

The Z in Detroit is among the landmarks that will light up for NF Awareness Month this May.



MAY IS

**NFAWARENESS
MONTH**

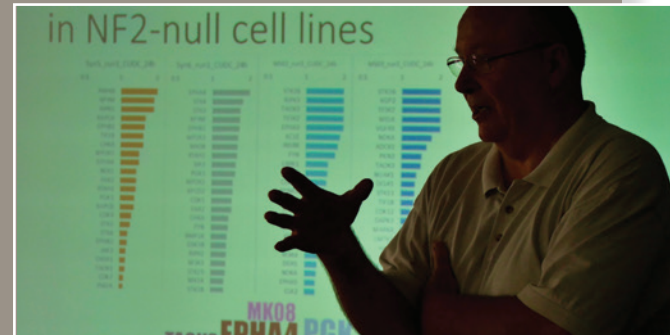
ctf.org

For one month every year, the Children's Tumor Foundation (CTF) doubles down on our efforts to raise awareness and expand knowledge around neurofibromatosis (NF). May is NF Awareness Month, a time for members of the NF community to harness their power, drive awareness, educate those around them, and raise money to support research that will lead to effective treatments for NF.

Last year, you let the world know that those living with NF are fighters. "I Know A Fighter" took on personal meaning to everyone who wore a T-shirt, took a photo, and shared on social media. This year, we're building on that momentum by adding "Born a Fighter," because we know that our NF Heroes fight courageously every day of their lives.

Continued on page 8

NF DATA RELEASES



The Children's Tumor Foundation is pleased to announce that new data from our research programs has now been released. Throughout 2016, further data will become available, including results from the Synodos for NF2 consortium, NF2 cell screens, and the characterization of dermal fibromas.

Working in partnership with Sage Bionetworks, free access to collected data is provided to the research community through an open data portal. This ensures that data and knowledge are quickly disseminated, and an online, public record of the research becomes accessible.

Continued on page 3

YOUR DONATION MATCHED

in honor of
Sherri Silesky

Throughout the month of May, for every dollar donated to CTF, a dollar will be donated to NF Clinic initiatives in honor and memory of Sherri Silesky, up to \$75,000.



A much beloved member of the CTF family, Sherri passed away on January 25, 2016, at her home in Mountlake Terrace, Washington. Sherri's life was a wonderful gift to both her family and many friends. She demonstrated tremendous strength and power of spirit, often sprinkled with her wonderful sense of humor. Our thanks go to the Silesky family for continuing Sherri's fight to end NF through this generous matching gift.

Please go to ctf.org/donate to double your donation.

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LETTER FROM THE PRESIDENT

Annette Bakker, PhD

May is a time when many of the Foundation's most exciting outreach initiatives, campaigns, and advocacy efforts shine through to make NF better known to the world. It's also a unique time that illustrates the determination that fuels the NF community—a determination to never give up in our fight against NF.



I changed my profile picture to celebrate NF Awareness Month. You can too!

The NF community is vibrant, comprised of so many different types of people who make vital contributions to this cause. Day in and day out, I am inspired by each and every one of you, and am proud to be a part of this powerful family.

We are inspired by our scientists, who are collaborating and breaking down research barriers as part of CTF's Synodos research model. As you'll read on the front page of this newsletter, we recently released data from several important NF research projects through an open data portal we've created with Sage Bionetworks. This open data model promises to advance the speed with which we get to effective treatments. We look forward to announcing further data releases at our NF science conference in June.

We are deeply grateful to our donors and fundraisers for their ongoing support. Our generous funding partners, such as our friends at Cupid's Charities and Flashes of Hope, teach us that the NF fight can be fun-loving, courageous, and generous of spirit. The Pirelli World Challenge Championship Series also recently named CTF as their official Children's Charity. We are so encouraged by this incredible support.

We are moved by the family of Sherri Silesky, who is honoring her long fight with NF by offering a funding match during NF Awareness Month. Like all of our NF Heroes, both past and present, her life is an inspiration, and inspires the work we do each and every day.

We are motivated by our athletes, walkers, and race car drivers who contribute both their physical and emotional strengths to the NF cause by rowing, biking, swimming, running, walking, and racing – you name it, they do it – all to fight NF.

We are absolutely enthralled by the NF volunteers who have banded together these past few months to get monuments, buildings, bridges, and more, to "Shine a Light on NF" this May. These landmarks will light up in NF awareness colors - blue and green – to spread awareness of NF to the world.

And we are most inspired by all the NF Heroes, who live each day with bravery and courage, perhaps uncertain where their NF story will take them next, but confident that there's a whole community – a family – behind them every step of the way.



Synodos for NF2 investigators discuss results.



NF DATA RELEASES

Continued from cover

The data will be available through “Synapse,” the Sage Bionetworks’ portal dedicated to researchers who collaborate. This exchange of once confidential information opens up many more opportunities for NF research, and for the medical research community beyond.

Synodos for NF2

The Synodos for NF2 team started its research project in May 2014, to be concluded in May 2017. In the spring of 2015, the project presented the first set of results, including screening of approximately 20 compounds in the many different cell systems of NF2 schwannoma and NF2 meningioma. This set has been used by the team to make important decisions on how to move forward with research. Now, this first dataset is ready to be released to the public, as the 12-month exclusivity window expires in the spring of 2016. Additional results were produced by the team in 2015, and those will be released in due course throughout 2016. The

team is now working on scientific papers to be published in high impact journals, which will examine and support the data release.

Preclinical drug screening for NF2

In December 2012, CTF funded a joint industrial–academic research partnership, with the aim of accelerating the translation of scientific understanding from the academic labs into a therapeutic pipeline. The research was carried out by Cenix BioScience and Cristina Fernandez-Valle, PhD, at the University of Central Florida. The main goal of the study was to identify therapeutic targets and drug candidates for NF2, using pre-clinical models. The study has been completed and CTF has just released the data. Researchers now have free access to the data through the open data portal at Sage Bionetworks.

Cutaneous neurofibroma data

In 2013, the Foundation launched the CTF Biobank and started biobanking cutaneous (dermal) neurofibromas in collaboration with Hubert Weinberg, PhD, of New York City. Once the Cancer Genome Atlas (TCGA)-advised minimum of 50 tumors was reached, the tumors and matched blood samples were sent to the Genomic Services Laboratory at HudsonAlpha for a full “omics” characterization. This includes whole genome sequencing, RNA sequencing, and proteomics profiling. The data has been delivered to Sage Bionetworks, and is currently undergoing a preliminary analysis before being uploaded to the Synapse platform. Initial access to this data will be restricted to an expert panel, with the aim of producing a white paper on potential biomarkers. Access to the dermal data will be publically available following the white paper publication.



The NF Forum is a national patient and family gathering that allows those living with NF and their families to connect, support, and learn from each other while attending seminars on relevant topics pertaining to neurofibromatosis. Plus, there will be fun activities, meals, social time with friends and family, and much more!



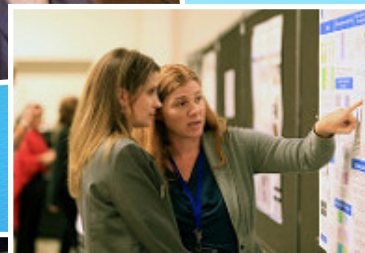
Tumor Tissue Needed

CTF has launched two new studies of brain tumors arising in people with NF1. If you or your child is scheduled to undergo surgery for a brain tumor (low-grade or high-grade glioma), and you are interested in donating leftover tumor tissue for these studies, please contact CTF's Basic Science Manager, Vidya Dhote at vdhote@ctf.org or 646-738-8586.

2016 NF CONFERENCE ctf.org/nfconference



The NF Conference is the premier annual event on the neurofibromatosis (NF) research and clinical calendar. This event attracts hundreds of the world's leading clinicians and researchers to present the latest developments in NF research and clinical care.



Know a Great NF Specialist?

The Children's Tumor Foundation is dedicated to connecting families to healthcare providers experienced with neurofibromatosis, and a group of volunteers, the NF Clinic Task Force, is spearheading this task! They are working to develop a comprehensive list of healthcare providers that are experienced with any aspect of NF care, including surgeons, orthopedists, eye doctors, etc.

The NF Clinic Task Force would like to hear about your experiences with specialists familiar with NF. To submit a recommendation of an NF specialist that you or your child has seen, please visit the survey link today at ctf.org/nfspecialists.

Register Today!

MEET A YOUNG INVESTIGATOR:

Vanessa Merker

Vanessa Merker, a predoctoral student at Massachusetts General Hospital, is a 2015 Young Investigator Award (YIA) recipient. For her YIA project, "Understanding Diagnostic Delay in Schwannomatosis: A Patient-Centered Approach," she will investigate the extent of, and causes for, the significant delays patients experience from first symptoms to a diagnosis of schwannomatosis.

Here, Vanessa tells us a little more about herself.

Can you tell us a little bit about where you are from?

I was born and raised in Colonia, New Jersey. After spending my college years in Providence, Rhode Island, I moved to Boston to start work at Massachusetts General Hospital. While I'm a Jersey girl at heart, I love living in the Boston area, and will hopefully be here for many years to come!

Where did you attend undergraduate and graduate school, and what were your focus areas?

I attended Brown University, where I got a BS in Cognitive Neuroscience. I'm currently in graduate school at the Boston University School of Public Health. I'm studying to get my PhD in Health Services Research.

What brought you into the NF field?

I came upon an ad for a research position in the NF Clinic at Massachusetts General Hospital, working with Dr. Scott Plotkin. I had never heard of neurofibromatosis before, but Scott hired me anyway. And now I am incredibly glad that he did! I love meeting patients and their families, and getting to collaborate with talented researchers from so many fields – genetics, neurology, surgery, radiology, otolaryngology, and more.

What made you select your YIA project subject matter?

My YIA idea came straight from listening to patients. While I was with Dr. Plotkin in clinic, I kept hearing patients with schwannomatosis tell us about the long journey they had to take to get to our clinic. Many had their first symptoms years, or even decades ago, but were only just now finding out they had schwannomatosis. I wanted to investigate the reasons why it is so hard to get a diag-



nosis, so we can find ways to make it easier and faster for future patients to get the care they need.

What is challenging about this research?

This research can be challenging because it involves so many levels of the healthcare system. To really understand why it takes so long to get a diagnosis of schwannomatosis, we have to look at everything patients and doctors do, how doctor's offices and hospitals are organized, and even how insurance companies cover MRIs and other tests. But that's also what makes this research important - it will identify the specific areas that we (the entire NF community) can target to improve NF care.

What do you hope to eventually achieve in your career?

After I receive my PhD, I hope to become an independent investigator, either at an academic medical center or a policy research institute. I want to focus my career on the issues that face patients with NF, such as how to give people access to specialty clinics, and how to coordinate care between many different specialists.

What do you do when you're not in the lab?

I am an unabashed cat lady, and will be happy to show you pictures of my cat Dexter anytime we meet. I love to read, and I get an old-fashioned paper copy of the *New York Times* delivered to my door every Sunday. I'm also a TV junkie – I can't wait for *Game of Thrones* to start again!

2015 DRUG DISCOVERY INITIATIVE AWARDEES

CTF awarded three additional Drug Discovery Initiative (DDI) Awards in its second of two calls for applications in 2015. The DDI Award program supports early stage testing of candidate drug therapies for the treatment of NF1, NF2, and schwannomatosis. These awards fuel the drug pipeline with promising leads.



A. THOMAS LOOK, MD, of the Dana-Farber Cancer Institute, was granted an *in vivo* DDI Award for his proposal, **“Drug discovery for NF1-associated malignant peripheral nerve sheath tumors using the zebrafish model.”**

NF1-related MPNSTs are very aggressive tumors with poor prognoses for the patients who are diagnosed with it. Surgery to remove MPNSTs is not effective because they often recur and metastasize. Chemotherapy regimens are not only ineffective, but toxic to the patient. Dr. Look and his team have developed a zebrafish model, through which they will rapidly screen drugs that are already in use in humans, obviating the need to perform expensive and time-consuming toxicology studies. They predict that they will be able to identify one or more already-FDA-approved drugs, which have been developed for other diseases, that will show activity against MPNSTs. These drugs could potentially be “repurposed” to more effectively treat this small subset of NF1 patients.

JOSEPH KISSIL, PhD, of the Scripps Research Institute, was granted an *in vivo* DDI Award for his project, **“Assessing the anti-tumor activity of crizotinib in NF2-deficient meningioma.”**

Dr. Kissil and his team have identified an already-FDA-approved drug, known as crizotinib, as having anti-tumor activity against NF2-related schwannomas. This drug is already in use in patients with lung cancer and has demonstrated few side effects, and is therefore safe. A clinical trial is currently being initiated to test crizotinib against schwannoma in NF2 patients. The group will now assess whether crizotinib can also be useful against another NF2-related tumor, meningioma, by testing this drug in cell and animal models. Should this show a desirable effect, it would indicate that the trial being initiated should be expanded to include meningioma in addition to schwannoma.



NANCY RATNER, PhD, of Cincinnati Children’s Hospital, was granted an *in vitro* DDI Award for her study, **“Mechanisms of resistance to MEK inhibition in neurofibroma.”**

This study aims to find drugs that reduce neurofibroma size and are potentially curative. We already know that drugs that target MEK proteins shrink most neurofibromas. In patients with NF1, the mutated gene, neurofibromin, can no longer do its proper function of turning off a protein called Ras. When Ras is on, downstream pathways (that include MEK) are also active, contributing to neurofibroma formation. By using a drug to inhibit MEK, the over-active pathway is turned off, which can shrink neurofibromas. However, both in humans and in preclinical trials in mice, inhibiting MEK doesn’t always work and some neurofibromas show resistance to MEK inhibition. Dr. Ratner and her team will work to determine what else is being turned on during MEK inhibition so that it can also be targeted, prevent drug resistance, and identify an increasingly successful treatment for patients with NF1.

STORIES OF NF **Brady Ward**

Brady was officially diagnosed with NF1 when he was three years old. Along with NF1, Brady has ADHD and struggles with multiple learning disabilities. Although Brady struggles with things that come easily for other kids, he never gives up, and it makes his success that much sweeter. This year, he learned to ski independently, and his confidence has soared! He worked really hard preparing for his ski trip with extra physical therapy exercises, and it paid off. His courage and resiliency are inspiring to all. For the second year, our community has pulled together to host a fundraiser for our NF Walk Team, Brady's Buddies, and we are hoping this event will be bigger and better than ever. Brady's engaging personality makes it easy to raise awareness for NF, and we will continue to be involved until we help find a cure!



—*Erin Ward, Brady's mother*

STORIES OF NF NF Hero Bella Paesano and Her Hero, Liz Fernandez

Bella Paesano is seven years old and was diagnosed with NF1 in October 2015.

Bella had been suffering from headaches, which we attributed to seasonal allergies. However, during a routine annual checkup, our pediatrician noticed multiple café au lait spots and a random freckle under Bella's armpit, which caused concern. After numerous doctor visits and a brain MRI, our suspicions were confirmed; Bella has neurofibromatosis.

In addition to living with learning disabilities, Bella has an infancy-stage tumor growing on her optic nerve. At this point, her vision is not affected, but it needs to be closely monitored. Bella has scoliosis and poor muscle tone. She started yoga and swimming to help strengthen her core. Bella is scared but determined. We don't know what the future holds, but it is our job to make her life as normal as possible.

Bella is lucky to be partnering with Liz Fernandez, a family friend who will be raising funds for the Children's Tumor Foundation by racing at the IRONMAN World Championship in Kona, Hawaii. I have known Liz for years; our kids went to preschool together. I see her running all over town, in rain and snow—nothing stops her! I knew she competed in triathlons, but I didn't know she had an affiliation with the Children's Tumor Foundation's NF Endurance Team.

When I found out, I emailed her right away, asking if she would consider racing in honor of Bella. Without hesitation, she said, "YES!" I get emotional just thinking about it. The time commitment to train and travel that Liz has made is huge, especially since she has three small children. Her devotion is above and beyond, and I appreciate her willingness to help more than she will ever know.

Together we can make a difference in Bella's life and in the lives of all people with neurofibromatosis.

—*Kathy Paesano, Bella's mother*



STORIES OF NF **Andy Hollenbeck**

My 13-year-old son, Andy, has NF1. On October 8, 2015, he had his second brain surgery; the first one happened when he was eight. The tumor on his brain ate through his left optic bone, causing his eye to bulge and pulsate. The doctors had to remove the tumor, take a piece of his skull to rebuild his eye bone, and insert screws to hold it together. We were blessed with amazing doctors, an incredible neurologist, an outstanding oncologist, and lots of love and prayers, all of which pulled him through!



Andy has also had three other surgeries. He is such a strong boy.

Andy enjoys art and science classes in school; his favorite book is *Diary of a Wimpy Kid*; his favorite movie is *Mr. Bean*; his favorite TV show is *Austin & Ally*; and he loves to play video games and create anything out of everything!

He is my hero, and I am proud to be his mother.

—*Sara Henkle, Andy's mother*

CTF NAMED OFFICIAL CHILDREN'S CHARITY OF PIRELLI WORLD CHALLENGE

The Children's Tumor Foundation has been named the Official Children's Charity of the Pirelli World Challenge Championship Series, North America's top production car-based racing championship. As the Official Children's Charity, all of the competitors in this important series will now have the option to carry the Foundation's logo.

Racing4Research Program Director Jill Beck was enthusiastic. "I am incredibly grateful to Greg Gill and everyone at PWC for their unwavering support of Racing4Research, and for allowing us this opportunity to expand the Foundation's presence in the paddock. They say it will take a team to end NF and this is a pretty impressive team to have on our side."



Rolex 24 at Daytona Victory

They say that the third time is the charm, and that old adage proved true at this year's Racing4Research (R4R) event at the Rolex 24 at Daytona. For the third year, the Foundation partnered with the highly competitive team of Magnus Racing, and for the first time ever, a car carrying the Children's Tumor Foundation logo finished the historic race on top of the podium, with the all-new No. 44 Magnus Racing Audi R8 LMS taking top honors in the GT-Daytona class.

For the past eight years, the names of NF Heroes—children and adults living with neurofibromatosis—have been carried on a single car during the historic 24-hour race weekend. For 2016, CTF began a new tradition by spreading the NF Hero names across multiple International Motor Sports Association (IMSA) teams. In addition to Magnus Racing, partner teams carrying the CTF logo included Park Place Motorsports, Turner Motorsport, BAR1, Konrad Motorsport, and Performance Tech Racing.

The weekend began with the families enjoying the opening race of the weekend, the BMW Performance 200, featuring longtime Foundation partners C360R (Compass360 Racing) and their three cars, carrying both the CTF and "END NF" logos. The first podium of the weekend went to the C360R squad, with the newest Children's Tumor Foundation "Art Car"—the No. 76 Ford Mustang GT350R-C, driven by Paul Holton and Pierre Kleinubing—taking second place in its first-ever race.

The Foundation's traditional Friday night Team and Family Dinner was hosted, for the second year, by FOX Sports reporter, and former R4R driver, Justin Bell. Park Place Motorsports team owner and driver Patrick Lindsey stopped by to meet with the guests, as did a number of the C360R crew, who were greeted by cheers from the thankful NF families.

On Saturday, beautiful sunny weather greeted the CTF group, outfitted in their now-familiar blue T-shirts, as they made their way through the IMSA garage to meet with the teams and drivers supporting the Foundation. Four primary cars carried the names of the NF Heroes in attendance: the No. 73 Park Place Porsche, the No. 44 Magnus Audi, and the No. 96 and No. 97 Turner BMWs. Each NF Hero was able not only to sign the car carrying their name, but to feel what it's like to sit behind the wheel of a race car.

When all was said and done, the No. 44 team emerged victorious, welcoming our NF Heroes to join them atop the podium in Victory Lane, creating memories that will last a lifetime.

MAY IS NF AWARENESS MONTH

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



• WEAR •

our exclusive "I Know A Fighter" and "Born A Fighter" t-shirts



• LIKE •

Children's Tumor Foundation on Facebook



• SHARE •

exclusive NF Awareness Month graphics



• CHANGE •

your profile picture to one that celebrates NF Awareness



• EDUCATE •

using fact sheets



• TAKE •

a photo that shows how you "Picture a World without NF"



• WATCH •

our May Awareness Month Videos



• SHINE •

a light in your community and add to the growing list of landmarks that will glow in CTF blue and green



• JOIN •

the NF Registry if you or your child lives with NF



• DONATE •

and double your gift throughout the month of May



• TAG •

your posts on social media with #EndNF and add to the conversation



• PARTICIPATE •

in a CTF event or start your own



• COMMUNICATE •

Spread the word and increase awareness about NF!

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

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

Download your NF Awareness Month toolkit at ctf.org/nfawareness.

WHAT DOES A WORLD WITHOUT NF LOOK LIKE?



Enter the "Picture a World Without NF" contest: Take a photograph with any item that shows the CTF or End NF logo. Express yourself and show the world that, no matter where you are, who you are with, or what you are doing, you're fighting for a world without neurofibromatosis.

Submit your photo to media@ctf.org with your name and a comment about where it was taken and what it says about your fight to end NF. The best photo will receive a prize at the end of the month and be featured in our next newsletter and across CTF online platforms. Multiple submissions encouraged!

2016 Walk Dates

Staten Island, NY	May 14, 2016
Orlando, FL	May 21, 2016
Cincinnati, OH	May 22, 2016
Providence, RI	May 22, 2016
Columbia, SC	May 22, 2016
Kernersville, NC	June 4, 2016
San Jose, CA	June 11, 2016
Austin, TX	June 19, 2016
Casper, WY	June 25, 2016
Philadelphia, PA	June 25, 2016
Boston, MA	June 26, 2016
Chicago, IL	July 9, 2016
Portland, OR	July 24, 2016
Iowa City, IA	Aug. 13, 2016
Denver, CO	Aug. 20, 2016
Salt Lake City, UT	Aug. 27, 2016
Meridian, ID	Sep. 10, 2016
Richmond, VA	Sep. 10, 2016
Rochester, NY	Sep. 10, 2016
Moorhead, MN	Sep. 11, 2016
Seattle, WA	Sep. 11, 2016
Saco, ME	Sep. 17, 2016
Hamilton Twp, NJ	Sep. 17, 2016
Concord, NH	Sep. 17, 2016
Addison Oaks, MI	Sep. 18, 2016
New York, NY	Sep. 24, 2016
Putnam, CT	Sep. 24, 2016
Houston, TX	Oct. 1, 2016
Washington, DC	Oct. 1, 2016
Milwaukee, WI	Oct. 1, 2016
San Antonio, TX	Oct. 15, 2016
Dallas, TX	Oct. 15, 2016
Hoover, AL	Oct. 16, 2016
Long Island, NY	Oct. 22, 2016
Los Angeles, CA	Oct. 22, 2016
Atlanta, GA	TBA
Boca Raton, FL	TBA
Columbus, OH	TBA
Jacksonville, FL	TBA
Corbin, KY	TBA
Las Vegas, NV	TBA
Nashville, TN	TBA
Phoenix, AZ	TBA
St. Louis, MO	TBA

For a complete list, please visit nfwalk.org.



NF WALKER SPOTLIGHTS

TEAM MAX WALKS TO RAISE AWARENESS AND SHINE A LIGHT OF HOPE TO END NF!

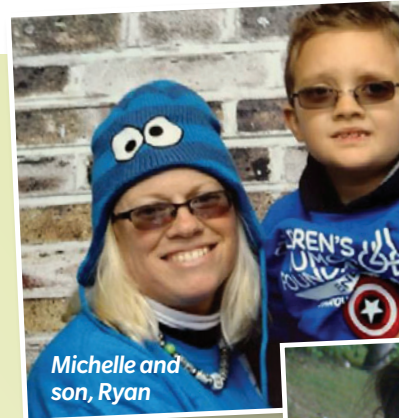


After her son Max was diagnosed with NF, Tina Lien knew she had to do something. Tina Lien and her family found the NF Walk program! ***“We created Team Max for the Moorhead, Minneapolis NF Walk, and raised more than \$12,000 toward research to end NF! Go Team Max!”***

— TINA, mom to Max, an NF Hero

From the Rochester Walk and beyond, Michelle Lampman leads the fight!

Michelle Lampman became part of the NF family when her son Ryan was diagnosed with NF at age three. Ryan immediately had his first MRI and began chemo within weeks of that initial diagnosis. Since then, Michelle has never ceased fighting for Ryan, and for an end to NF.



Michelle and son, Ryan

“I work in the Pediatric department at Golisano Children’s Hospital, so I see NF families every day. I speak with new families, and contact families that just need some help. I have organized the Rochester NF Walk for over 3 years, been interviewed on the news for awareness, and am active on the NF Clinic Task Force. I get very enthusiastic about NF Awareness Month. I obtained a proclamation of NF Awareness Day in Rochester last year, and had two buildings light up in tribute - all while taking care of our own NF specialist visits, chemo treatments, and now autism education.

“I met an amazing mom at our Walk in October who had just lost her son Evan, and it really burst my safe bubble. Monique is so strong. I admire her strength, so I am going to get muddy by her side at the Tough Mudder in August. That event commands focus, dedication, craziness, and motivation. What more to motivate me than the love I have for my son? Everyone asks me how do you do it? How do I NOT do it—it’s my son’s life!”

— MICHELLE LAMPMAN, mom to Ryan, an NF Hero

I KNOW A FIGHTER:
NF Endurance
Athletes raise
funds to
fight NF!!

MITCH ZELMAN / IRONMAN

Mitch Zelman will again join the NF Endurance team, this time in the 2016 IRONMAN World Championship in Kona, Hawaii.

“My journey began when I signed up to race IRONMAN Florida in November of 2014. While that race came with its struggles, it is not nearly as difficult as the challenges that those with NF face in their daily lives. My emotional support comes from the NF Hero that I am partnered with, a five-year-old girl named Clara, who was diagnosed with NF1. Clara’s family believes that in the next ten years, they will come up with treatments to ensure Clara has a normal, healthy, and happy life. My journey, and the \$40,000 that I will raise this year in her honor, will get them one step closer to those treatments.”

— MITCH ZELMAN, athlete for Clara, who lives with NF



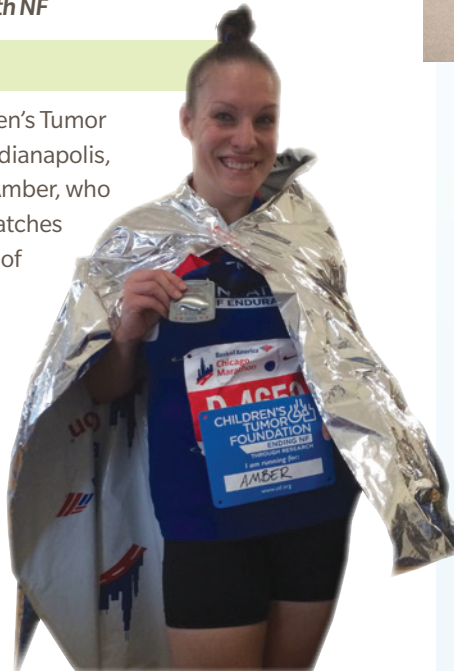
Mitch Zelman

JACQUELINE JASEK / Marathon

Jacqueline Jasek ran her first step with the Children’s Tumor Foundation at the 2008 Indy Mini Marathon in Indianapolis, Indiana. That’s when she first met her NF Hero, Amber, who is living with NF2. The Adopt-a-Hero program matches athletes who may not have had prior knowledge of neurofibromatosis with an “NF Hero.”

“Meeting Amber and her incredible family helped me raise the bar on my running. I began running for a reason back in 2008—to find a cure for neurofibromatosis.”

—JACQUELINE JASEK, marathon runner for Amber, who lives with NF



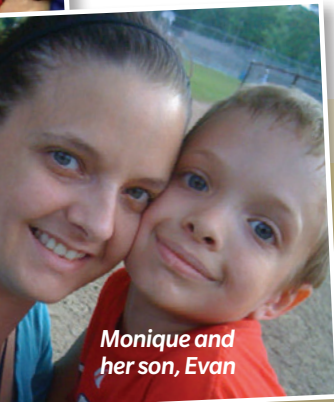
Jaqueline Jasek

MONIQUE HEBERT-BUBLYK / Tough Mudder

Monique Hebert-Bublyk’s son Evan passed away due to complications from neurofibromatosis. Monique continues to fight for a cure in his honor, and for all the other families living with NF. This August, Monique will compete with the NF Endurance Team in Tough Mudder, a team-oriented obstacle course designed to test teamwork, physical strength, and mental grit.

“I was looking for something to do for Evan, or in Evan’s memory. When I saw that through CTF I could compete in the Tough Mudder, I knew that this was what I wanted to do. I am trying to raise \$1,127 because 11/27 was Evan’s birthday. Challenging myself and focusing on fundraising and preparing for the Tough Mudder will help me have something to work toward. I know this will help me through the grieving process. Plus, I get to say I completed in the Tough Mudder! That’s pretty impressive, I think.”

—MONIQUE HEBERT-BUBLYK, remembering her son Evan, who lived courageously with NF
To read more about Monique and Evan visit ctf.org/blog



Monique and her son, Evan

Upcoming Events

- 4/24 **Big Sur Marathon**
Big Sur, CA
- 4/24 **London Marathon**
London, England
- 5/1 **TD Five-Boro Bike Tour**
New York, NY
- 6/4 **IRONMAN Hawaii 70.3**
Kohala Coast, HI
- 6/17 **Summer Solstice 10K and Kids Run**
Spokane, WA
- 7/24 **New York City Triathlon**
New York, NY
- 8/28 **Chicago Triathlon**
Chicago, IL
- 10/9 **Bank of America Chicago Marathon | Chicago, IL**
- 10/22 **IRONMAN North Carolina 70.3 and 140.6**
Wilmington, NC
- 11/5 **IRONMAN Florida**
Panama City Beach, FL
- 11/6 **TCS New York City Marathon**
New York, NY
- 11/13 **Rock ‘n’ Roll Marathon Las Vegas**
Las Vegas, NV
- 12/4 **California International Marathon | Sacramento, CA**
- 12/11 **Honolulu Marathon**
Honolulu, HI

For a complete list, please visit nfendurance.org.

REGIONAL NEWS

Great Events from Across the NF Community

The Foundation has a presence across the United States and facilitates local patient support groups, medical symposia, and fund-raising events. Learn more about the Children's Tumor Foundation in your area by visiting www.ctf.org.

CALIFORNIA

On January 24th, nearly 2,000 runners and walkers, adults and kids, all took their mark at the Fourth Annual Kaiser Permanente Carmel Valley 5K and Fun Run, to raise money for local schools and select nonprofit organizations, including the Children's Tumor Foundation.

CTF Board Member Rob Brainin crossed the finish line with his son Charles and his daughter Ellie, who lives with NF. He took a moment to tell ABC News reporter Melissa Mecija all about the day:

"We've certainly had some challenges... It's tough for a six-year-old, it's been tough for us as a family, but Ellie's spirit is just so great. Folks at Carmel Valley have been great. We're lucky to live in a community where people really support us."



NF Hero, Ellie, and her dad, Rob Brainin

CALIFORNIA

On March 4th, the CTF California office met with the President of CBS Studio Center and a group of doctors and researchers from Children's Hospital Los Angeles (CHLA) to illustrate what's being done in research to fight NF. Tena Rosser, MD, head of the NF Clinic at CHLA, put together a tour of two research labs for the CBS Studio Center guests, who have been the host of the Los Angeles NF Walk for the past four years. We're grateful for the ongoing support of CBS Studio Center, and look forward to many more years working with them.



CONNECTICUT

Haddam Killingworth High School celebrated its 27th annual Holiday Show Telethon on December 23rd, benefiting the Children's Tumor Foundation. The Holiday Show is produced each year by Haddam Killingworth Television (HKTV), a nationally recognized high school digital communications program. This year, CTF was honored to be selected as the telethon's charity recipient, thanks in part to Emma Becker, a local student who has been diagnosed with NF. Despite her intense treatments, Emma takes the time to help other sick children by hosting lemonade stands, making cards, and donating money to CTF. The telethon this year raised NF awareness and drew in more than \$18,000 toward NF research. A huge thank you to the Haddam Killingworth staff and students!



From left: Kim Robinson (CTF); Linda Randolph, MD (CHLA); Mark Krieger, MD (CHLA); Tena Rosser, MD (CHLA); Mike Klausman (President, CBS Studio Center); Sandra Reed-Funnell (Executive Assistant, CBS Studio Center); Bob Schadt (President, Crest Office Furniture); Kelly Mills (CTF); Lisa Betesh (CHLA); and Anat Erdreich-Epstein, MD (CHLA)



TENNESSEE

Five-time Grammy Award-winner Michael McDonald put on a one-night concert to benefit the Children's Tumor Foundation and raised more than \$26,000 for NF research! Also known for his work with the Doobie Brothers, Michael McDonald played Tennessee's Franklin Theatre on March 10th, and honored his friend, Robert Sebastian, who lives with NF. McDonald wrote on his Facebook wall, "*[Robert] is a fabulous guitarist who suffers from neurofibromatosis... He perseveres in spite of it as a dedicated musician and courageous young man. An inspiration to all of us who know him.*" Thank you to Michael, Robert, and to all who took part in this spectacular concert!



From left: Rob Pompo; Nicolás Pompo (NF Hero); Raj Khosa (owner, Tandoor of India); Gianna Pompo; and Nicole Pompo.

NEW YORK

On February 19th, Tandoor of India, Fairport, New York, hosted a CTF event fundraiser in honor of NF Hero Nicolás Pompo. The outpouring of support from the community at this event was wonderful, as was the generosity of the Tandoor of India restaurant. Over the next six months, they will be giving a 50% donation from each kid's meal that is sold. Thank you to Tandoor of India for your continued support, and to Rochester Bhangra and Masla Bhangra.

OREGON

Inspired by their daughter Andréé, who has NF1, Todd and Lisa Tucker hosted Eugene's first ever "Evening with Oscar" fundraiser for CTF on February 28th. The goal for the evening was to spread awareness about NF and to raise money for CTF research and camp scholarships. A crowd of more than 100 attendees gathered at Venue 252 to view the televised Oscar ceremony, enjoy sips and bites, and participate in a paddle raise for scholarships. The evening ended with a heated battle during the live auction for a gorgeous vacation on Kauai, Hawaii. More than \$57,000 was raised at this wonderful new event!



CALIFORNIA

Karlie Savage, along with her family and son, NF Hero Ryder, were part of the California Racing4Research Race Day Party on January 30th at BJ's Restaurant in Torrance, California. This event was in honor of all the California NF Heroes. At the event, there was face painting, arts and crafts, and a special award for the NF Heroes in attendance. Thank you to BJ's Restaurant for donating all the pizza, soda, and BJ's original Pizookie to the 25 guests.

"It's so wonderful to have these types of opportunities at the community level. Not only can we meet and talk with other NF families, but we are able to take our minds off the day-to-day battles that NF brings and just enjoy some fun time. And seeing so many race car drivers supporting NF Heroes on national TV makes it that much cooler!" —Karlie Savage, mom to NF Hero, Ryder



NF Hero, Ryder, and his brother, Tyson



CUPID'S UNDIE RUN

\$3.8 Million Raised for NF Research

What good can a bunch of pants-less party animals do for a charity? Let's just say that \$3.8 million for neurofibromatosis research doesn't just appear out of thin air. This past February marked the seventh consecutive Cupid's Undie Run to benefit the Children's Tumor Foundation. Cupid's has grown in leaps and bounds since 2010, when participants raised \$10,000, to now in 2016, when they've raised more than \$3.8 million. Everyone's favorite Valentine's Day-themed party has shown what an amazing

group of generous do-gooders can do for a cause they believe in.

In 36 cities across the US, as well as 3 in Australia, Cupid's Undie Run is a fun and unique way to raise money specifically for NF research. Presented nationally by Sock It to Me, Quicken Loans, Sidebar Eyewear, and Fathead, Cupid's Undie Run has been described as "a big party" for charity.

Executive Director Chad Leathers recently remarked, "Last year in this publication I stated, 'It is truly unbelievable seeing a dream become a reality.' But truly

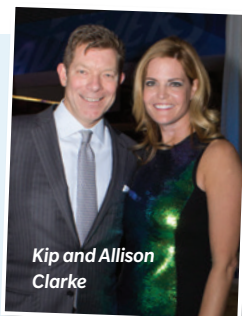
our dream is a world free of NF. The success and growth of Cupid's Undie Run is just one step toward realizing that dream. Who knew being near-naked could positively affect research? But I guess that's what happens when a lot of passion meets direction. And now our trust moves to the continued success of the CTF research department. We are on our way!"

If you're interested in learning more about participating in or donating to Cupid's Undie Run, visit the website at www.cupidsundierun.com.

Thanks to All the "Big Shots and Little Stars"

Cleveland's Quicken Loans Arena transformed into Motown last November, as the Cleveland Cavaliers and Flashes of Hope welcomed 1,000 guests for the 2015 Big Shots and Little Stars fundraiser. The annual event benefits Flashes of Hope and the Children's Tumor Foundation.

Allison Clarke, founder of Flashes of Hope, and Dan Gilbert, CTF Board Member and majority owner of the Cleveland Cavaliers basketball team, kicked off the evening. The highlight of the night was the runway show. The Cavaliers roster was joined by other "Big Shots" from the Cleveland business community, who escorted their "Little Stars" – pediatric cancer survivors – down the runway. There was twirling and posing galore, all to the beat of popular Motown songs like "Sugar Pie, Honey



Kip and Allison Clarke



Bunch" and "Stop in the Name of Love."

Flashes of Hope is a nonprofit organization that raises funds to accelerate a cure for children's cancer while honoring the unique life and memories of every child fighting cancer. Thanks to the Big Shots and Little Stars event, Flashes of Hope made a donation of \$600,000 to the Children's Tumor Foundation, which will go toward critical research into malignant peripheral nerve sheath tumors.

The Children's Tumor Foundation extends our utmost thanks to Kip and Allison Clarke, Dan Gilbert, and the Cleveland Cavaliers; to all the Big Shots and Little Stars; and to Flashes of Hope for their continued support in funding NF research. For more information, go to flashesofhope.org.



FLASHES of HOPE

MEET THE STAFF

Carey Milligan



HOMETOWN: Kingston, Jamaica

CURRENT TOWN: Bronx, New York

EDUCATION: BA in Accounting from Lehman College, New York

YOUR WORK WITH THE FOUNDATION: I am the Accountant for the Foundation. I make sure our books are correct, our bills are paid, and that all the numbers add up. Plus I'm always actively looking for ways to save money!

YOUR FAVORITE EXPERIENCE WITH THE FOUNDATION: When I first started at CTF, my position had been open for some time, so the work was very overwhelming. Two of my colleagues, on separate days, came into my office and hugged me, saying, "Everything is going to be okay, Carey." It meant a lot. Another one of my favorite experiences was working the New York Gala at Cipriani last October. It was a beautiful night, and nice to meet so many of our donors. I also really enjoyed the CTF staff retreat last summer. It was exciting to brainstorm with my colleagues and come up with new ideas to better the Foundation.

FAVORITE HOBBY: I like to travel! I recently went to Puerto Rico to visit Old San Juan. On the weekends, I enjoy hanging out with friends and spending time with my family. I'm a "fix-it" guy too, so I've always got home improvement projects to keep me busy. One of my new hobbies is going to the gym. I recently joined a gym, so I've been spending a lot of time there.

FAVORITE MOTTO OR APHORISM: The most important thing is to enjoy life – to be happy – it's all that matters.

FAVORITE BREAKFAST FOOD: Ackee and Saltfish – a good Jamaican breakfast.

IF YOU COULD HAVE ANY SUPERPOWER, WHAT WOULD IT BE? Healing. Help ease the pain of people suffering from serious illnesses.

GO TO KARAOKE SONG: "Getting Jiggy Wit It" by Will Smith

WEIRDEST THING YOU'VE EVER EATEN: Frog legs. They were really bad.

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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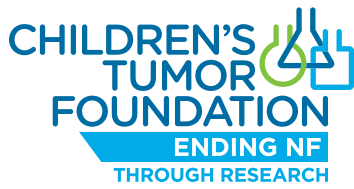
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