulations Cathie

Congratulations to our NFE alumni Cathie Leys on completing the Camino de Santiago. Her two-month backpacking journey took her over 500 miles of trails in Spain. Not only was this a spiritual journey, but an opportunity for her to raise awareness of NF. She continuously supports the Foundation in honor of her granddaughter, Kylie, who is affected by NF1.

UPCOMING EVENTS:

- December 4th:** California International Marathon and Relay
 - December 11th:** Honolulu Marathon
 - February 26th:** Little Heroes 5K of North Georgia
 - March 5th:** Little Rock Marathon and Little Rockers Kids Marathon
 - March 19th:** NYC Half Marathon – NFE Alumni Event
 - April 24th:** Virgin London Marathon
 - April 30th:** Big Sur Marathon
 - May 7th:** TD Five Boro Bike Tour
- Sign up today at nfendurance.org.

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.

NEW JERSEY

October 3rd was the perfect day for a golf outing and the Colin's Courageous Team was one of many at the Caddies for Colin event. More than 100 golfers came together at White Beeches Golf & Country Club in Haworth, New Jersey. After a long day of golf, the players took part in a cocktail reception which included a raffle, and silent and live auctions. Colin's Courageous Team raised more than \$80,000. Thank you to Mike and Heidi Cashell, and your right hands, Ken and Bethany Walsh. Together, with passion like this, we will End NF.



PENNSYLVANIA

This past September 11th, members of the Pennsylvania NF community came together at St. Martin-in-the-Fields in Philadelphia to enjoy some magnificent music and celebrate the advances being made in science. Musician Eugene Friesen and his friends gave an inspirational, emotional, and uplifting performance. What a gift! More than \$2,500 was raised to further the mission of the Foundation.



NEW YORK

The first NF Hike took place this October at the Cranberry Lake Preserve. It was a beautiful day, and the hikers were able to take in some of the most beautiful views in Westchester, New York. The NF Hike was a perfect way for all the participants to get to know their NF community and get a little fresh air too!



CALIFORNIA

The Annual Elks Mega Golf Tournament in honor of our NF Hero Dakota Anderson was held on September 17th, in Atwater, California. Special thanks go to Dakota and all her friends for their amazing work on this event.

REGIONAL NEWS



RHODE ISLAND

On September 10th, the 2nd Annual Pretty Fun Day for NF was held at Brewer Cowesett Marina in Warwick, Rhode Island, to support NF Heroes in and across the community. The more-than-fun day included famous Rhode Island clam cakes, chowder, live entertainment, boat cruises, and was capped off by a competitive game of NF-themed Jeopardy. More than \$4,300 was raised to support NF research.



MISSOURI

Under sunny skies, more than 100 golfers teed off in Eureka, Missouri in memory of Nicole Riley, who passed away due to complications from NF. After 18 holes of golf, guests enjoyed dinner and an awards ceremony.



NATIONWIDE

On September 10th, 35 Sweet Tea for Sophie stands were hosted in 7 different states and throughout 21 zip codes, but the mission for each was the same: to share a glass of sweet tea and talk about why we need a cure for NF. This awareness effort raised more than \$5,000 for CTF, and had people across the nation talking about neurofibromatosis with their neighbors. Sweet Tea for Sophie has been submitted for the World Record for Most Simultaneous Sweet Tea Stands for a Cause!



INDIANA

Once again, Stephanie and Matt Reeve opened their Fishers, Indiana, home for a CTF fundraiser. With all of the expenses covered by donation, including dinner for 90 people, guests enjoyed a photo booth, music, donuts for dessert, and lots of laughter. \$12,000 was raised for NF research.



MASSACHUSETTS

NF Hero Celia LaBarbera and friends took to their neighborhood in Western Massachusetts to raise awareness and money for CTF, raising more than \$400 for NF Research! Great teamwork!



"Our mission is to find a cure for NF in Isla's lifetime. With the love and help from everyone on Team Isla, and in thanks to ALL of the amazing teams across the country, we will do this. We will end NF."

— Matt Riley, Isla's dad and Team Isla Captain



Seattle NF Walk

On September 11th, more than 200 people came out to beautiful Owen Beach to show their support for local NF Heroes. The day was filled with food, music, Zumba, face-painting, balloon sculptures, cape-decorating, and special guests Elsa, Olaf, Wonder Woman, and Superman. Each year, this Walk continues to gain momentum in the Pacific Northwest, this year surpassing the event goal and raising \$89,000. The number of volunteers doubled this year, with a local softball team and some members of the military who came out to help!



Richmond NF Walk

We walked NF right out of Richmond! With more than \$30,000 raised, 300 supporters, and a car show, this event was one for the books! Thanks to Walk Organizer, Teresa Williams, everyone left feeling hopeful, passionate, and part of our NF community.



NYC NF Walk

Manhattan was full of life on the morning of September 24th. The New York City NF Walk brought together NF Heroes and their families from all five boroughs. Because New Yorkers are always on the go, the New York City Walk was a laid-back, picnic-style event, with pie-eating, raffles, and relay games.

DC NF Walk

Although it rained all day, it was all smiles at the Washington, DC NF Walk. Bringing together the region's biggest number of families yet, the Walk had over 170 participating NF supporters, many of whom also enjoyed relay races and face-painting. The DC NF Walk is building up the area's NF community one step at a time.



NF WALK

LA Glow Walk

The LA Glow Walk was held on October 22nd at CBS Studio Center in Studio City, California. This year's LA Walk was a glow-in-the-dark themed event with a Celebrity Karaoke After Party. More than 550 walkers attended and raised more than \$140,000 for NF research. A special thank you goes to our LA Walk Ambassador Jonathan Sadowski who did an outstanding job emceeding the event and the Celebrity Karaoke Live Auction. The Walk also featured a kid's carnival, face painting, pumpkin decorating, a raffle, and a whole lot more!



Addison Oaks NF Walk

More than 400 people came together in Michigan to walk and run for NF. The 5th annual event featured a kid's dash, 5K and 10K runs, and a Walk, making it a great day for everyone!

Orlando NF Walk

Sonny's BBQ joined the Orlando NF Walk this year to recognize an amazing volunteer, Farida Timal, with the Random Acts of BBQ award! This award recognizes people in the community who spark the spirit of BBQ and who give selflessly of their time and talent to others. Congratulations Farida, and thanks for all you do!



Central Jersey Walk

On Saturday September 17th, the Central Jersey Walk took place at Veterans Park in Hamilton Township. Superheroes in costume mingled with families and posed with them at the photo booth! Plenty of donated coffee and baked items by Panera Bread kept everyone's hunger at bay, and the cape-decorating table, face-painting, and "bouncy house" activities kept the kids occupied. More than a dozen registered 5K runners (along with a few superheroes!) took their start 15 minutes prior to the Walk, and the event concluded with raffle prizes, speeches, and a group photo. It was a fun-filled day for all!

Salt Lake City NF Walk

The 6th Annual Utah NF Walk was held on Saturday, August 27th, 2016 in Sugar House Park! The day was filled with sunny skies, great food, bright smiles, and some of the cutest NF Heroes around! The Utah NF Walk continues to grow every year, and this year was no exception. Thank you to all of our participants and community supporters!





MEET THE STAFF

Lauren Walsh,
NF Endurance Manager

HOMETOWN: Glenview, Illinois

CURRENT TOWN: Chicago, Illinois

EDUCATION: Marquette University
in Milwaukee, Wisconsin

WORK WITH THE FOUNDATION: For the last three and a half years I've been a Manager for the NF Endurance Team. I work with athletes for the London Marathon, Chicago Marathon, Chicago Triathlon, Big Sur Marathon, and California International Marathon.

FAVORITE EXPERIENCE WITH THE FOUNDATION: My favorite experience was the first time I attended the IRONMAN Florida in 2014. They cancelled the swim because it was freezing, and the athletes were running on nothing but fumes and grit. Halfway through the run, they each got a bag with a letter from his or her NF Hero. It gave them the little push that they needed to finish the final 13.1 miles strong and it made all the difference.

At midnight, after the last athlete had come by, we had a dance party on the finish line to celebrate!

FAVORITE HOBBY: Baking pies—I make a mean banana cream

FAVORITE MOTTO OR APHORISM: "The same boiling water that softens the potato hardens the egg. It's about what you're made of, not the circumstances."

FAVORITE BREAKFAST FOOD:
Cinnamon rolls

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

GO-TO KARAOKE SONG:
"I Wanna Dance with Somebody" by Whitney Houston

WEIRDEST THING YOU'VE EVER EATEN:
Chicken feet

NF News is the official publication of the Children's Tumor Foundation and is published quarterly. All issues are available on our website at www.ctf.org. Please direct any questions or feedback to info@ctf.org.

The Children's Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to finding effective treatments for the millions of people worldwide living with neurofibromatosis (NF), a term for three distinct disorders: NF1, NF2, and schwannomatosis. NF 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.

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Reid Horovitz, Chief Operating and Financial Officer

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AND YOU CAN HELP **END NF**



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NF1

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