

NF NEWS

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION
WINTER 2023

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*Mekka Garcia, MD,
presenting at the
2023 NF Conference.*

The 2023 NF Conference occurred in conjunction with the NF Summit in Scottsdale, Arizona, from June 21 through June 27. The gathering offered novel insights into NF research and generated enthusiasm that effective therapeutics are on the horizon.

The NF Conference is a global event that attracts nearly 750 participants worldwide across a wide range of scientific disciplines. The meeting is focused on improving outcomes for patients living with any type of neurofibromatosis or schwannomatosis. The NF Conference 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.

To read a research report with highlights of the research presented at this year's NF Conference, please visit nfconference.org

FROM the President

Annette Bakker, PhD



As we commemorate the 45th anniversary of the founding of the Children's Tumor Foundation (CTF), it is with immense gratitude that I convey this pivotal moment in the search for treatments for the millions of individuals worldwide living with NF, which refers to all types of neurofibromatosis and schwannomatosis.

"The time is now to end NF!" – the theme of our year-end campaign – resonates loudly with me as I reflect on the historic steps that have been made in NF research, thanks to your ongoing commitment and support.

This June, the NF Conference was held in conjunction with the NF Summit. The two events united over 1,000 passionate individuals from all facets of the NF community – patients, families, researchers, clinicians, industry partners, and fellow advocacy organizations. It was more than an event; it was a convergence of belief, education, empowerment, and a call to action. We stand at the forefront of progress, fueled

by the unwavering support of people like you. Though we've achieved significant milestones, there's a resounding realization that there is more work ahead.

While we currently have one approved drug for NF1, the momentum of progress and the promising developments on the horizon signal that now is the time to push further. We have two treatments ready to enter the last phase of clinical trials. While clinical trials are the most hopeful path to ending NF, they are also the most expensive - which is why we need your support now more than ever. Your belief in the future of research, the dedication of our researchers, and the empowerment of our patients fuels our conviction that we will see 100% tumor reduction in 100% of patients.

I am delighted to invite you to read the many narratives within these pages, featuring compelling scientific advancements, fundraising galas, community runs and walks, and the Foundation's awareness month initiatives. The extraordinary spirit of individuals like Carly McKay, Nissa Novas, and many more, inspire us in this ongoing battle—a battle fueled by you, our family of donors. Thank you for your ongoing trust and commitment. By joining forces and giving it our absolute best, we have the power to put an end to NF.

With shared determination,

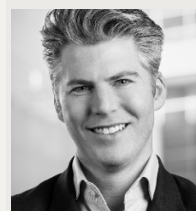
Annette Bakker, PhD
President

IN THE NEWS:

PUBLICATIONS FROM CTF President Annette Bakker

A thought-provoking topic from CTF President Annette Bakker was published in the research journal *STAT* about the critical need to distinguish between "repurposing" FDA-approved drugs for new indications vs "repositioning" non-FDA-approved shelved assets for emerging indications. The terms are often used interchangeably, but clarifying the distinction will help accelerate the development of cures not just for NF but for all rare diseases. Dr. Bakker was subsequently interviewed on the same topic by a leading industry publication, *PharmaVoice*. Both articles can be found at ctf.org/news

Welcome New Board Members

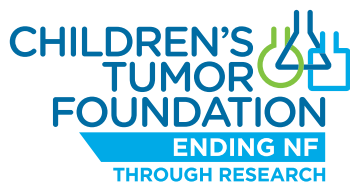


Mark Oppenheimer



Montse Montaner Picart

Board of Directors



NF refers to neurofibromatosis type 1 (NF1), and all types of schwannomatosis (SWN), including NF2-related schwannomatosis (NF2-SWN), formerly called neurofibromatosis type 2.

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2023 is the Year of Open Science

Celebrating the Benefits and Successes of Open Science



CTF collaborates with NASA on the Year of Open Science

The Children’s Tumor Foundation’s latest partnership is out of this world! CTF is euphoric to be part of the #YearofOpenScience, a collaboration spearheaded by the Center for Open Science, with support from NASA. Together with 15 additional organizations, these groups will convene for a series of working sessions to align collective action, culminating with a Year of Open Science conference in 2024 to showcase outputs, coalition-building, and ongoing work from these joint efforts.

The Foundation firmly believes in open science and data sharing. As a private funder in the area of neurofibromatosis and schwannomatosis, CTF spearheaded the NF Open Science Initiative (NF-OSI) in 2018. In 2014, CTF

launched the first-ever NF Data Portal, working collaboratively with all major NF private funders and federal funders. The NF Data Portal centralizes access to data for the NF research community in a public repository hosted by Sage Bionetworks. Users are able to openly explore and share NF datasets, analysis tools, resources, and publications related to all types of NF.

We believe that our standard policies for data sharing and open science will accelerate the advancement of our mission to find a cure for all forms of NF.

Read more at ctf.org/news

Brigid Garelik, MD, MPH, Named Chief Medical Officer of the Children’s Tumor Foundation



The Children’s Tumor Foundation is pleased to share that Brigid Garelik, MD, MPH, has been appointed Chief Medical Officer, overseeing the Foundation’s research and clinical initiatives. In this role, Dr. Garelik will set the direction for the Foundation’s innovative research and development programs, expanding our clinical and preclinical strategies to deliver treatments to patients. She will also direct the Foundation’s educational programs in support of NF healthcare professionals, growing the NF field, and patient engagement.

Dr. Garelik is an accomplished pediatric oncologist, scientist, and senior-level pharma/biotech executive with extensive experience in the healthcare landscape, spanning basic research, patient care, and global drug development. She brings to the role broad therapeutic expertise and leadership in developing novel therapies in small molecules. Her experience includes biologics, as well as cell and gene therapy, from the preclinical stage to successful approvals and product launches. Her prior experience includes more than 10 years as a physician scientist at a large academic medical center, followed by over 15 years in oncology clinical development in both global pharmaceutical corporations and biotechnology organizations.

Please join us in enthusiastically welcoming Dr. Garelik to the CTF Team.

Healx receives U.S. Orphan Drug Designation for its AI-discovered treatment for NF1

We are delighted to share that our partners at Healx have received Orphan Drug Designation from the US Food and Drug Administration (FDA) for their AI-discovered treatment for NF1. Their team of experts discovered HLX-1502 as a potential treatment for NF1 by applying their innovative AI drug discovery platform.

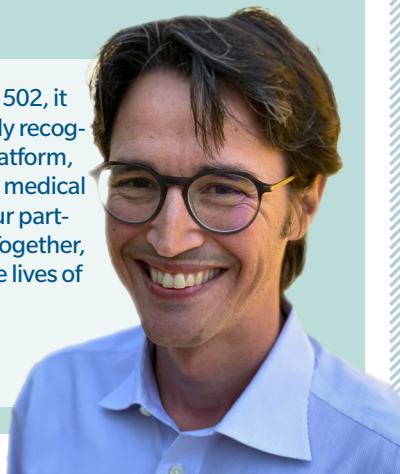
NF1 is a rare genetic condition that causes tumors to grow along the nerves. The two most common types of tumors are plexiform and cutaneous. Currently, there is only one approved treatment for a sub-population of plexiform NF1 patients, a MEK inhibitor with known side effects. There are no approved treatments for cutaneous NF1 patients. This represents a

significant unmet need for millions of people. Currently, other companies are focused on the development of other MEK or kinase inhibitors for the treatment of NF1. Healx’s novel AI-informed approach discovered HLX-1502, which has a first-in-class mechanism and data that gives confidence that a good safety profile should be achievable.

Healx aims to develop HLX-1502 for both plexiform and cutaneous subtypes of NF1, thus enabling access to treatment for a wide range of NF1 patients. Healx plans to submit an Investigational New Drug (IND) application to take its wholly-owned HLX-1502 program into clinical trials in 2024.

“We are proud to receive the Orphan Drug Designation for HLX-1502, it marks a significant milestone for Healx. This designation not only recognizes the innovative potential of our AI-driven drug discovery platform, but also underscores our commitment to addressing the unmet medical needs of NF1 patients and the value of working together with our partner, The Children’s Tumor Foundation, and the NF community. Together, we have a unique opportunity to make a profound impact on the lives of people living with NF1, which is what matters the most.”

SIMONE MANSO, HEAD OF NEUROFIBROMATOSIS THERAPY DEVELOPMENT AT HEALX, AND CTF & CTF EUROPE BOARD MEMBER



YOUNG INVESTIGATOR AWARDS 2023

The Children's Tumor Foundation is pleased to announce the 2023 Young Investigator Award recipients of this latest round of funding, an investment of nearly \$1.2 million through the CTF Discovery Fund. These exciting new projects span all types of NF, including NF1, NF2-SWN, and SWN. The YIA is the Foundation's oldest grant-giving mechanism, given to early-career researchers. CTF's seeding of the NF field with new talent has been hailed as one of the key reasons for rapid advancements in NF research in recent years.

JADWIGA BILCHAK

University of Pennsylvania

*Investigating the Link Between Sensory and Social Deficits in a *Drosophila* Model of Neurofibromatosis Type 1*

NF1 is characterized primarily by tumors of the nervous system, but in addition, up to 50% of patients experience learning and social communication deficits. The present study will investigate the molecular mechanisms in sensory neurons affected by *NF1* variants and how disrupted sensory messages are transformed in the brain to shape behavior. The results from this study will shed light on how *NF1* affects behavioral circuits in the brain and how this relates to differences in social interactions.



SRIRUPA BHATTACHARYA

Massachusetts General Hospital

To Understand the Role of Apelin-Mediated Angiogenesis in NF2-Associated Tumors

NF2-associated tumors have shown inconsistent response to treatment with the antiangiogenic drug bevacizumab (Avastin), which targets vascular endothelial growth factor (VEGF). Avastin can cause severe side effects like bleeding and high blood pressure. Previous work from the Ramesh lab showed increased expression of the angiogenic peptide apelin (APLN) in NF2-negative tumor cells. This study aims to understand the role of apelin in NF2 tumors and will explore if targeting apelin disrupts angiogenesis and tumor growth.



ROOPE KALLIONPÄÄ

University of Turku, Finland

Risk Factors and Characteristics of NF1-Associated Cancer

NF1 increases the risk for various cancers, such as MPNST and breast cancer, and such cancers are a major cause of premature deaths among individuals with NF1.

The three main objectives of this study are determining the risk for multiple cancers in individuals with NF1, determining the role of family history in cancer risk in NF1 and correlating it with NF1 gene variants, and identifying breast cancer characteristics unique to NF1. The study will analyze a Finnish cohort of over 1800 NF1 patients, for whom data are also available through other comprehensive Finnish population and disease registers. Results from this analysis can lead to improved personalized care strategies for NF1 patients.



CLARA NOGUE I ANSON

IDIBELL Spain

Dissecting DGCR8 Syndrome and the Molecular Mechanisms Driving DGCR8-Associated Schwannomatosis

The Rivera group recently identified a variant in the *DGCR8* gene, also located on chromosome 22, responsible for a familial form of multinodular goiter that manifests together with peripheral schwannomas. This proposal will investigate the characteristics of *DGCR8*-mutated schwannomas and identify the mechanisms that lead to their formation. Given the global role of *DGCR8* in cellular processes, knowledge of key dysregulated events in *DGCR8*-schwannoma formation can also apply to other schwannomas with alterations on chromosome 22.

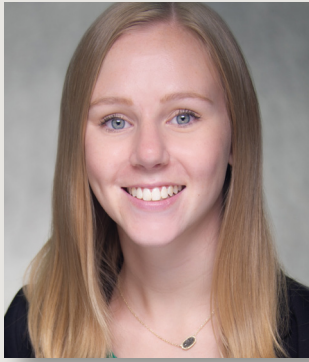


ALEXA SHEEHAN

The University of Iowa

Mechanisms of MPNST Metastasis

Malignant peripheral nerve sheath tumors (MPNSTs) are aggressive tumors with high metastasis rate and poor clinical prognosis in NF1 patients. The present study will test newer formulations of Lox inhibitors, which are more specific and less toxic, to decrease MPNST metastasis. Since PRC2 loss also changes global gene expression in MPNSTs, this study will also test a second category of drugs called epigenetic modulators for their effect on metastasis. Overall, this study will determine if targeting Lox proteins induced by PRC2 loss is a viable treatment option for patients with metastatic MPNST.



ADITYA SHETH

Indiana University

CENPF as a Biomarker and Therapeutic Target for NF1-Associated MPNST

Preliminary data shows that the CENPF gene, which codes for the Centromere Protein F (CENPF), is activated when plexiform neurofibromas (PNFs) progress into MPNSTs. Higher levels of CENPF are detected in MPNSTs compared to PNFs, suggesting that this gene may promote the progression of PNFs into cancerous MPNSTs. This study will evaluate whether increased CENPF correlates with PNF progression and whether CENPF loss prevents MPNST formation.



JUN SUN

Weill Medical College of Cornell University

A Skeletal Stem Cell Basis and Novel Therapeutic Approaches for Fracture Healing Defects in NF1

Pseudarthroses or non-healing fractures are major skeletal manifestations of NF1 that contribute to overall pain and disability. MEK inhibitors, which are effective against NF1 tumors, are not clearly known to treat skeletal problems in NF1. This study will investigate the mechanism by which NF1 loss in skeletal stem cells contributes to impaired fracture healing, MEKK2's role in this process, and the effect of MEKK2 inhibitors in reversing this effect. It will also develop a method to selectively deliver drugs to the non-healing fractures, avoiding unwanted side effects in other organs.



SARA VEIGA

Massachusetts General Hospital

Tumor: Macrophage Interactions in Schwannoma

Schwannomas are made of different cell types, including Schwann cells, axons (part of a nerve cell), blood vessels, immune cells, and an extracellular matrix. This complex microenvironment makes tumors very heterogeneous and is also suspected to contribute to the diverse clinical response of these tumors to drugs. Macrophages, a type of immune cells, are found in developing schwannomas and influence the presence or absence of pain. However, how these immune cells are recruited to the tumor is poorly understood. The goal of this proposal is to study how macrophages are recruited to schwannomas and to understand how they interact with schwannoma tumor cells to help the tumor grow. This understanding will be valuable for developing new therapies to fight tumor growth and alleviate symptoms such as pain.



ZHENZHEN YIN

Massachusetts General Hospital

Co-Targeting HMGB1 and EGF Signaling for the Treatment of NF2 and Associated Hearing Loss

Preliminary studies have shown that a protein called HMGB1, a potent inflammation initiator and amplifier is released by schwannomas and can cause inflammation in the ears, leading to hearing loss. The aim of this study is to test if blocking HMGB1 can prevent hearing loss in mice. Since the HMGB1 blockade activates epidermal growth factor (EGF) signaling, which may compensate for tumor growth, this study will also explore how combined HMGB1 and EGF receptor (EGFR) blockade can prevent hearing loss and delay tumor growth in mice with schwannomas. The study will help us understand how HMGB1 causes inflammation in the ears and how we can stop the tumors from growing, which can be useful in designing future treatments for patients with vestibular schwannoma.



2023 Drug Discovery Initiative (DDI) Awardees

The Children's Tumor Foundation is pleased to announce the 2023 Drug Discovery Initiative (DDI) award recipients, an investment of nearly \$300,000 through the CTF Discovery Fund. The DDI stimulates NF drug discovery by funding researchers proposing to investigate novel or repurposed therapies for NF or to develop tools that support such research.

Sherif Ahmed

Massachusetts General Hospital

Development of Nanobody-decorated Bacterial Outer Membrane Vesicles for Schwannoma Immunotherapy

This research group recently showed that injecting attenuated *Salmonella typhimurium* alone or in combination with systemic checkpoint inhibitor directly into tumors in a schwannoma mouse model showed an anti-tumor effect. The present work, instead of using live bacteria, will utilize bacterial outer membrane vesicles (OMVs) for schwannoma therapy. OMVs are nanosized vesicles released by bacteria and possess the same immunostimulatory molecules, and preferentially accumulate in tumor tissues. Preliminary data showed that a single systemic injection of attenuated *S. typhimurium* OMVs, loaded with novel bispecific nanobody against CD74 and PDL-1 receptors, resulted in rapid tumor cell death and synergistic tumor regression in schwannoma mouse models, without any noticeable adverse effects. This study will further evaluate the effect of this novel therapy and investigate its long-term effects.



Dominique Lallemand

INSERM, France

Development of cell-penetrating peptides targeting the Yap/Tead complex in the context of NF 2

NF2-related schwannomatosis (NF2-SWN), characterized by the development of intracranial tumors, is caused by the inactivation of the NF2 gene. The absence of merlin, the NF2 gene product, inactivates the Hippo signaling pathway, resulting in the accumulation of YAP and TEAD proteins in the nucleus of affected cells. YAP and TEAD bind to each other and activate mechanisms that lead to tumor development. Thus, preventing the association of YAP with TEAD is a possible strategy to prevent tumor development. Previous work by the Lallemand group identified a candidate peptide that can enter cells and disrupt the binding of YAP to TEAD. The current study aims to improve this peptide to make it more stable and efficient at dissociating the YAP/TEAD complex. The study will also create new models of schwannomas that better replicate the proliferation of tumor cells and the growth of schwannomas.



Eduard Serra-Arenas

Health Sciences Research Institute of the Germans Trias i Pujol Foundation, Spain

Identification of Drugs Targeting Epigenetic Regulators in an iPSC-Based 3D MPNST Model

The Serra-Arenas group has developed a new cell-based model system for NF1 using induced pluripotent stem cells (iPSCs), cells that have the capacity to differentiate into any cell type. Using this system, they generated iPSCs with variants in multiple genes like in malignant peripheral nerve sheath tumors (MPNSTs). These cells can be grown in 3D spheres and exhibit the genetics and biological characteristics of MPNSTs. In this study, they propose to use this new 3D MPNST model system to rapidly screen ~600 compounds. Based on the results, a selected group of compounds will be tested further as single agents or in combination with other known drugs to identify new therapies for MPNST.



Lawrence Sherman

Oregon Health and Science University

Developing a Thrombopoietin Inhibitor to Treat NF2 Hearing Loss and Schwannoma Growth

Patients with NF2-SWN often suffer hearing loss, balance problems, and facial paralysis due to schwannomas on their acoustic nerves. The Sherman group previously found that a drug called losartan could prevent hearing loss in a mouse model of NF2-SWN. Although losartan is generally safe, it is unclear if it will be effective in NF2-SWN patients and sometimes has severe side effects. The proposed study will use a different drug, a thrombopoietin antisense oligonucleotide (TPO-ASO) that is being tested in clinical trials for other diseases and which also regulates platelets but does not have side effects linked to losartan. This study will test if TPO-ASO could be a drug candidate to protect or improve hearing and reduce tumor growth in NF2-SWN patients.



CTF's BOLD NEW VISION: PRECLINICAL HUB

The April 2020 approval of Koselugo (selumetinib) as the first FDA-approved treatment for NF1 sparked more interest and attention toward NF. As our understanding of NF has grown, more potential treatments are now within our grasp, and effective preclinical testing will better predict success once the drug moves into clinical trials.

The Children's Tumor Foundation pledges to accelerate this path to drug discovery by constructing an NF-focused Preclinical Hub to supercharge the development of NF treatments.

CTF's Preclinical Hub is a commitment to speed innovation and build bridges across academia, industry, and the medical community. The Preclinical Hub will streamline access to the best preclinical

models and guide each potential treatment through a swift and appropriate screening journey. This solution will pave the way for the efficient selection of NF-relevant treatments for clinical trials.

The CTF Preclinical Hub is a life-changing innovation that uses CTF's network of experts, collaborators, and resources to close major gaps.

The Preclinical Hub will offer:

- Negotiated Master Service Agreements
- Predetermined protocols and tests
- Access to CTF models, data tools, libraries, and biomarkers

With a proposed investment of \$7 million over five years, our Preclinical Hub will catalyze drug discovery, increase testing, and speed the approval of potential

treatments. This isn't just a resource—it's a revolution in NF treatment and research.

Watch for more news and information about this exciting new initiative at ctf.org

Researchers interested in contributing to or learning more about the Preclinical Hub are invited to contact Irene Morganstern at imorganstern@ctf.org.

What is a preclinical model?

A preclinical model is a simplified representation of a disease or condition that scientists use in a laboratory before testing potential treatments in humans. It could involve studying cells, tissues, or animals to gain a better understanding of the condition and to evaluate the effectiveness and safety of new drugs before moving on to clinical trials involving humans.

CTF and Global Coalition for Adaptive Research Announce Strategic Alliance to Implement NF Platform Clinical Trial

The Children's Tumor Foundation and Global Coalition for Adaptive Research (GCAR) recently announced their alliance to accelerate the development of treatments for patients with all types of neurofibromatosis or schwannomatosis. CTF and GCAR are partnering to operationalize a first-of-its-kind clinical trial for patients with NF that was initially designed through the EU-PEARL initiative.

The announcement of this strategic alliance follows a 3-year, 26-million-euro investment from the Innovative Health Initiative (IHI), formerly called the Innovative Medicines Initiative (IMI). EU-PEARL was a public-private partnership dedicated to transforming clinical trials by making them more efficient and patient-centered. Through this partnership, leading organizations

representing patients, clinicians, researchers, health authorities, and industry collaborated to design the first-ever Phase 1 / Phase 2 global platform basket trial for patients with neurofibromatosis type 1 (NF1) or schwannomatosis (SWN), including NF2-related schwannomatosis (NF2-SWN), formerly referred to as neurofibromatosis type 2.

GCAR was formed with the mission to speed the discovery and development of treatments for patients with rare and deadly diseases by serving as the sponsor of innovative trials.

The NF platform trials will be built to complement CTF's NF Preclinical Hub, a comprehensive infrastructure to accelerate the availability of clinical trial-ready treatments, including gene therapy.

NF CLINIC NETWORK EXPANDS

CTF is excited to announce newly approved NF Clinic Network (NFCN) clinics in Arizona and California. With these clinics, the NFCN now recognizes 70 NF clinics throughout the U.S. and Canada, giving patients and their families more access to quality NF care. The three new clinics to the NFCN include:

Phoenix Children's Hospital in Phoenix, Arizona

UCSF Benioff Children's Hospital, serving San Francisco and Oakland, California

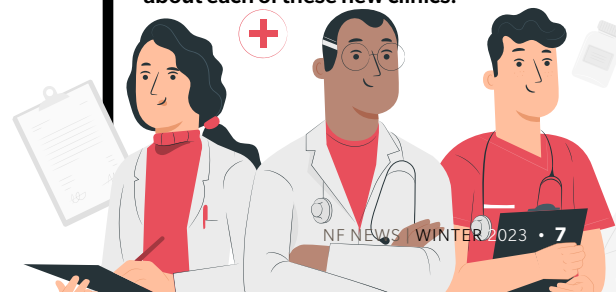
Valley Children's Health in Madera, California

The NFCN recognizes clinics that provide comprehensive medical care to individuals with NF, foster patient education, and encourage participation in clinical research trials and the NF Registry. Since the inception of the NFCN in 2007, CTF has distributed over \$2.5 M to clinics to support quality care and education.

Please visit ctf.org/doctor for more details about each of these new clinics.

“We are excited to work with the Children's Tumor Foundation to build a patient-centric clinical trial that will rapidly and efficiently evaluate multiple investigational therapies for the treatment of NF... Our alliance with CTF exemplifies a collaboration that places patients and the community at the forefront of clinical research.”

—DR. MEREDITH BUXTON, CEO & PRESIDENT OF THE GLOBAL COALITION FOR ADAPTIVE RESEARCH



Fall Fundraising Events

45th ANNIVERSARY NATIONAL GALA

The Time is Now

2023 NATIONAL GALA

The Children's Tumor Foundation's 2023 National Gala unfolded on November 13th, dedicated to recognizing the NF Community and our joint endeavors in supporting crucial NF research. The gathering occurred at the opulent Gotham Hall, situated in the heart of New York City. The evening's proceedings were also live-streamed globally, accessible for viewing on the Foundation's YouTube channel. Taking on the role of the evening's host was the accomplished actor and producer Jonathan Sadowski. The evening celebrated CTF's 45th anniversary with a theme of "The Time is Now," creating an inspirational evening filled with hope.

Mark and Michelle Oppenheimer were presented with a Humanitarian Award for their passion and vision to help the Foundation end NF. Owners of the fastest-growing executive search firm in the world, Modern Executive Solutions, Mark and Michelle became involved with the Foundation earlier this year when their nearly three-year-old daughter, Riley, was diagnosed with NF1. Resolved to do everything they can, Mark recently joined the Foundation's Board of Directors, and he and his wife have dedicated themselves to ensuring that NF patients have the best care possible.

The Foundation also honored Jim Thoms and the Thoms family with the evening's second Humanitarian Award for their lifelong support of the Foundation and their leadership in funding CTF's NF2-SWN Accelerator Initiative, a \$2.3 million program investing in gene therapy and new drug development for patients like Camille Thoms, who lives with NF2-SWN. Without the Thoms family, this program would not have been realized. The Thoms family also hosts the annual Halloween Bash (read more below), which has raised more than \$1 million toward the CTF mission over the past 18 years.

Kevin Martin was named the 2024 CTF National Ambassador, an honor that was bestowed upon him by last year's Ambassador Michele Holbrook. Kevin was diagnosed with NF1 at just two years

old by his pediatrician, then later diagnosed with dwarfism at five years old. Kevin is the son of Honorary Board Member Linda Halliday Martin and he and his family have been actively involved with the Children's Tumor Foundation since he was a young child, attending many yearly events and fundraisers. Fueled by a passion for video production and storytelling, Kevin has channeled his talents into meaningful contributions as a member of the CTF Junior Board and is enthusiastic about his upcoming Ambassadorship.

The Foundation was honored to present the Cloud Carrier award to the Gilbert family in honor of Nick Gilbert. For decades, Dan and Jennifer Gilbert, Nick's parents, have been steadfast supporters of the Children's Tumor Foundation and the broader NF community through the Gilbert Family Foundation and NF Forward, both of which are dedicated to funding cutting-edge research aimed at accelerating a cure for NF.

The Children's Tumor Foundation recognized the legacy of Nick Gilbert at our National Gala. Nick was a shining light for all of us. His laughter, his smile, his bow tie, and his relentless work on



2023 Humanitarian Award recipient, Mark Oppenheimer and his daughter, Riley



2023 Humanitarian Awardee Jim Thoms



2024 CTF National Ambassador Kevin Martin



Dan and Nick Gilbert



behalf of his fellow NF patients will be remembered by all of us in the NF community and beyond. In 2011, he was distinguished as the Foundation's NF Ambassador, and in recent years, he actively served as a dedicated member of the CTF Junior Board. His life and spirit will continue to inspire our work for years to come.

Our gratitude to our distinguished group of Gala Co-Chairs, including Erica Hartman-Horvitz, Tila Falic Levi, Liz Rodbell, and Clara Wilpon. For photos, videos, additional details, and fundraising totals, go to ctf.org/news.

beNeFit XI

On November 18th, over 1,800 supporters gathered at Huntington Place in downtown Detroit, Michigan, for *beNeFit XI*, NF Forward's annual fundraiser hosted by Dan and Jennifer Gilbert. The sold-out event was a "Color Filled Night to Cure NF" and included appearances by members of the Detroit business and philanthropic community, as well as family and friends of Nick Gilbert. The evening honored the life and legacy of Nick and included an inspiring video about his journey and struggles with NF.

Over the last eleven years, the annual *beNeFit* has raised more than \$60 million to fund audacious research in the areas of gene therapy, vision restoration, and more, giving hope for a future without NF to the NF community.

DANCING WITH OUR STARS

Dancing with Our Stars Little Rock 2023 was bigger than ever, with over 500 guests and raising a record-breaking \$335,000. This year's six stars were Burt Hicks, Cat Sims, Gina Radke, Luke O'Gary, Nathan Kirby, and Tanya James. All six performed a two-minute dance routine as a grand finale to their fundraising campaign. The Mirror Ball Champion trophy went to Encore President Burt Hicks, and the Best Performance trophy went to Luke O'Gary, of Keet O'Gary Construction. The night was hosted by the 2023 DWOS Co-Chairs, Ted and Julie Mullenix.

Thanks to our five amazing presenting sponsors, Encore Bank, Galley Support Innovations, Jersey Mike's Subs, Lori and Mark England, and Keet O' Gary Construction, for fueling the CTF mission.

HALLOWEEN BASH

The 18th Annual Halloween Bash took place on October 21st. Each year, the Halloween Bash raises critical funds for the Children's



Roland and Nicole Thoms with daughter, Camille at the Halloween Bash

Tumor Foundation and is hosted by the Thoms family in honor of their daughter, Camille, who lives with NF2-SWN.

Special appreciation goes to Roland and Nicole Thoms of Varsity Painting, along with their family and the participants and backers of the yearly Halloween Bash. The dedicated Varsity team, comprising friends, employees, and customers, has played a major role in funding research aimed at developing treatments for individuals affected by NF.

CELEBRITY POKER TOURNAMENT

On October 26th, CTF hosted an annual Charity Poker Tournament hosted by partners Poker4Life, in which 100 players raised more than \$60,000 for NF research. The event featured celebrities, including Mark Feuerstein, Jonathan Sadowski, Josh Brener, and Ben Shenkman. The organizing committee was chaired by NF dad David Nimmons. Special thanks to our Full House Sponsor, Colbeck Capital Management.

BOSTON DONOR RECEPTION

On November 1st, the Boston community came together for a second year at Season's 52, once again raising more than \$100,000 toward CTF's mission. The evening included mingling, cocktails, and a lively conversation with NF researcher Vanessa Merker, PhD, of Harvard Medical School, who works on the INTUITT Trial for NF2-SWN (co-funded by CTF) and CTF Director of Preclinical Initiatives Irene Morganstern, PhD. The discussion was moderated by Michele Przyppyszny, CTF's Chief Advancement Officer. A special thanks to the host and planning committee: Shannon Chandley, Mady Donoff, Leslie Kates, Stacy Kates Levy, Lisa Utzinger Shen, Judy Shwachman, Richard Soll, and Carol Walsh.

The Children's Tumor Foundation expresses profound appreciation to the organizers, attendees, sponsors, and donors who contributed to the success of these celebratory events. Your invaluable support is crucial to advancing our mission of discovering treatments for all individuals affected by NF, and for that, we extend our heartfelt thanks.

From Nissa Novas on behalf of the Children's Tumor Foundation

Nissa lives with NF2-related schwannomatosis (NF2-SWN), formerly known as NF2.

To all my fellow CTF warriors,

Today, I am reaching out to you with the same urgency that I feel in my life right now: **The Time is Now** to end NF.

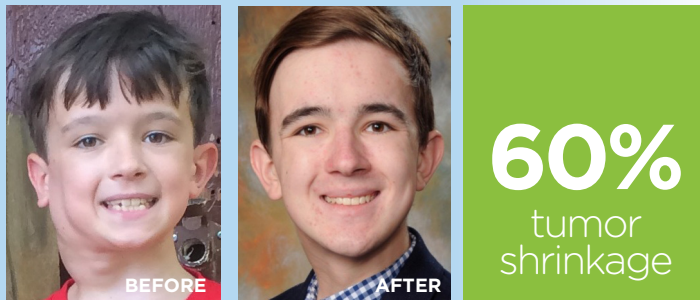
Your past donations and involvement with the Children's Tumor Foundation (CTF) have made a huge impact on my life. I'm asking you to join me at ctf.org/now with a donation of any size. Let me tell you how much your gift this year will make a difference.

My life's journey has been profoundly affected by NF. I am living with NF2-related schwannomatosis, a complex condition that has shaped my life, and the lives of so many others. Around 4 million individuals around the world live with some type of NF. Perhaps you are one of them, or you know someone who is?

A major turning point in the lives of all of us who are affected by NF is best told in a story you might remember: that of **Philip Moss**.

Back in the spring of 2011 at the tender age of 6, Philip encountered the unexpected. Philip's neck began to swell, which set off alarms for his parents. Despite medical intervention, the swelling persisted, prompting surgery to investigate further. The revelation was life-altering: a plexiform tumor and a diagnosis of NF1.

But Philip's journey led him to a groundbreaking clinical trial for a medicine called selumetinib. The road was marked by initial challenges and side effects, but after six months, a transformation began. The tumor halted its growth, and over time, it receded. Selumetinib became Philip's superpower, shrinking the tumor by 36% after one year and over 60% after nearly five years.



Philip Moss before and after taking selumetinib

We all celebrated as the Children's Tumor Foundation announced the FDA approval of selumetinib (now available as Koselugo) back in 2020, making it available for thousands like Philip who battle inoperable plexiform neurofibroma tumors from NF1. **This was the first ever - and still the only - FDA drug approval for NF.**

Philip's story is one of resilience, hope, and gratitude for the CTF-initiated research that crafted the road to drug approval. **Research that was funded by your donations! But we're not done yet!**

I celebrate Philip's triumph and the hope it represents for NF patients, yet my heart is heavy as it longs for a treatment like Koselugo. **I yearn for the moment when there is a breakthrough for patients like me.** As I reflect on Philip's success, I can't help but wish for a similar chapter in my own story.



I was diagnosed with NF2-SWN at the age of 22, just as I embarked on the challenging yet rewarding path of medical school. Two months after my diagnosis, a successful surgery removed a meningioma pressing against my brain, allowing me to pursue my dream of becoming an emergency room physician. For ten years, I practiced medicine, navigating the hurdles that NF2-SWN presented with determination.

However, NF2-SWN is an unrelenting force, and its impact on my life deepened. Deafness enveloped me, and vocal cord paralysis silenced my voice. A tracheostomy tube became a lifeline in 2013, altering the essence of how I breathe and speak. Vision problems, severe dry eyes, and a partial retinal detachment added to my intricate tapestry of challenges.

Chronic pain, vertigo, tinnitus, and severe headaches became constant companions. Complete loss of balance, swallowing difficulties, facial nerve paralysis, and muscle weakness added to the battles I waged. I endured extensive tumor removal from my abdomen and pelvis, coupled with a radical hysterectomy and bowel resection. A brain surgery in 2019, placement of a brain shunt and a surgical feeding tube, marked another chapter in this ongoing journey.

Despite these immense challenges, early in 2023, I was determined to travel from Maryland to New York to participate in CTF's Make NF Visible photo shoot. I'm forever grateful that I made that trip, because my weakness has worsened significantly in the short time since, and I would never be able to make that trip today. As part of that project, I reflected on the profound impact of your support.

Each advancement in NF research, every discovery, promises hope to those like me, and is a testament to your generosity and belief in a better tomorrow.

So, I thank you. And I humbly ask you to continue and deepen your CTF support by returning the enclosed envelope or donating online at ctf.org/now.

With every donation, NF research moves forward. Your gift will fuel the quest for treatments for every manifestation of NF, including my own, NF2-SWN, as well as NF1 and all types of schwannomatosis. Together, let's create a future full of success stories like Philip's.

The Time is NOW for the Children's Tumor Foundation to end NF. CTF-funded research paved the way to an approved drug for NF1, and is now leading the way with a platform trial for NF2-SWN, with more platform trial designs in progress for all types of NF. This impact is because of you - your gifts are desperately needed to create a future filled with hope and triumph over NF.

Please donate today at ctf.org/now to change the course of our tomorrows.

With heartfelt gratitude,



Nissa Novas
NF Warrior and Advocate

Scan this QR code
with your
mobile phone to
donate online.



Donor Acknowledgments

As of September 2023, CTF launched a new process for acknowledging donations and donations made in tribute. Your donation receipts will now be emailed, regardless of whether you donated online or via check, wire, or stock. You will be mailed a letter if we have no email address on file, and if your contribution is more than \$5,000, you will also be mailed a letter.

As a result of this new process, donor acknowledgments can be emailed in as little as 48 hours and can be easily retrieved in our database for future reference. We made these changes with our donors in mind and hope that a more efficient acknowledgment of your gift will benefit you as trusted investors in our mission.

Should you have questions or comments regarding this change in process, please don't hesitate to get in touch with donorrelations@ctf.org

Extraordinary Spirit: **CARLY MCKAY**

As a child, Carly McKay participated with the NF Endurance team as an NF Hero, a former CTF program in which young people living with NF served to inspire endurance athletes—which Carly did in bundles with her story, strength, and joyful personality. Now an adult, Carly has joined the NF Endurance team as an athlete, raising money and awareness for NF.

Between classes and extracurriculars at San Jose State University, Carly spent the early part of 2023 training for the Rock 'n' Roll Half Marathon. The race took place on June 4, and Carly ran with a handful of classmates that she recruited to join the race. This is the second year that she has participated on the NF Endurance Team in her hometown of San Diego – joining a family tradition since she was four years old.

“By the age of 3, I developed tumors on my optic nerves—optic gliomas that could cause vision loss for me,” said Carly about her diagnosis. “It was then that my parents began taking me to Children’s Hospital in San Diego for weekly chemotherapy for two-and-a-half years, with the hope that my tumors would not cause vision loss. After the chemo worked and shrunk my tumors, I have followed up with yearly MRIs and everything is still stable and looking great!”

The photo of Carly below is from the 2023 Rock 'n' Roll Half Marathon, and was the winner of our summer Make NF Visible photo contest!



“Without CTF, I probably would have never met anyone else with NF since it was so rare.”

NF HERO CARLY MCCAY

It was when she was four that her mom, stepdad, and brother joined the NF Endurance team in honor of Carly, and ran for many years to raise funds for NF research – research that has resulted in advances in treatment since Carly went through chemotherapy.

“There has been a lot more research and development since I was first diagnosed,” Carly said.

NF Endurance is a national program that allows supporters to join endurance events and raise funds for NF research. Joining this Children’s Tumor Foundation effort connected her to other people with NF and helped her meet others facing similar issues, which normalized her experience.

With the run, Carly says she is giving back to the community that shaped her. By raising awareness, she hopes other families who receive an NF diagnosis will be less scared.

“[NF is] part of who I am, but it doesn’t define what I’m capable of,” she said. “I’ve always wanted to [run with NF Endurance] after watching my family run for me. I thought it was about time for my turn! And to do it for all of the other NF kids and show you can do anything, that just because I have NF doesn’t mean it will stop me from doing anything. Crossing the finish line was the best feeling in the world, and I have never felt prouder of myself.”

The run came at a significant time in her life. Carly is graduating with her teaching credential in December. As a student, she struggled with a learning disability due to NF and now wants to help other children with learning disabilities.

Through the Children’s Tumor Foundation, she connected with other NF patients and has been inspired by their stories. After overcoming her own struggles in school and giving back to the community through her fundraising runs, Carly has an inspiring story of her own.

When asked what advice she has for others who are considering running for the cause, Carly said, “The best advice I have is your [race] time does NOT matter! You are one step further than the day before, and you should be proud of yourself and how far you have come!”

Visit nfendurance.org to find a race and join the team.



stories

OF NF

Benjamin NF1

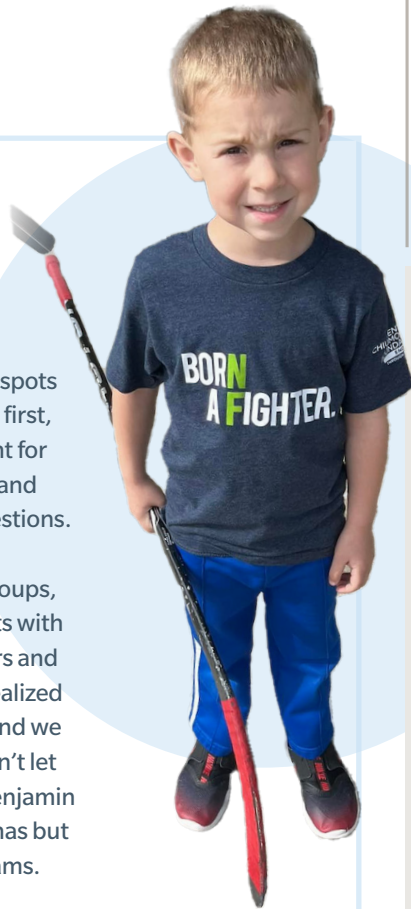
Benjamin was diagnosed at 18 months old due to having too many café au lait spots and freckling in the groin. At first, we didn't know what it meant for his future. We were worried and scared and had so many questions. Then we started to educate ourselves, joined support groups, and scheduled appointments with all the recommended doctors and specialists. As a family, we realized that this is not going away, and we needed to make sure we didn't let this diagnosis define who Benjamin is, but rather something he has but still can do whatever he dreams.

All his appointments are normal now, and we do our best to educate those around us every day. Benjamin has always been very calm and such a brave and strong kid going through more in a year than most kids do their entire lives, including countless appointments, MRIs under general anesthesia, blood draws, unexplained headaches, vomiting, random pains, and balance issues.

Benjamin enjoys swimming in his Papa's pool all summer long and doing just about anything kids like to do outside. He has such a big heart and loves animals (especially his three cats Loki, Raya, and Maui) and his friends and family, especially his big brother Freddie. He enjoys game nights with his family, going golfing, and seeing his favorite hockey team play—the Detroit Red Wings!

We don't want to think any of his dreams or goals could be negatively impacted by NF so we just keep pushing forward in a positive way. It is what keeps us happy and enjoying life!

- Submitted by Rachel, Benjamin's mom



Dana K. NF2-SWN

I was diagnosed [with NF2-related schwannomatosis] at 14 years old and had a really hard time fitting in as my hearing got worse. Not too long after I switched schools, I had to figure out how to fit in with people who already had friend groups. Almost everyone was really nice, but it is hard to fit in when everyone else is hearing. I decided I wasn't going to let that interfere with my high school journey so I chose to own my NF2-SWN and be positive and not care what others thought.

Living with NF2-SWN has its up and downs for me. When I started high school, I told myself I was going to own it and not let my diagnosis get in the way of doing what I love to do. I graduated college with a degree in Graphic Production in 2020 during COVID. Between my brain surgeries and the pandemic, I found myself struggling to find jobs because there were minimal opportunities for deaf people with learning difficulties that can't drive. I know I have to accept my limitations but am still hopeful for my future with the support of my family and NF support groups.

I have loved photography ever since I picked up my camera back in high school. I went to the Deaf and Hard of Hearing program at Rochester Institute of Technology and got a vocational degree in Graphic Production. I love to spend time with my family and our dog and am very excited to be in the process of getting a Hearing Service Dog.



NF Registry is a patient-driven resource for accelerating research and finding treatments for all forms of NF. It is the most efficient way to raise awareness for NF, expand the NF community, and connect to help end NF. Joining the NF Registry is easy, and will make an important difference in the fight against NF.



Join today at nregistry.org

NF SUMMIT

The 2023 NF Summit

The NF Summit is CTF's annual patient and family gathering, which brought together more than 450 NF patients and families, volunteers, event organizers, researchers, clinicians, patient advocates, friends, and supporters—who all have a connection to NF.

The 2023 NF Summit hosted many notable sessions, including:

Christopher Moertel, MD, NF Summit Co-Chair and Clinical Director of the Pediatric Brain Tumor Program at the University of Minnesota shared updates on clinical trials in nutraceuticals that lead to less toxic treatment and prevention strategies through a specific dietary component.

A panel of experts presented resources for living with hearing loss. This session included Heather Thompson, PhD, NF Summit Co-Chair, a Speech-Language Pathologist and Department Chair at California State



University, Sacramento; Ariel Cassar, AuD, Director of the Audiology Clinic at Sacramento State University; and Ken Arcia, who lives with NF2-SWN and has served as the President of ALDA, Association of Late Deafened Adults.

Bruce Korf, MD, PhD, who chaired CTF's Medical Advisory Committee for many years, is a leading NF expert and clinical geneticist at the University of Alabama. He discussed the NF Clinical Trials Consortium, reviewing its structure and discussing trials completed or ongoing, and sharing plans for the future of

the Department of Defense-funded program.

Special thanks to our sponsors, including: Presenting Sponsor, Alexion AstraZeneca Rare Disease; NFlection Therapeutics; SpringWorks Therapeutics; Colbeck Capital Management; Recursion; and to B the Difference for supporting patient scholarships.

All educational sessions from the 2023 Summit are now available to view online at nfsummit.org

2023 Make NF Visible Award Winners

The Children's Tumor Foundation announced the second annual Make NF Visible Community Recognition Awards at the 2023 NF Summit. These awards recognize individuals or groups at every level of involvement who Make NF Visible either in the local community, nationally, or globally.

2023 Volunteer of the Year
Peter Lindeback

Community Advocate Award
Jessica Jemente

Clinician Award
Verena Staedtke, MD, PhD

Young Leader Award
Corey Altman

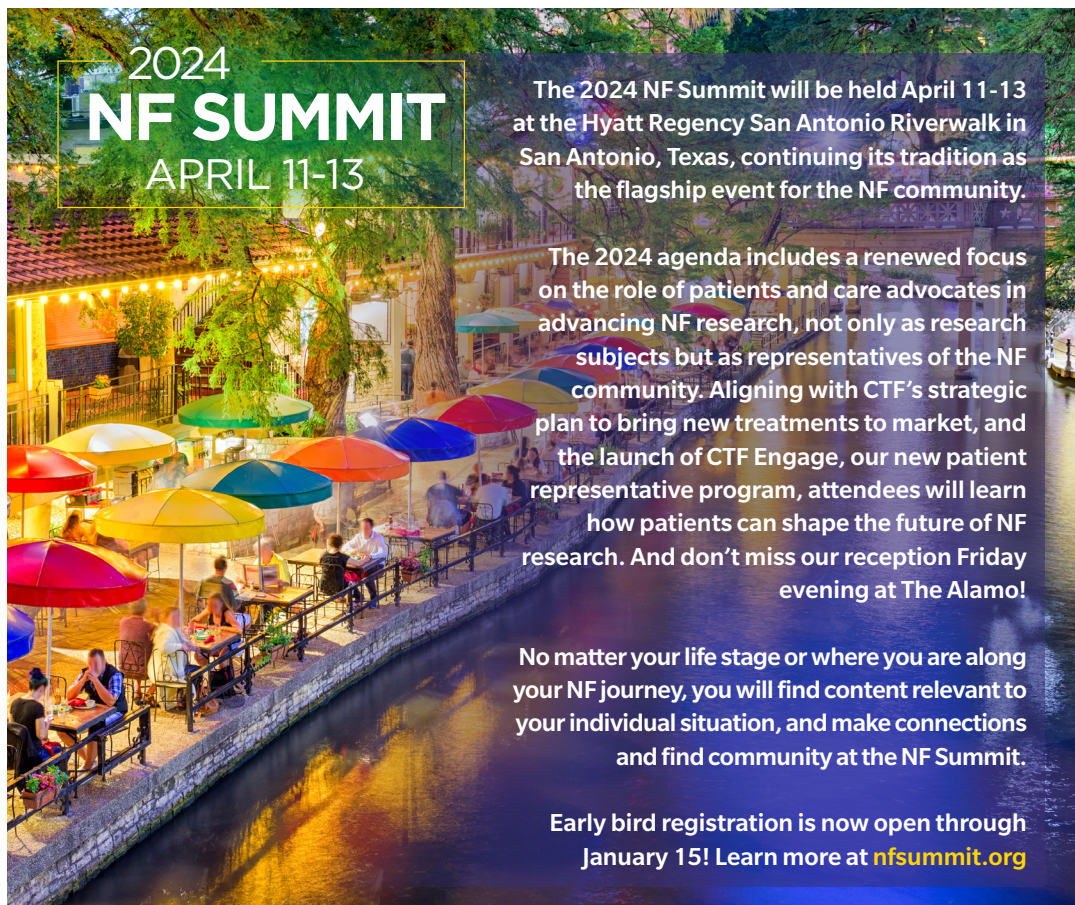
Patient Advocate Award
Danielle Bonadies

Researcher Award
Angela Hirbe MD, PhD

Make NF Visible Corporate Champion Award(s)
American Airlines and Love, Tito's

Global Reach Award
Samia Arslane

Fight NF Your Way Award
Emily Tseffos



The 2024 NF Summit will be held April 11-13 at the Hyatt Regency San Antonio Riverwalk in San Antonio, Texas, continuing its tradition as the flagship event for the NF community.

The 2024 agenda includes a renewed focus on the role of patients and care advocates in advancing NF research, not only as research subjects but as representatives of the NF community. Aligning with CTF's strategic plan to bring new treatments to market, and the launch of CTF Engage, our new patient representative program, attendees will learn how patients can shape the future of NF research. And don't miss our reception Friday evening at The Alamo!

No matter your life stage or where you are along your NF journey, you will find content relevant to your individual situation, and make connections and find community at the NF Summit.

Early bird registration is now open through January 15! Learn more at nfsummit.org

ENJOY A UNIQUE TOUR OF NEW YORK CITY!

The United Airlines NYC Half Marathon offers a behind-the-scenes run through several iconic Big Apple sights, including the Manhattan Bridge, Times Square, and Central Park. Guarantee your entry to this sell-out event by signing up with the NF Endurance team. Raise funds to end NF while you motivate yourself to train for a 13.1-mile race!

United Airlines NYC Half
March 17

Flying Pig Marathon (Cincinnati)
May 3-5

TD Five Boro Bike Tour
May 5

Colfax Denver Marathon
May 18-19

Rock 'n' Roll San Diego
June 1-2

BMW Berlin-Marathon
September 29

Bank of America Chicago Marathon
October 13

TCS New York City Marathon
November 3

For more information
visit nfendurance.org

CHECK OFF YOUR MARATHON MAJORS WITH THE CHILDREN'S TUMOR FOUNDATION

The NF Endurance team has entries available for three of the six highly coveted Abbott World Marathon Majors: BMW Berlin-Marathon, Bank of America Chicago Marathon, and TCS New York City Marathon. Each event has its own fundraising requirements, but all offer guaranteed race entry, a host of fundraising incentives, virtual training, and the inspiration of your NF community!

Bank of America Chicago Marathon

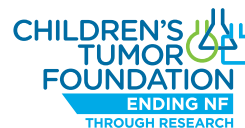


2023 BMW Berlin Marathon



PATIENT ENGAGEMENT

INTRODUCING CTF ENGAGE: A Patient Engagement Initiative from the Children's Tumor Foundation



This fall, CTF Engage welcomed its first cohort of NF patients and their families to serve as advocates in NF research.

CTF Engage is a new patient engagement program from the Children's Tumor Foundation that is designed to prepare individuals to add their perspectives during all phases of the research process – from the laboratory to the clinic to the community. Patient engagement promises to accelerate

the development of new treatments by focusing researchers on real-life issues they may not have otherwise considered.

Now selected, these Patient Representatives will undergo training on research and the drug development process and learn how to work with researchers, regulators, and other stakeholders. They will act as advisors, consultants, and co-investigators to help these experts understand what it is like to live with NF and what outcomes are

important to patients. Congratulations to our new Patient Representatives!

To learn more about the program, go to ctf.org/patientengagement, or contact us at info@ctf.org



Scan the QR code for more information!

SHINE A LIGHT NF WALK

The Shine a Light Walk is the premier fundraising program of the Children's Tumor Foundation. This year, 22 events across the country brought together thousands of people to support and celebrate our NF heroes and their families. Participant feedback from this year included "Shine a Light Walk was a great way to see the NF Heroes and help spread the word that more research is needed to find a cure!" and "This is a great way to meet others with NF!" and "Great time for a great cause!" Fundraising will continue until the end of December and we are well on our way to hitting our \$1.6 million dollar goal. Thank you to our local NF Heroes and their supporters, Walk Organizers, volunteers, participants, fundraisers, donors, and of course, National Presenting Walk Sponsor, Alexion AstraZeneca Rare Disease.



UTAH

Utah continues to raise the bar and grow year after year! From raising \$18,000 in 2021, to \$20,000 in 2022, to bringing in 285 Attendees and 19 Fundraising Teams to help get them over \$30,000 in 2023! Congratulations to Walk Organizer Brandie Evans for working so hard and breaking Utah Walk records!



IOWA

With 297 attendees and 11 teams, the Iowa Walk continues to strengthen the NF community and raised more than \$41,000 at this year's Shine a Light NF Walk! Iowa welcomed several new teams and had plenty of support from the community with sponsorships from seven local businesses. The Walk had face painting, balloon animals, safety services officers, dance teams, mascots, a DJ, food, and more! There was plenty of family fun for everyone. Congratulations to Walk Organizer Brittany Warren for her hard work year-round to make this an amazing day!

Cincinnati

Cincinnati had its biggest year ever in 2022 and carried that momentum forward into their 2023 campaign. With 495 attendees, the day was filled with family, friends, and fun, culminating in more than \$104,000 already raised to help end NF. Cincinnati consistently produces a day of engagement and fun for everyone with characters, mascots, games, lunch, live music, and more. Congratulations to walk organizers Jessica Samblanet and Shannon Savage on another successful year!



Learn more about the Shine a Light NF Walk program at shinealightwalk.org

CUPID'S UNDIE RUN

JOIN US IN 2024 IN ONE OF THESE LOCATIONS:

ATLANTA, GA
AUSTIN, TX
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BOISE, ID
BOSTON, MA
BUFFALO, NY
CHARLESTON, SC
CHICAGO, IL
CINCINNATI, OH
CLEVELAND, OH
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DENVER, CO
DETROIT, MI
JACKSONVILLE, FL
KANSAS CITY, MO
LOS ANGELES, CA
MINNEAPOLIS, MN
NASHVILLE, TN
NEW YORK, NY
ORLANDO, FL
PHILADELPHIA, PA
PHOENIX, AZ
PITTSBURGH, PA
RALEIGH – DURHAM, NC
RENO, NV
SAN FRANCISCO BAY AREA, CA
ST. LOUIS, MO
ST. PETERSBURG, FL
VIRGINIA BEACH, VA
WASHINGTON, D.C.
WILMINGTON, DE

Sign up today at:
cupids.org

2024 CUPID'S UNDIE RUN REGISTRATION IS OPEN!

Thank you for an incredible 2023! Our fight to end NF continues – register today for Cupid's Undie Run 2024.

Cupid's Undie Run is a mile(ish) fun run in which brightly adorned, underwear-clad team members run outdoors to support the CTF mission. Cupid's has rapidly expanded to cities across the United States and abroad, and has raised millions for NF research.

"It's an opportunity to feel like you are directly impacting the research efforts already underway to find a cure. You can feel the communal energy at the party and the run to support the family members who are living daily with NF."

"The most fun charity event I've ever been to, for an amazing cause."

Summer Fun at NF CAMP

This summer, the Children's Tumor Foundation welcomed 64 kids from 20 states and 3 countries to NF Camp in Utah. With almost 50 new faces, these youngsters living with NF had a week of forming friendships and non-stop fun! At the host camp, campers enjoyed horseback riding, rock climbing, fishing, arts and crafts, and swimming. They also went on fabulous field trips to an amusement park, a waterpark, an arcade/bowling alley/GoKart center, and an aerospace museum. The week ended with a team-based "Survivor Day," and a Q&A with Utah's very own Dr. David Viskochil, who joins CTF's NF Camp each year to answer questions about NF from kids, young and old.

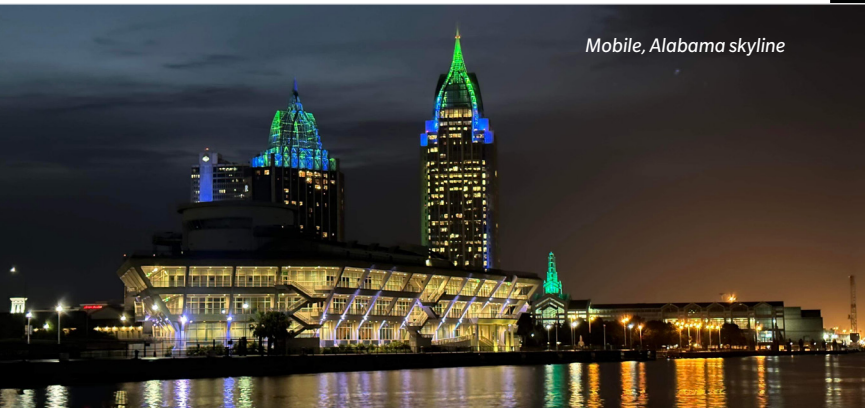


Awareness Month HIGHLIGHTS

NF Awareness Month

Each May, the Children's Tumor Foundation celebrates NF Awareness Month, a multifaceted global campaign in which we work 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.

World NF Awareness Day takes place on May 17, and brings attention to the inspirational and remarkable stories of those living with NF and the critical need for research to better their lives. Shine a Light on NF is one part of a month-long awareness campaign called 'Make NF Visible' that consists of online activities and community events designed to educate the public about NF.



Mobile, Alabama skyline

SHINE A LIGHT ON NF 2023

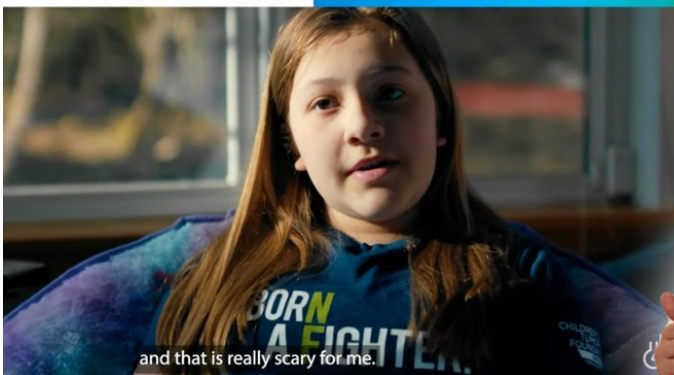
Nearly 500 world-famous buildings, bridges, and architectural icons participated in this year's Shine a Light on NF campaign, showing their support in the global fight against NF by lighting up in blue and green, the official colors of the NF cause.

Launched by the Children's Tumor Foundation in 2014 to increase public awareness of NF, the Shine a Light on NF campaign has grown substantially over the years. CTF partners with NF organizations, medical and research institutions, and corporate and media partners worldwide to expand awareness globally. In addition to the building light-ups, donated billboards from Lamar Advertising Company amplified the NF awareness message into homes and communities nationwide.



New York City's Empire State Building

To Make a DONATION Call 1-800-323-7938



WORLD NF DAY LIVE EVENT

In celebration of May 17, World NF Awareness Day, the annual Make NF Visible: A World NF Day Live Event took place virtually and in person at watch parties nationwide. The livestream included the world premiere of CTF's two new short documentary films about two young teens navigating NF, school, friends, and family. Along with these films, additional patient story videos from CTF's Make NF Visible campaign were shared.

PROCLAMATIONS & EVENTS



Twenty states and 31 cities issued proclamations declaring May as NF Awareness Month or May 17 as NF Awareness Day. Many more family and community events occurred throughout the month, both online and in person, as the NF community donned blue and green, posted NF Facts each day of the month, and shared videos and photos about the NF journey.

Raising awareness of NF is the critical first step in generating the funding that's needed for research that will improve the lives of all NF patients. For more information about NF Awareness Month and Make NF Visible, visit makenfvisible.org.



Europe Paris Reception

CTF Europe hosted an intimate reception on November 6th in Paris for some of our closest friends in France and across Europe to talk about the Foundation's efforts to fund the first-ever platform trial for NF in Europe. The panel was joined by special guest Thomas Young, an NF patient and UK Paralympic Champion who spoke about his journey and what treatments for NF would mean to him and the global NF community. Moderated by CTF Europe's Chief Scientific Officer Marco Nievo, PhD, our panel of European Experts included Pr. Mattieu Robert, Service d'ophtamologie, Hopital Necker-Enfants Malades; Pr. Pierre Wolkenstein, Chef du Service de Dermatologie, Hopital Henri-Mondor; and Pr. Michel Kalamarides, Directeur Medical du DMUCHIR Chirurgie, Innovations, Recherche, Hopital Pitie-Salpetriere. Hosted by CTF Europe Board members Samia Arslane and Sissy Windisch, along with donor and NF parent Sandra Saidi, this is the first of many events to be held prior to the 2024 NF Conference in Brussels.

Welcome New CTF Europe Board Member



CTF EUROPE BOARD MEMBERS

- Annette Bakker, *Chair*
- Samia Arslane
- Magda Chlebus
- Nikola Gazdov
- Richard Horvitz
- Simone Manso
- Sabine Moravi
- Stuart Suna
- Sissy Windisch

MASTERCLASSES IN NF

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

Reserve your spot today:
ctfeurope.org/nfmasterclasses

INFER is an initiative of Children's Tumor Foundation Europe

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 conditions that cause tumors to grow on nerves. These conditions 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.

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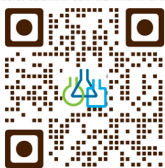
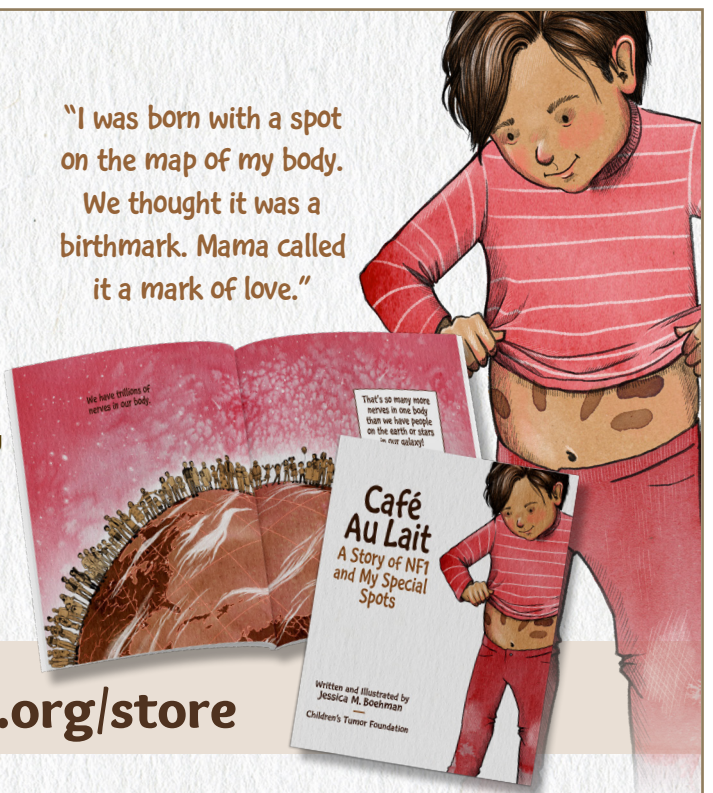
Café Au Lait

A Story of NF1 and My Special Spots

A new book for children from the
Children's Tumor Foundation

In *Café Au Lait*, young Enzo goes on a journey to discover the meaning of his special spots. He uses the map on his skin to help him understand another map – the nerves inside his body. We learn along with Enzo that he lives with a condition called neurofibromatosis type 1, or NF1, that causes tumors to grow on nerves. Because NF1 is most often diagnosed in childhood, this book is meant to inspire conversation and understanding for children living with NF1 and their classmates, friends, and families.

"I was born with a spot
on the map of my body.
We thought it was a
birthmark. Mama called
it a mark of love."



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