

NF NEWS

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION
SPRING 2022

Shine a Light on NF is a global grassroots initiative that brings NF awareness into the community by lighting up architectural icons in blue and green. Last year the NF community secured over 300 landmarks across the country and around the world. For NF Awareness Month 2022, even more buildings, bridges, landmarks, and homes are lighting up to Make NF Visible and Shine a Light on NF. To see a full list, go to ctf.org/shinealight

INSIDE:

- 3** CTF's New Event: NF Summit
- 4** Announcing DDIRR Awardees
- 6** Flying High: American Airlines Charity Day
- 8** NF Awareness Month: Make NF Visible

Pictured: The Bob Kerry Bridge in Omaha, NE, will light up blue and green on May 17. Shine a Light on NF is one part of a month-long awareness campaign that consists of online activities and community events.

FROM the President

Annette Bakker, PhD



Each year in May, the Children's Tumor Foundation (CTF) doubles down on our efforts to make neurofibromatosis (NF) known worldwide. Thank you for joining us again this year as we Make NF Visible through our awareness month efforts, including our Shine a Light campaign, proclamations, video contest, and more. Our upcoming World NF Awareness Day Live event will take place on May 17, and I would like to invite you to join me at this beautiful evening of music and celebration.

In this newsletter, we share details about the upcoming NF Summit and NF Conference. It will be a joy to gather together again – in person – to meet, learn, and share. We also have new awardees to announce, an

NF Hero in the comics, and the news of an incredible Charity Day event with our partners at American Airlines, who are continuing to work with us to use data in new ways in the fight to end NF.

Throughout this newsletter and on social media, you will see beautiful photographs taken by our Extraordinary Spirit, Craig Warga. Craig's photos of NF Heroes like Marcus (page 9) have been instrumental in the Foundation's outreach efforts, and we are grateful for his ongoing support of the work we do.

Thank you to all those who braved the winter cold this February at their local Cupid's Undie Run, and the thousands of walkers, runners, swimmers, and donors who join together in our Shine a Light NF Walk and NF Endurance programs. Most of all, thank you to the NF patients who come to our Foundation looking for hope. We are genuinely dedicated to you and believe that we will succeed in ending NF together.

Annette Bakker, PhD
President

UPDATE:

CTF President Published: **Don't Let Shelved Assets Gather Dust**

Children's Tumor Foundation President Annette Bakker was published in *STAT*, the influential life sciences publication, on a critical topic: gaining access to shelved drugs that could help NF patients and others. In this article, Dr. Bakker explores the opportunities for pharma and biotech to release drugs that can help patients as well as benefit the companies. She writes: "Repurposing shelved drugs that have already been proven safe in humans can save companies millions of dollars and years of research and development, allowing potential treatments to reach kids—and adults—with cancer and other diseases as quickly as possible." Read more at ctf.org/news.

Welcome New Board Members



Sally Gottesman



George Thuronyi



Emily Parker

Board of Directors

Officers

Tracy Galloway
Chair

Gabriel Groisman
Vice Chair

Randall Stanicky
Treasurer

RB Harrison
Secretary

Annette Bakker, PhD
President

Richard Horvitz
Chair Emeritus

Board Members

Daniel Altman
Robert Brainin
Daniel Gilbert
Sally Gottesman
Carol Harrison Kalagher
Frank Haughton
Simone Manso
Emily Parker
Michael Peterson
Liz Rodbell
Kenneth Rudd
Richard Soll
Stuart Suna
George Thuronyi

Advisory Board Chairs

D. Wade Clapp, MD
Chair, Medical Advisory Committee

Scott Plotkin, MD, PhD
Chair, Clinical Care Advisory Board

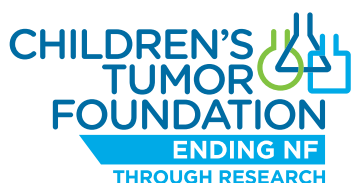
Lu Le, MD, PhD
Chair, Research Advisory Board

Volunteer Leadership Council Chair

Anita Gribben

Honorary Directors

Suzanne Earle
John Golfinos, MD
Linda Halliday Martin
Steven L. McKenzie
Carolyn E. Setlow
Nate Walker
Ed Stern,
Pro Bono Counsel
Allan Rubenstein, MD
Director of Medical Affairs Emeritus



NF Registry Now Available in Five Languages

English, Spanish, French, Italian & Portuguese

The Children's Tumor Foundation is proud to share that the NF Registry is now available in five languages: English, Spanish, French, Italian, and Portuguese. This enhancement will grow and diversify the Registry population, making it a bigger and more powerful tool in the fight against all types of neurofibromatosis and schwannomatosis.

NF patients are showing the world that the NF community is united in its desire to drive the search for better treatments and care. By making themselves available and sharing de-identified data about their experiences over time, patients have become an active part of NF research, and proven to be interested in clinical trials.

Thank you to our partners Linfa NEUROFIBROMATOSI (LINFA), Associação Portuguesa de Neurofibromatose (APNF), and Groupe d'Entraide Romand pour les Neurofibromatoses (GER-NF) for working with us to expand the reach of the NF Registry.

With more than 10,000 participants, the Registry has already made a tremendous impact on NF research: it has alerted participants to over 50 clinical trials, sped up study recruitments for faster results, focused research to match patient priorities, and attracted pharmaceutical companies to the NF field.

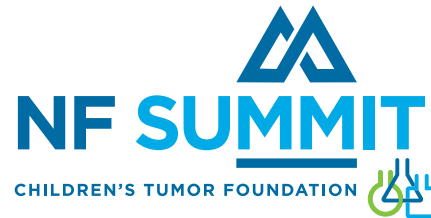
Visit nfregistry.org to join or update your record. To change the language, look for the flag in the upper right corner.



THE NF REGISTRY IS AVAILABLE IN 5 LANGUAGES!

ENGLISH
ESPAÑOL
FRANÇAIS
ITALIANO
PORTUGUÉS

NFREGISTRY.ORG



This year the NF Forum and the Volunteer Leadership Conference will combine to create a new, dynamic international event that brings together patients, volunteers, organizers, researchers, clinicians, patient advocates, friends, and supporters who have a connection to NF.

The NF Summit is not just the combination of two events, it is a reimagining of how CTF connects and supports the NF community around the world. The event will include more than 40 speakers, 3 days of content, and 30 exhibitors you don't want to miss. Everyone can join, either in person or virtually, using a new highly engaging app on a phone, computer, or tablet.

The NF Summit will be held in person in Chicago, Illinois on July 21-24, 2022. For more information and to register, go to nfs Summit.org

Multi-year past participant Kristin Meek had this to say about the upcoming event:

"As the chair of the Chicagoland Shine A Light NF Walk and a VLC member, I am very excited to welcome everyone to my hometown of Chicago for this year's NF Summit! I have attended two past Volunteer Leadership Conferences and one NF Forum and found them to be powerful, emotional, and motivating. The connections made with NF Heroes and NF family members are the greatest gift of these events. Coming together to share experiences, struggles, tears, and laughter renews my drive to fight and work to end NF!"



From left, Anna Meek, Kristin Meek, and Ben Meek at their local Shine A Light NF Walk

2021 Drug Discovery Initiative Registered Reports (DDI-RR) Awardees

Through a collaboration with top scientific journal *PLOS ONE*, in a process known as “Registered Reports,” awardees are offered financial support from CTF and in-principle acceptance for publication by the journal. This model allows for more rigorous, reproducible, and transparent science, guaranteeing these awardees publication, regardless of study outcome.

Jonathan Chernoff, MD, PhD, Fox Chase Cancer Center



Evaluation of a PAK1-Selective PROTAC, Alone and With Hippo Inhibitors, as a Targeted Therapy in NF2

This project aims to test whether a newly characterized PROTAC version of NVS-PAK1-1, a Pak1-selective small-molecule inhibitor, impedes oncogenic signaling and cell survival in NF2. The drug will be tested in a panel of NF2-deficient schwannoma cells alone and in combination with a Hippo pathway inhibitor.

Wade Clapp, MD, Indiana University



Preclinical Therapeutic Evaluation of ALY101 in a Murine Model of Neurofibromatosis type 2

The aim of this project is to test a novel Pak1 inhibitor, ALY101, in a genetically engineered mouse model of NF2. ALY101 blocks RHOJ and CDC42 binding to Pak1, thereby inhibiting Pak1 while also avoiding off-target inhibition of Pak2 and other proteins. The investigator hypothesizes that ALY101 will successfully reduce tumor burden and hearing loss in the NF2 mouse model.

Brian Stansfield, MD, Augusta University



Targeting Endothelial Cell to Macrophage Communication in NF1 Tumors

This proposal will assess the efficacy of imipramine, an FDA-approved macrophage macropinocytosis inhibitor, in suppressing macrophage-mediated angiogenesis and tumor growth in NF1. The study will use NF1 mouse models to generate imipramine dose response curves to facilitate easier translation to phase 1 clinical trials.

Thomas DeRaedt, PhD, The Children’s Hospital of Philadelphia



Targeting Combined MEK and HDAC Inhibition as an Effective Therapeutic Strategy for NF1 High Grade Glioma

This project is based on the observation that NF1-associated High Grade Glioma (HGG) cell lines are extremely sensitive to combined MEK-HDAC inhibition and will evaluate if this combination is also able to shrink NF1-associated HGG in mice and extend their survival.

Breakthrough Treatment for Kids with NF1 Muscle Weakness

We are happy to share an exciting breakthrough treatment from a research study co-led by CTF-funded researcher Aaron Schindeler, PhD of The Children’s Hospital at Westmead, Australia. This treatment was successfully trialed in a study and has the potential to help children with NF1 who live with muscle weakness and fatigue. The researchers found that L-carnitine, a supplement used by athletes to prevent muscle fatigue, can considerably improve muscle function in children with NF1. The work was supported by the Children’s Tumor Foundation.

CTF has contributed to both the preclinical and clinical studies that led to this incredible and very promising result, most recently in the Drug Discovery Registered Reports program, and the CTF-funded preclinical study. The CTF Clinical Research Award scheme partially funded the clinical study back in 2018 which led to a publication in the *American Journal of Medical Genetics*.

Read more about the impact this new treatment has had on the participants in the 12-week trial who live with NF1-related muscle weakness at ctf.org/news.

Clinical Care Advisory Board (CCAB) Retreat Held Virtually in February

The Children's Tumor Foundation Clinical Care Advisory Board (CCAB) is committed to improving NF clinical care. Composed of 14 expert clinicians and three patient representatives, the group met virtually this February for their annual retreat to review current projects and create goals for 2022.

Last year's CCAB achievements included creating presentations about the revised NF1 diagnostic criteria, evaluating COVID-19 outcomes in NF patients, and designing a pilot program to improve access to adult NF care. The group also kicked off a multi-year project assessing the use of NF clinical care guidelines. The first part of the study surveyed clinicians on their awareness and agreement with current NF care guidelines and was published this year (citation in list at right). A parallel patient survey offered through the NF Registry in May 2021 produced an informative data set now being analyzed. The patient survey will be repeated through the Registry every May to track progress over time as the CCAB works to increase the number of patients receiving NF care consistent with current guidelines.

In addition, the CCAB also approved the acceptance of two new clinics into the NF Clinic Network: Dell Children's Medical Center in Austin, Texas, and the NFCN's first Canadian clinic, Centre Hospitalier de l'Université de Montreal (CHUM) in Montreal, Quebec.

New or updated resources and publications from the CCAB include a video for patients about the revised NF1 diagnostic criteria which is available to view at ctf.org/nfcriteria.

To support the CTF Communications team, the CCAB reviewed these new or updated patient resources:

- NF1 Guide for Educators
- Learning with NF1
- A Guide for Adults
- A Guide for Those Living with NF1

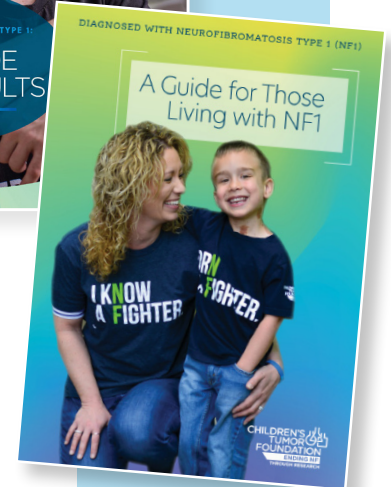
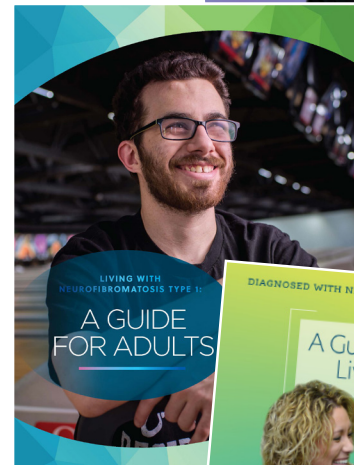
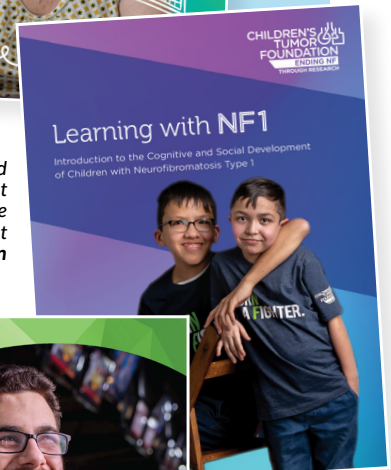
CCAB medical publications include:

- The Use of MEK Inhibitors in Neurofibromatosis Type 1-Associated Tumors and Management of Toxicities. *Oncologist*. 2020 Jul;25(7):e1109-e1116.
- The impact of the COVID-19 pandemic on neurofibromatosis clinical care and research. *Orphanet J Rare Dis* 16, 61 (2021).
- Awareness and Agreement with Neurofibromatosis Care Guidelines among U.S. Neurofibromatosis Specialists, *Orphanet J Rare Dis* (2022) 17:44

CCAB projects for 2022 discussed at the February retreat include assessing CTF's current Diversity, Equity, and Inclusion (DEI) efforts and finding opportunities to expand them; evaluating the use and access to NF1 genetic testing; and developing educational tools about the NF2 and schwannomatosis revised diagnostic criteria.



New and updated CTF patient brochures are available at ctf.org/education



NF CONFERENCE

2022 NF Conference June 18–21

The NF Conference attracts more than 750 clinicians, researchers, industry representatives, and patient advocates, in person and virtually, who are interested in hearing about the most recent advancements in NF research and clinical care. The event is a critical forum for consensus-building and advancing basic, translational, and clinical research in NF and related fields while fostering collaborations within and beyond the NF community.

This year's NF Conference will take place June 18-21 in Philadelphia, Pennsylvania. For more information, please go to nfconference.org.

Charity DAY



UPDATE

Hackathon

Last year's Hack4Rare event brought together researchers, developers, solutions architects, and hackathon enthusiasts for exploration, experimentation, and analysis into NF. Among the participants was Team American, which was comprised of members of the Operations Research team at American Airlines.

Team American built a Graph Neural Network (GNN) model to leverage genomic data to help classify patients into high/low risk categories, and find similar patients with known treatments. This novel approach demonstrated high accuracy in clustering tumor samples, with the promise of improved predictability for diagnosis.

Since then, with the support and mentorship of researchers from Children's Hospital of Philadelphia (CHOP), DNA Nexus, and the Children's Tumor Foundation, along with an incubation grant from the Gilbert Family Foundation, the team has expanded their research to a bigger NF dataset. All involved are enthusiastic about the promise this work holds for the NF space, and particularly for patients. We'll continue to provide updates as this research progresses.

LETTING GOOD TAKE FLIGHT TO END NF

American Airlines Data Experts Dedicate Charity Day to the Children's Tumor Foundation

Motivated by the credo to "care for people on life's journey," more than 135 data technologists at American Airlines (AA) came together for a Charity Day dedicated to the Children's Tumor Foundation. With plenty of coffee and pizza at hand, the 'data do-gooders' committed their world-class technological and analytical skills to bolster the CTF mission. Together with CTF staff, the AA team analyzed donor data, identified information gaps, created data visualizations, and helped CTF improve constituent outreach and engagement through enriched information strategies.

Under the American Airlines banner of "Let Good Take Flight," the American Airlines team was inspired by their colleague and team member Patricia Ptasznik, with a personal connection through her daughter, who was born with NF. Initially envisioned as a way to utilize individual skillsets to help CTF, the idea caught attention across AA's cross-functional data teams and grew into a high-energy gathering dedicated to improved understanding and analysis of available data. By leveraging the skills that fuel AA's customer-focused success, the AA team members stretched their

wings and applied that unique knowledge to the nonprofit space on behalf of CTF and NF patients.

The day was a win-win all around: CTF staff received insights and expertise that will serve the Foundation in its future planning and growth, and the AA team engaged in a high-impact event that supported team-building, problem-solving, and giving back. The day also serves as a model for how corporations and nonprofits can work together to solve significant problems.

In addition to our immense gratitude for the support of the American Airlines team, we also send big thanks to these partners, participants, and donors to Charity Day: Matillion, Snowflake, Teradata, Microsoft, and Amazon Web Services. Their participation, including an additional 15 employees from their organizations, brought together more than 150 people on Charity Day in the fight to end NF.

The charitable (and fun) spirit of the day was captured in photos and video which can be viewed at ctf.org/americanairlines.



Noah Chambers, NF1

We first learned of Noah's diagnosis when he was seven months old. We started noticing things about two weeks after Noah's birth, so Noah's pediatrician sent us to Washington University St. Louis Children's Hospital. That's when he received the diagnosis of NF1.

NF impacts our lives in many ways, one being the constant doctor appointments. Noah sees so many specialists on a regular basis. He's also in speech therapy five days a week.

Like so many individuals with NF, Noah has already had a number of surgeries and procedures at just five years old. Noah was diagnosed with bilateral moderate-to-severe hearing loss at three years old, and he was just diagnosed with bilateral optic gliomas in December 2021.

Life with NF can be so hard and overwhelming for everyone. For our family, we look at Noah and his strength and ability to overcome anything thrown his way, and we

know we have no other option than to be strong for him as well.

Noah is a super happy little boy. He is very outgoing and kind, and he enjoys soccer and takes Ninja Warrior classes. Noah loves school, his friends, and his incredible team of educators. His teachers say he's a wonderful student who is happy and eager to learn.

Noah is so brave; he never cries or shows fear at any appointments. It's kind of crazy, he's going through so much himself, yet he's the one giving us strength to get through it all. His positive outlook on everything is infectious.

“For our family, we look at Noah and his strength and ability to overcome anything thrown his way, and we know we have no other option than to be strong for him as well.”

— TAMI, NOAH'S MOM



stories

OF NF

Renee Eastburn Schwannomatosis

The nerve pain that I felt for over half a decade was nearly all-consuming. The best way I would describe it to others was it felt like someone was stabbing me in my leg hundreds of times per day. (That's not an exaggeration - I tallied up the number of times I felt pain one day, and it was more than 300 times!)

Before an MRI revealed the tumors, I had tried various medications to help ease the pain over the years, but nothing helped. Some medicines even caused negative mental side effects, like depression. Not having answers as to why I was experiencing this awful pain took a toll on my mental health. Because no pain medications helped, and I was desperate for relief, I knew that surgery was my only chance at a pain-free life once the tumors were discovered.

In late 2019, I underwent an invasive surgery at Johns Hopkins. My surgeon removed an entire chunk of nerves surrounded by tumors, spanning roughly 9cm. I now have no sensory feeling in my left thigh, and I have a massive scar from the surgery. Thankfully, though, I am no longer plagued with the horrible pain caused by my schwannomas. My doctor has presumed that I have mosaic schwannomatosis, though I have not undergone genetic testing yet.

It is never great to learn you have a genetic disorder, and of course, I am scared that I will grow more tumors in the future. Despite that fear, I am enjoying my pain-free life and am thankful that I had a successful surgery.

During this period, I was also a student in college. Sometimes the pain was so horrible I couldn't sleep at night. I would have to leave class because I'd nearly burst into tears from the extreme pain. Somehow, I managed to power through the pain and graduate from engineering school in 2018 from Temple University.

NF has made me stronger because I know that if I can get through years of excruciating, chronic pain while accomplishing all that I did, then I can get through anything.



MAY is NF Awareness Month!

Visit makenfvisible.org to learn more ways YOU can **Make NF Visible!**



WEAR

our exclusive CTF blue and green gear all month, especially on May 17 & 22



DONATE

to fund the cutting-edge research that will end NF



CHANGE

your profile picture to one that celebrates NF Awareness



JOIN

the NF Registry if you or your child has NF



PROCLAIM

NF Awareness Month by securing a proclamation in your city or state



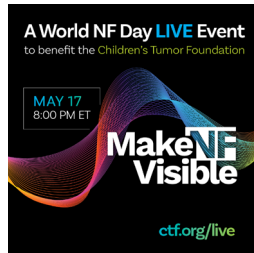
LIKE

Children's Tumor Foundation on social media, and tag your posts with #EndNF



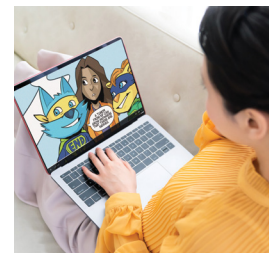
SHARE

our exclusive photo series, Make NF Visible



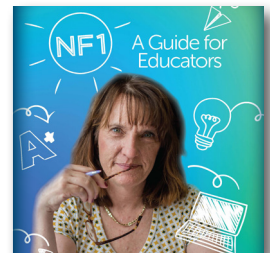
PARTICIPATE

in our webinars and our World NF Day Live Event on May 17



WATCH

our NF Awareness Month videos on our YouTube channel



EDUCATE

using informative fact sheets and brochures



NATIONAL BILLBOARD CAMPAIGN

Our thanks to Lamar Advertising who again this year is helping the Children's Tumor Foundation Make NF Visible through a national PSA digital billboard campaign to celebrate NF Awareness Month. Between the Lamar billboards and those secured by local NF families, more than 120 digital billboards are spreading NF awareness across the country.

Download your NF Awareness Month resources at: makenfvisible.org

Be a part of the movement and submit your personal video to the Make NF Visible YouTube Gallery!
ctf.org/myvideo

Simply use your smartphone, computer, or camera to record a video of yourself, then upload it on our easy form.

In your video answer these five questions:

1. Begin with, "My name is <name> and I have <NF type>"
2. What is something about YOUR DIAGNOSIS people can't see?
3. What is something ABOUT YOU that your diagnosis keeps people from seeing?
4. Can you share a PERSONAL MOMENT that increased awareness impacted your life?
5. End your video with, "I want you to see me, and see NF."

Please adjust any questions as needed to work for you and your situation. Go to ctf.org/myvideo to submit your video today!

Marcus, who lives with NF1



MAKE NF VISIBLE

Throughout the year and especially during NF Awareness Month, the Children's Tumor Foundation is passionate about working with you, our dedicated donors and friends, to **Make NF Visible**. We want to make sure the world sees NF, and sees each person living with it.

We count on your donations each year to fund the vital CTF programs that are making a difference for the 2.5 million patients worldwide who live with some type of neurofibromatosis or schwannomatosis. We work to make a difference for patients like **Marcus (pictured here) who live with NF1**.

Marcus is thirty-six years old and was diagnosed with NF1 when he was just two months old. He was the only person in his family with NF, and neither his parents nor his sister had ever heard of the disorder. Because NF is so unpredictable, Marcus and his family had no way of knowing how it would affect him. He worried throughout middle and high school, and into adulthood when he had terribly severe headaches that would overtake him.

But Marcus is a person of faith who has never let NF stop him from pursuing his goals and following his dreams. He graduated high school, went to college, and as an adult has become active with the Children's Tumor Foundation, attending many fundraising events to benefit the Foundation's mission to end NF through research.

"I have a plexiform tumor wrapped around my pelvis, so sometimes I have pain. Recently it really impacted my walking and my mobility and balance. When I walk into a room where I don't know anyone, I'm nervous about how they are going to perceive me. But I just make sure to focus on the things that I have accomplished in the past and remember who I am, that I'm a fighter. I'm a good person." —Marcus

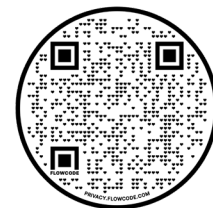
Together with Marcus, we envision a day when NF patients can live their lives without the stigma of a disorder that so few know about, and even fewer understand. We want adults and children living with all types of neurofibromatosis and schwannomatosis to be free of the pain and fear that come with these conditions.

Make your donation now at ctf.org/hope to help fund more treatment options for all types of neurofibromatosis and schwannomatosis. We are counting on your help to continue the life-changing progress underway for patients with NF. There is so much more work to be done — and we need your help today.

Sincerely,

Annette Bakker, PhD
Children's Tumor Foundation President

P.S. Please don't wait. Your gift will make a difference!
Return the attached envelope or go to ctf.org/hope.



Scan the code above or go to ctf.org/marcus to watch a video featuring Marcus and learn more about his NF story.

World NF Awareness Day **LIVE**

to benefit the Children's Tumor Foundation

ctf.org/live

Make **NF** Visible

Live from LA's
The Three Clubs on Vine
AND livestreamed
globally at ctf.org/live

To register for free,
text **CTFLIVE** to 41444

To donate, text **ENDNF**
to 41444

TUESDAY, MAY 17

8:00 PM ET | 5:00 PM PT

HOSTED BY:

Jonathan Sadowski | Actor/Director

Celebrity guests, musical performances, and NF Heroes join together to **Make NF Visible**.

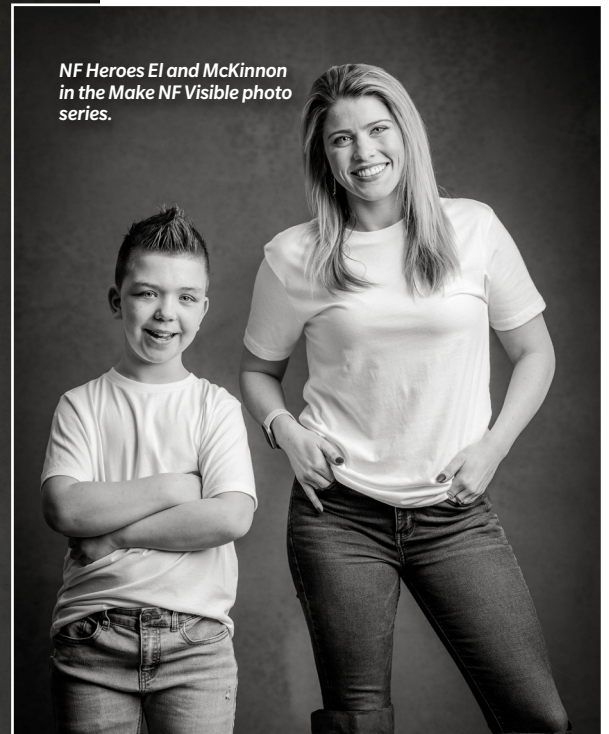
This event will be livestreamed across the world and available to view post-event on YouTube. Those who have registered will receive a link to view the event live on May 17th. Closed captioning will be available.

Questions? Please contact Kim Robinson at krobinson@ctf.org

CTF Educational Webinars

CTF recently hosted two community patient-focused webinars in both English and Spanish. Beth Burke of CureNFwithJack led an informative webinar discussing MPNSTs, and a panel of experts spoke about the INTUITT-NF2 platform clinical trial in a webinar moderated by CTF President Annette Baker. These webinars and more informative videos can be found at ctf.org/education in the "Educational Webinars" menu.

Photographer and
Extraordinary Spirit Craig
Warga with his son Aiden.



Extraordinary Spirit / CRAIG WARGA

In 2017, the Children's Tumor Foundation launched an exclusive photo series with award-winning photojournalist Craig Warga, an NF parent who set out to inspire his son Aiden, who lives with NF1. That collection was called "This is NF," which pictured adults living with NF - not just living, but succeeding and thriving.

Craig and his son traveled near and far to capture individuals at work, enjoying hobbies, or alongside loving family members. With this project, Craig told a side of the NF story that isn't often told: the passion that those living with NF bring to their daily lives, to their work, their goals, their relationships, the things they want to get out of life, with or without NF.

The unique and inspirational photo series launched online with portraits and profiles of 11 adults living with NF, and the series grew in 2018 to include 10 more adults living with NF.

"I was very happy to work on a project with the Children's Tumor Foundation to try and raise awareness about what NF is, and to introduce

people to those living with NF," Craig told us. "When Aiden was diagnosed with NF, the first thing we did was go online, my wife and I, and we did some research. We were frightened by all the pictures that we saw ... I thought it would be a great idea to take portraits of people with NF. The NF community needed to be represented. My son Aiden was able to assist me, and it was a fantastic way for him to meet people with NF, and learn about his disease."

Craig's passion for this series didn't end with the "This is NF" series. In 2020, CTF launched another exclusive collection with Craig Warga called "Make NF Visible." In this series, individuals with both visible and invisible manifestations of NF were paired together for group portraits. The collection looks at the visible and invisible experiences that contribute to the ways NF makes itself visible in a person's life. Individuals with differences like brain tumors and café au lait spots, neurofibromas and learning difficulties, successful surgeries, failed clinical trials, physical scars, emotional wounds, unspoken

understanding, and unbroken bonds.

"One of the difficult things that we've dealt with in our experience through our son, is if you were to look at Aiden, you would never know that he had an underlying condition. NF has such a broad spectrum of how it manifests in different people. You have people who you would never know in a million years have any underlying health issues, and then you have people who are very visibly afflicted and you can't miss it. One of the things that I've come to learn is that what is presented visually by a person with NF doesn't necessarily reflect overall health, what the person might be dealing with."

Craig's beautiful photography has led the Foundation's awareness month efforts for the past five years. His extraordinary spirit has captured the heart of the NF community.

"You can read a story about NF, and read that it can cause tumors to grow anywhere on the nervous system. But when you can actually see the people who are affected by it, I hope that drives a little bit of impact for people so they feel moved to action."

You can view the *This is NF* photo series at ctf.org/thisisnf, and the *Make NF Visible* series at ctf.org/makenfvisible. More of Craig's corporate photography and photojournalism can be found on his website, www.craigwarga.com.

SHINE A LIGHT NF WALK

Shine a Light NF Walk is an annual event that brings communities together to honor and support individuals and families living with NF. Each walk around the country is a chance for participants to meet other NF families and raise awareness about all types of neurofibromatosis and schwannomatosis.

TEAM HARDWICK, SOUTH DAKOTA

“ Back when Ty’s dad was diagnosed with NF at six years old, there wasn’t a community like this, so to have this now for Ty and his dad, and everyone else affected by this illness, means more than we ever imagined. ”

Join us at a Walk near you!

GAVIN’S GLADIATORS, NEW JERSEY



“ The Shine a Light NF Walk last year was one of the most heartfelt, emotional days spent with our family celebrating our NFer. ”

UPCOMING WALKS

Register today at shinealightwalk.org

6/4/22	Cincinnati
6/25/22	Utah
7/31/22	Michigan
8/20/22	Iowa
8/27/22	Seattle
9/10/22	Virginia
9/10/22	Minnesota
9/17/22	Chicagoland
9/24/22	Denver
9/24/22	South Dakota
9/24/22	Kansas City
10/1/22	San Antonio
10/1/22	Philadelphia
10/8/22	Rochester
10/8/22	Buffalo
10/8/22	Carolinas
10/15/22	Atlanta
10/22/22	Southern California
10/22/22	Long Island
11/5/22	Florida
11/5/22	New Jersey
11/12/22	Houston
11/2022	Arizona
Virtual -	New England

MIGHTY MEREDITH, THE CAROLINAS

“ Meredith was just diagnosed with NF in 2020 and it was wonderful to be able to connect with other families in the NF community for the first time. I left the walk with such a sense of hope! ”



NF ENDURANCE



NF Endurance Alumni Event: Little Rock Marathon

Congratulations to our NF Endurance team members who took part in the 20th Annual Little Rock Marathon Weekend on March 5-6, 2022! CTF staff and local Arkansas volunteers welcomed new teammates to the NFE family and reunited with committed alumni from across the years. Nearly 70 NFE runners hailing from coast to coast (California to New York, Pennsylvania, and Florida) and north to south (Michigan to Louisiana, Texas, and Alabama) were treated to Southern hospitality, thanks to local hosts and CTF volunteers, Lesley and Connie Oslica, and their family and friends.

Racers got a warm welcome at the CTF expo booth on Friday and Saturday, then were treated to a delicious homemade Team Pasta Dinner on Saturday evening. Larry Trussell and Christy Mohr were recognized as the team's Top Fundraisers, and Kathleen Sullivan's Team Ranger Strong as the Top Fundraising Team.

New connections were made and existing ones strengthened. Everyone is looking forward to the next Team Signature Event in 2023. Visit nfendurance.org for opportunities to join our team today!



“ I watch my husband Jason struggle daily due to complications related to NF1. He always has a smile on his face, never letting on to friends or family the enormity of his suffering. I run for him and for all others afflicted with this horrible disease. We are filled with gratitude for those who have helped us raise so much money. Our family, friends, and community have been so supportive – both emotionally and financially. We won't stop until there is a treatment or a cure! ”

—**JULIE BARUCH**, top NF Endurance fundraiser in the 2022 United Airlines NYC Half

2022
UPCOMING EVENTS
nfendurance.org

6/4-5 **Rock 'n' Roll San Diego**
9/25 **BMW Berlin Marathon**
10/2 **Virtual TCS London Marathon**

10/8-9 **Rock 'n' Roll San Jose**
10/9 **Bank of America Chicago Marathon**

11/5-6 **Rock 'n' Roll Savannah**
11/6 **TCS New York City Marathon**
12/3-4 **Rock 'n' Roll San Antonio**

CUPID'S UNDIE RUN

Cupid's Undie runners were excited to get back together in person after last year's virtual event. Our participants hit the streets, sidewalks, and beaches in 37 cities across the country. We welcomed over 6,000 runners and raised more than \$1.6 million and counting.

Diehard Cupid's participant Kevin Cahn from Denver, who never misses the event, said, "Cupid's is the best day of the year!" Kevin was joined by 3,700 new participants, many of whom were on one of the 840 participating teams.

This rebuilding year got much of its momentum from our 67 AMAZING volunteer Event Directors, 12 of whom were new. What a beautiful way to welcome Cupid's back home to CTF and start our 2022 fundraising season! Learn more at cupids.org.



NF2 in Archie Comics!

Meet *GRACE*, the first Archie Comics character dealing with hearing loss, sponsored by the Children's Tumor Foundation

The Children's Tumor Foundation (CTF) is pleased to announce that the latest issue of ARCHIE JUMBO COMICS DIGEST will introduce the first hearing-impaired member of its iconic cast of characters. Meet Grace Alondra, who also marks the first time a character living with neurofibromatosis (NF) or schwannomatosis has appeared in the pages of a comic book from a major publisher. Grace will make her debut in an eight-page short called "Sounds Like Music" that will appear in ARCHIE JUMBO COMICS DIGEST #329 in comic shops April 20, 2022.

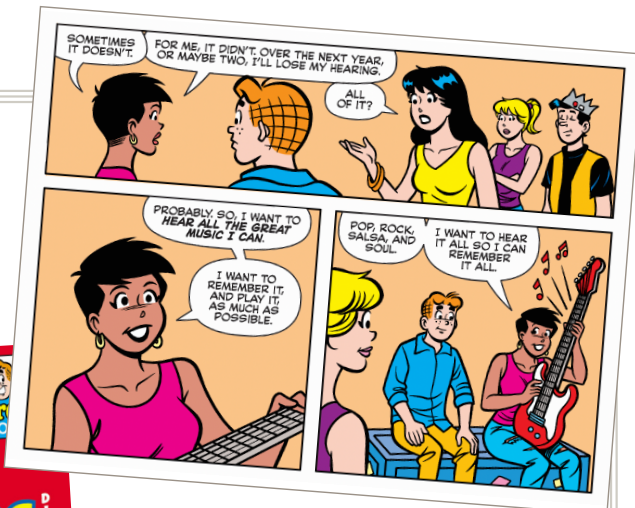
Archie worked with the Children's Tumor Foundation to create this character to shine a light on the many individuals living with NF2, which often leads to hearing loss. The comic is part of an awareness campaign that launches at the end of April and continues throughout May, which is NF Awareness Month.

In "Sounds like Music," Archie and the gang meet Grace, a young Latina woman who loves music and stans her favorite band, The Archies. Spunky and smart, Grace isn't letting her journey toward hearing loss define her. Instead, she is eager to hear all the great music she can, while she can.



Grace's journey is all too familiar to individuals with this diagnosis, which is most often discovered in the teen to young adult years. "As a long-time music fan, I first learned that I would lose my hearing in college, so I set out to listen to all the music I could so I could keep it deep in my memory," said Matt Hay, who lives with NF2. "I was creating a soundtrack for a life I had not yet lived." Matt was diagnosed in his early college years and eventually lost all hearing due to NF2.

The inclusion of Grace continues Archie's commitment to introducing new diverse



and differently-abled characters in its various ongoing comics series. Archie Comics Editor-in-Chief Mike Pellerito is enthusiastic about bringing this character into the classic Archie Universe. "Grace is a talented and whip-smart teenager," he said. "The fact that she's experiencing hearing loss is only one part of her story. To me, this is the stuff that really matters, and we're proud to be working with the Children's Tumor Foundation on an important story like this."

"Sounds like Music" was written by veteran comic book writer Alex Simmons, with art by Bill Galvan, Ben Galvan, Glenn Whitmore, and Jack Morelli.

The Children's Tumor Foundation has developed and released three previous comics stories independently, with three more currently in progress. CTF's current "NF Comics" titles include "Understanding NF2," "Moxie and Sparx Explain NF1," and "Moxie and Sparx Introduce the Accelerator"; the Foundation's comic books, including Archie's "Sounds Like Music," are available to freely download or read on the CTF website at ctf.org/comics.

Advocacy Update

Thanks to bipartisan leadership in the House of Representatives and the Senate, plus the strategic advocacy of the Children's Tumor Foundation and the outreach efforts of the NF community, President Biden signed into law H.R. 2471, Consolidated Appropriations Act, 2022, which secures \$20 million for NF research through the Congressionally Directed Medical Research Program – NF Research Program (CDMRP-NFRP).

Thanks to your calls, letters, and visits, this funding continues Congress' longstanding support of the NFRP, which has brought NF research to the commencement of clinical trials, and the continued funding will help translate these trials into effective treatments. Thank you to the entire NF community – working together, we are advancing scientific discoveries and improving outcomes for NF patients.

The activities of CTF Europe have been focused on four fronts: co-leading the team that is developing platform trials for NF in Europe; building an NF clinic network as well as a clinical trial network in Europe in preparation of the roll-out of the new platform trials; raising awareness for NF at the European level by actively participating in public consultations, and launching a new NF educational program entitled iNfer. The iNfer training program is for healthcare providers who are not NF experts and is offered in seven languages. Tell your doctors that these informative sessions can be found at ctfeurope.org/nfmasterclasses.

MASTERCLASSES IN NF

A series of online educational lectures for medical professionals by leading neurofibromatosis experts

Reserve your spot today:
ctfeurope.org/nfmasterclasses

INFER is an initiative of Children's Tumor Foundation Europe, supported by an educational grant from AstraZeneca.

INFER
INTERNATIONAL
NF
EDUCATIONAL
RESOURCES

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

NF News Editor, Vanessa Younger
NF News Design Director, Susanne Preinfalk

The Children's Tumor Foundation is the world's leading nonprofit dedicated to funding and driving innovative research that will result in effective treatments for the millions of people worldwide living with NF, a group of genetic disorders that causes tumors to grow on nerves throughout the body. One in every 3,000 people is born with some type of neurofibromatosis or schwannomatosis, which may lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, or cancer. NF affects all populations equally, and while there is no cure yet, 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: ctf.org.

FOUNDATION STAFF

Annette Bakker, PhD, President

Research and Medical Programs

Salvatore La Rosa, PhD, Chief Scientific Officer
Vidya Browder, PhD, Senior Manager, Basic Science
Angela Dumadag, Senior Manager, External Relations
Kate Kelts, Coordinator, Patient Support
Pamela Knight, Senior Director, Clinical Program
Elana Loftspring, External Relations Coordinator
Jessica McElmeel, Coordinator, Clinical Science Team
Elizabeth Oliver, Senior Executive Assistant
Patrice Pancza, Vice President, External Relations
Heather Radtke, Senior Manager, Clinic & Symposium
Traceann Rose, Director, Patient Engagement

Development

Michele Przepyszny, Chief Advancement Officer
Jamie Balhon, Director, Development, Cupids
Claudia Becerra, Manager, Shine A Light NF Walk
Amy Boulas, Vice President, Development
Cassidy Brewer, Manager, Development, Cupids
Allison Cote, Senior Manager, Donor Relations
Emily Crabtree, Senior Director, Development Operations
Aidan Fraser, Development Assistant
Barbara Gallagher, Vice President, Development Corporate
Dan McAvoy, Operations Assistant
Julie Nassisi, Senior Manager, Special Events
Lydia Vanderloo, Senior Manager, NF Endurance
Kim Robinson, Senior Manager of Advancement
Connie Sorman, Senior Manager, Stewardship and Volunteer Development
Rebecca Taylor, Director, Shine A Light NF Walk

Finance and Administration

Sarah Bourne, Vice President, Finance and Operations
Rachel Anderson, Director, Donor Database Operations
Jennifer Ching, Director Human Resources
Brianna Daquino, Accountant
Carey Milligan, Senior Manager, Accounting
Brandon Weaver-Bey, Senior Coordinator, Gift Processing

Marketing and Communications

Simon Vukelj, Chief Marketing Officer
Rebecca Harris, Senior Manager, Public Relations
Alissa Marks, Director, Marketing
Susanne Preinfalk, Director, Design
Vanessa Younger, Director, Communications

LEAVE A LEGACY...BE A LEGACY

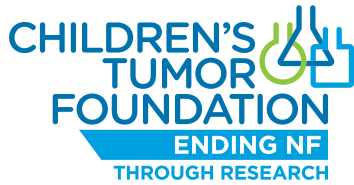
THE NF LEGACY SOCIETY

The NF Legacy Society consists of individuals who have taken the extra initiative to ensure the future of NF research, by including the Children's Tumor Foundation as a beneficiary in their will or trust, retirement account, or life insurance policy.

Make no mistake about it –the progress that has been made in the fight against NF is because of people like you, who are working to improve the lives of those with NF. It is a legacy of which you can be proud.

To learn more about making a planned gift, email info@ctf.org or go to freewill.com/ctf.





NON-PROFIT ORG
U.S. POSTAGE PAID
TWIN CITIES, MN
PERMIT NO. 29626

CHILDREN'S TUMOR FOUNDATION

National Office:

697 Third Avenue, Suite 418
New York, NY 10017

Send Donations To:

Mail Code: 6895
P.O. Box 7247
Philadelphia, PA 19170 - 0001



Donate to **End NF** in More Ways Than Ever

Through The Giving Block, we now accept cryptocurrency. It's easy to do, and it offers tax-saving benefits. Dozens of different cryptocurrencies are accepted, and more are continuously being added. To donate or learn more, visit ctf.org/crypto