ANNUAL REPORT

CHILDREN'S TUMOR FOUNDATION 2023

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

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What is NF?

NF refers to a group of genetic conditions that cause tumors to grow on nerves. NF includes neurofibromatosis type 1 (NF1) and all types of schwannomatosis (SWN), including *NF2*-related schwannomatosis (*NF2*-SWN), formerly known as neurofibromatosis type 2. Some type of NF occurs in approximately one in every 2,000 births. These conditions affect all populations equally, and may lead to blindness, deafness, bone abnormalities, disfigurement, learning challenges, disabling pain, or cancer.

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 who live with NF.

Our mission

Drive research, expand knowledge, and advance care for the NF community.

Our vision

End NF.

Chief Executive Officer Annette Bakker, PhD, with NF Hero Annabelle

Dear friends,

Throughout 2023, the Children's Tumor Foundation (CTF) celebrated 45 years of pioneering research and breakthroughs for neurofibromatosis and schwannomatosis (NF). Since 1978, CTF has illuminated the entirety of NF understanding, nurturing early-career researchers and supporting early-stage research to become a catalyst for groundbreaking advancements.

We are now in a new era, where our decades of research, drug discovery, and development are ready to become long-expected life-changing treatments for patients. We have over 60 clinical trials in progress, one drug approved, one drug submitted to the FDA, and another drug in Phase 3. Thanks to you, our steadfast donors, the field is more than ready, the science is ready, and the technology is ready. The time is now to reap the rewards of your dedication.

A decade ago, NF was not a viable interest for pharmaceutical companies. We proved this wrong by derisking NF for the entire industry, and your efforts are yielding significant returns. Ten pharmaceutical companies are now dedicated to NF, with two exclusively focused on this cause. Our investment in NFlection Therapeutics' clinical trial of a topical MEK inhibitor has led to exciting results, advancing the trial to its final phase. SpringWorks Therapeutics, a company we helped launch, submitted its MEK inhibitor drug for FDA approval. The INTUITT for NF2 platform trial, testing brigatinib—a compound discovered by our Synodos for NF2 researchers—published very positive results in the *New England Journal of Medicine*, and there is so much more to come!

Another of the year's most exciting developments is from a CTF-funded study pioneering a blood test to predict malignant peripheral nerve sheath tumors (MPNSTs) in NF1 patients. MPNSTs are rare but aggressive, and this study shared positive results that promise hope for early detection and intervention to prevent MPNST development. Next, we must fund the validation of these biomarkers to ensure their use in the clinic.

As we charge ahead, we aim to revolutionize NF care, addressing every step from diagnosis to therapeutic delivery for all NF manifestations. We continue to expand our NF Clinic Network, which now includes more than 70 clinics, ensuring that both new and previously diagnosed patients get the support and information they need.

We are committed to investing in patient-centered platform clinical trials that accelerate the process by testing multiple therapies simultaneously. In addition to INTUITT for NF2, our multi-year involvement with the European Patient-Centric Clinical Trial Platforms (EU-PEARL) has established a major platform trial for neurofibromatosis type 1(NF1) and schwannomatosis (SWN) in Europe. Through a strategic alliance with Global Coalition for Adaptive Research (GCAR), we are ready to implement this trial with our European colleagues.

Additionally, CTF launched a new framework to fast-track drug selection. This preclinical hub, based on our proven Synodos collaborations, will expedite potential treatments by providing all necessary drug screening tools and pre-negotiating required agreements. By addressing the significant delays that are all too often caused by contract negotiations, we can ensure that testing proceeds and speeds unhindered.

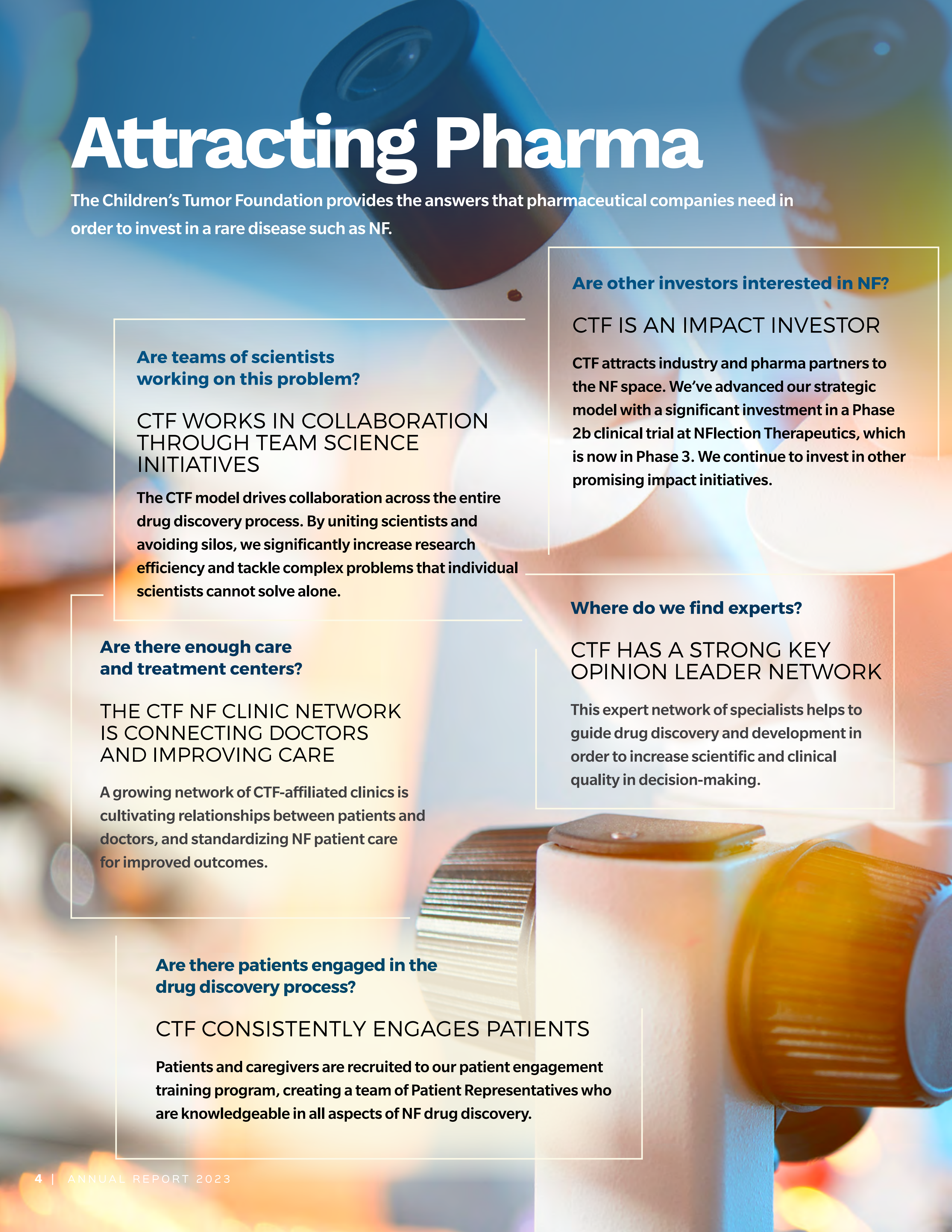
Throughout our history, we have taken risks where others would not and invested in possibilities ahead of the pack. In 2023, CTF partnered with NASA for the Year of Open Science, committing to data sharing, and we collaborated with the American Association of Physicists in Medicine (AAPM) to expand NF pain studies. Our investments in gene therapy, along with other funders, promise to change the future with next-generation therapeutics.

The NF Conference remains the world's premier NF event. In 2023, it brought over 600 researchers and clinicians to Scottsdale, Arizona, to discuss cutting-edge advancements. CTF Shine a Light Walk, NF Endurance, and Cupid's programs are flourishing, providing opportunities for the community to unite, grow, and raise funds. Our "Make NF Visible" and "Shine a Light on NF" awareness campaigns continue to attract more people to our cause.

I extend my heartfelt appreciation to our incredible community. Together, we are in this fight, and your vision of a world without NF guides our drive to bring treatments to patients. I am profoundly grateful to all of you and excited for what's to come.

Warmly and gratefully,

Annette Bakker, PhD, CEO



Attracting Pharma

The Children's Tumor Foundation provides the answers that pharmaceutical companies need in order to invest in a rare disease such as NF.

Are teams of scientists working on this problem?

CTF WORKS IN COLLABORATION THROUGH TEAM SCIENCE INITIATIVES

The CTF model drives collaboration across the entire drug discovery process. By uniting scientists and avoiding silos, we significantly increase research efficiency and tackle complex problems that individual scientists cannot solve alone.

Are other investors interested in NF?

CTF IS AN IMPACT INVESTOR

CTF attracts industry and pharma partners to the NF space. We've advanced our strategic model with a significant investment in a Phase 2b clinical trial at NFlection Therapeutics, which is now in Phase 3. We continue to invest in other promising impact initiatives.

Are there enough care and treatment centers?

THE CTF NF CLINIC NETWORK IS CONNECTING DOCTORS AND IMPROVING CARE

A growing network of CTF-affiliated clinics is cultivating relationships between patients and doctors, and standardizing NF patient care for improved outcomes.

Where do we find experts?

CTF HAS A STRONG KEY OPINION LEADER NETWORK

This expert network of specialists helps to guide drug discovery and development in order to increase scientific and clinical quality in decision-making.

Are there patients engaged in the drug discovery process?

CTF CONSISTENTLY ENGAGES PATIENTS

Patients and caregivers are recruited to our patient engagement training program, creating a team of Patient Representatives who are knowledgeable in all aspects of NF drug discovery.

Where can we find patients for clinical trials?

THE NF REGISTRY CONNECTS PATIENTS TO CLINICAL TRIALS

This patient-entered registry is structured to accelerate clinical trial recruitment, and fuels knowledge and understanding of the diversity of NF manifestations.

Where can we find new drug targets?

THE NF DATA PORTAL STORES OPEN DATA

Data is available and ready to use in the NF Data Portal, an open data repository established by CTF at Sage Bionetworks. The NF Data Portal is managed by expert specialists who collect, analyze, and release integrated data from top NF funding agencies, accelerating the identification of druggable targets.

Is there enough tissue available for testing?

THE NF BIOBANK PROVIDES TISSUE FOR RESEARCH

To solve the problem of a scarcity of relevant tissue to test, CTF created a centralized library of openly available samples for biomarker discovery and development. The NF Biobank is now managed by the Indiana University School of Medicine's DHART SPORE program.

How can we standardize the endpoints of clinical trials?

THE REiNS CONSORTIUM HELPS TO STANDARDIZE

REiNS (Response Evaluation in Neurofibromatosis and Schwannomatosis) is a worldwide consortium of clinicians and patients develops new clinical trial designs, and works with the FDA to establish drug approval criteria.

Have these drugs been tested in animal models?

CTF'S NF PRECLINICAL HUB ACCELERATES DEVELOPMENT

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

Strategic Plan

We Make Things Happen

The Children's Tumor Foundation is bettering the lives of more than 4 million people who live with some type of neurofibromatosis or schwannomatosis. We envision a world without NF, and our 2023–2028 Strategic Plan makes this vision a reality by driving research, expanding knowledge, and advancing care for the NF community.

For more than 45 years, CTF prepared for the critical work ahead by building NF awareness, education, and community. This complemented a robust emphasis on NF research funding and the building of essential networks. As the Foundation charges forward, our unwavering focus is to lead and accelerate the innovation that ends NF.

The Time Is Now

YESTERDAY
Established Research & Networks

TODAY
Catalyze & Accelerate Innovation

TOMORROW
Approve Treatments & End NF

Four Pillars of Innovation

Develop More Drugs - Expand the research field, develop panels of drug selection tools, double the number of research grants, and launch revolutionary projects.

Fast-Track Treatments - Expedite the discovery of life-changing therapies with an innovative preclinical hub model, the ultimate all-in-one solution for pharma and biotech pioneers.

Accelerate Clinical Trials - Strengthen the development and approval of drugs by catalyzing clinical trial consortia and platform trials.

Empower Stakeholders - Enhance the understanding of NF and the NF Registry, increase patient participation, and train ambassadors. Expand the NF Clinic Network and the number of physicians and specialists who treat NF, including adult care.

FUELED BY

- Research and Data That Is Patient and Clinician Informed
- Act Globally and Inclusively in All Elements of Our Support
- Action Over Talk: Be Assertive and Proactive
- Prioritizing Innovation and Leading Investments

Developing Drugs for NF

CTF research discovery resulted in the first FDA-approved drug for NF.

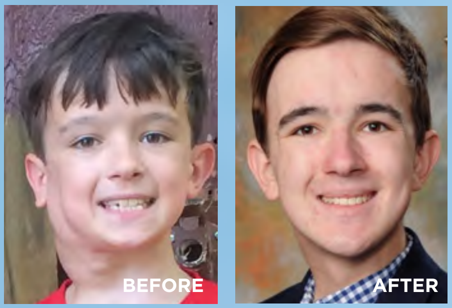
When the Children's Tumor Foundation announced the FDA approval of Koselugo (selumetinib) back in 2020, we celebrated along with the entire NF community. Selumetinib remains the first and only FDA-approved drug for any type of NF, specifically targeting inoperable plexiform neurofibroma tumors.

The FDA approval of Koselugo was the result of early-stage discoveries found in CTF's first team science innovation, the NF Preclinical Consortium. CTF researchers proved that MEK inhibitor drugs have the potential to affect the size of NF tumors. Their pioneering work took that potential and made it a reality: more than 70% of NF patients taking selumetinib in a clinical trial had shrinkage of 20% to 60% in the size of their tumors.

This groundbreaking research, made possible by the generous support of donors like you, underscores the crucial role you play in the CTF mission.

Koselugo:

Philip's Story of the Road to an FDA-Approved Drug for NF


BEFORE AFTER

60% shrinkage

"People don't ask me what is wrong with my neck anymore. I've found activities that I enjoy, and friends that enjoy being a part of my life. I enjoy reading, gaming, Boy Scouts, coding, and more. I'm thankful for all the donors that funded the doctors and researchers who made selumetinib possible. Now that it is FDA approved, I am thankful that others may experience what I have experienced."

— NF Hero Philip Moss

We did it once and we will do it again.

Building on this success, CTF has continued to invest in additional MEK inhibitor drugs and fuel major scientific collaborations. Currently, ten pharmaceutical companies are actively working on NF treatments. We are confident that these efforts will soon bring new treatments to patients and families affected by NF.

SpringWorks Therapeutics

In late 2023, SpringWorks Therapeutics, a company that CTF helped spin-off from Pfizer, announced positive results from their pivotal Phase 2b ReNeu trial evaluating mirdametinib, an investigational MEK inhibitor, in pediatric and adult patients with NF1-associated plexiform neurofibromas.

NFlection Therapeutics

CTF partnered with NFlection Therapeutics on a Phase 2b clinical trial evaluating NFX-179 Gel as a treatment for cutaneous neurofibromas (cNFs) in people with NF1. NFlection shared positive results this year, showing the topical gel significantly reduced the size of cNFs.

Fast Tracking Treatments

Preclinical Hub

The Children's Tumor Foundation is fast-tracking drug discovery by constructing an NF-focused Preclinical Hub to supercharge the development of NF treatments. The Preclinical Hub is built on the successes of the Preclinical Consortium and Synodos initiatives, both of which efficiently delivered treatments to patients.

The Preclinical Hub speeds up the approval of potential treatments by offering the following to academic, research, and pharmaceutical industry partners:

- **Access to disease models, data tools, drug libraries, and biological material**
- **Expert advice and support during preclinical study design and execution**
- **Prenegotiated Master Service Agreements**
- **Predetermined protocols and tests**

EXPERT COMMITTEES
Bring together experts to harmonize approaches and compose a robust and translatable workflow.

DRUG LIBRARIES
Enable rapid testing of compounds with demonstrated safety profiles in new indications.

IN VITRO TESTING
Assess which drugs have a beneficial effect on cells within an isolated environment.

IN VIVO TESTING
Assess the effects of drugs in a living organism, through mice and other animal models.

DRUG-BODY INTERACTIONS (PK/PD)
Focus on the effect of the body on a drug (PK) and the drug on the body (PD).

BIOBANK
Offer opportunity for scientists to derive knowledge from a biorepository of biological material from NF patients.

DATA/AI
Provide access to knowledge to ultimately inform the development of novel therapeutics.

Leveraging Our Proven Track Record

Synodos

Synodos was developed as the premier collaborative research model of the Children's Tumor Foundation. From 2014 – 2017, CTF assembled "dream teams" of doctors, scientists, and patients who worked together to solve problems too complex for any individual lab or researcher to solve. Dedicated teams of multidisciplinary investigators from world-class labs and medical centers performed rigorous drug testing for each type of NF. The progress from these initiatives laid the groundwork for further research and clinical trials that are currently in progress.

A landmark study recently published in the *New England Journal of Medicine* revealed exciting results for the use of brigatinib in treating *NF2*-related schwannomatosis (*NF2*-SWN). This breakthrough is a direct outcome of the Synodos for NF2 research initiative, which found promising evidence that brigatinib can help shrink the tumors of patients with *NF2*-SWN.

NF Preclinical Initiative

The NF Preclinical Initiative (NFPI) began in 2008 as the NF Preclinical Consortium (NFPC), a five-year, $7 million program that concluded in 2013. The NF Therapeutic Consortium (NFTC) continued the work of the NFPC, building on its infrastructure and discoveries.

Traditionally, it takes more than 15 years and costs hundreds of millions of dollars to translate a new discovery into one clinical treatment. The impact of the NFPI was clear: these teams completed 116 preclinical trials in 8 years, at a total cost of $11 million. The preclinical studies led to multiple clinical trials, including the MEK inhibitor selumetinib registration trial, which later became the first FDA-approved drug for NF.

Accelerating Clinical Trials

Platform Basket Trial: INTUITT for NF2

The Children's Tumor Foundation partners with Takeda Pharmaceuticals and six leading medical centers on a clinical trial called INTUITT for NF2, an innovative platform trial that evaluates multiple treatments simultaneously. Results of this landmark study, recently published in the *New England Journal of Medicine*, were extremely promising for the use of brigatinib in treating for the use of brigatinib in treating *NF2*-related schwannomatosis. The multi-center team found that brigatinib shrunk 10% of growing tumors and 23% of all tumors.

This initiative is a result of the landmark work of CTF's visionary Synodos for NF2 research collaboration and its leaders, CTF's NF2 Accelerator Initiative, an investment from Takeda Pharmaceuticals, and the participation of scientists at the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health (NIH).

Platform Basket Trials: EU-PEARL

CTF was a partner organization with EU-PEARL, a joint project under the European Innovative Health Initiative (IHI). This pursuit built platform trials in which multiple drugs are tested in parallel under the same clinical protocol. This approach allows more efficient identification of potential treatments. Thanks to CTF's advocacy efforts in Europe, NF was chosen as a prototype for rare diseases by the IHI. The NF component of EU-PEARL was co-lead by CTF and the Erasmus Medical Center in Rotterdam, Netherlands. In addition to an NF1 protocol, an SWN platform trial protocol has been developed that will enroll SWN patients, including *NF2*-SWNs patients, and will test the ability of drugs to shrink tumors.

GCAR Partnership

The Children's Tumor Foundation and the Global Coalition for Adaptive Research (GCAR), have aligned to accelerate the development of treatments for patients with NF1. Together, CTF and GCAR will operationalize a first-of-its-kind clinical trial for patients with NF that was initially designed through the EU-PEARL initiative. The platform trial will rapidly and efficiently evaluate multiple investigational therapies. The announcement of this strategic alliance followed a three-year, 26-million-euro investment from the IHI.

NFX-179 Impact Investment

CTF entered a new phase in its strategic NF research model by making a significant impact investment in a clinical trial at NFlection Therapeutics, a biotechnology company focused on the discovery and development of effective, targeted therapies for rare diseases. The trial involves NFX-179, a topical (on-the-skin) treatment. The NFX-179 treatment is for cutaneous neurofibromas (cNFs), which are tumors that grow in the skin or right underneath the skin, and result in disfiguring bumps. This trial has now moved into Phase 3 and is showing positive results.

Catalyzing Innovation

Strategic Partnership: Deep Science Ventures and Cancer Research Horizons

CTF has joined an alliance with Deep Science Ventures, a London-based venture and pioneer in the development of a curative gene therapy for patients with NF, addressing the root cause of the disease. CTF is a strategic partner to aid efforts in identifying possible opportunities in NF.

Focused Ultrasound Foundation and CTF Partner on NF Study

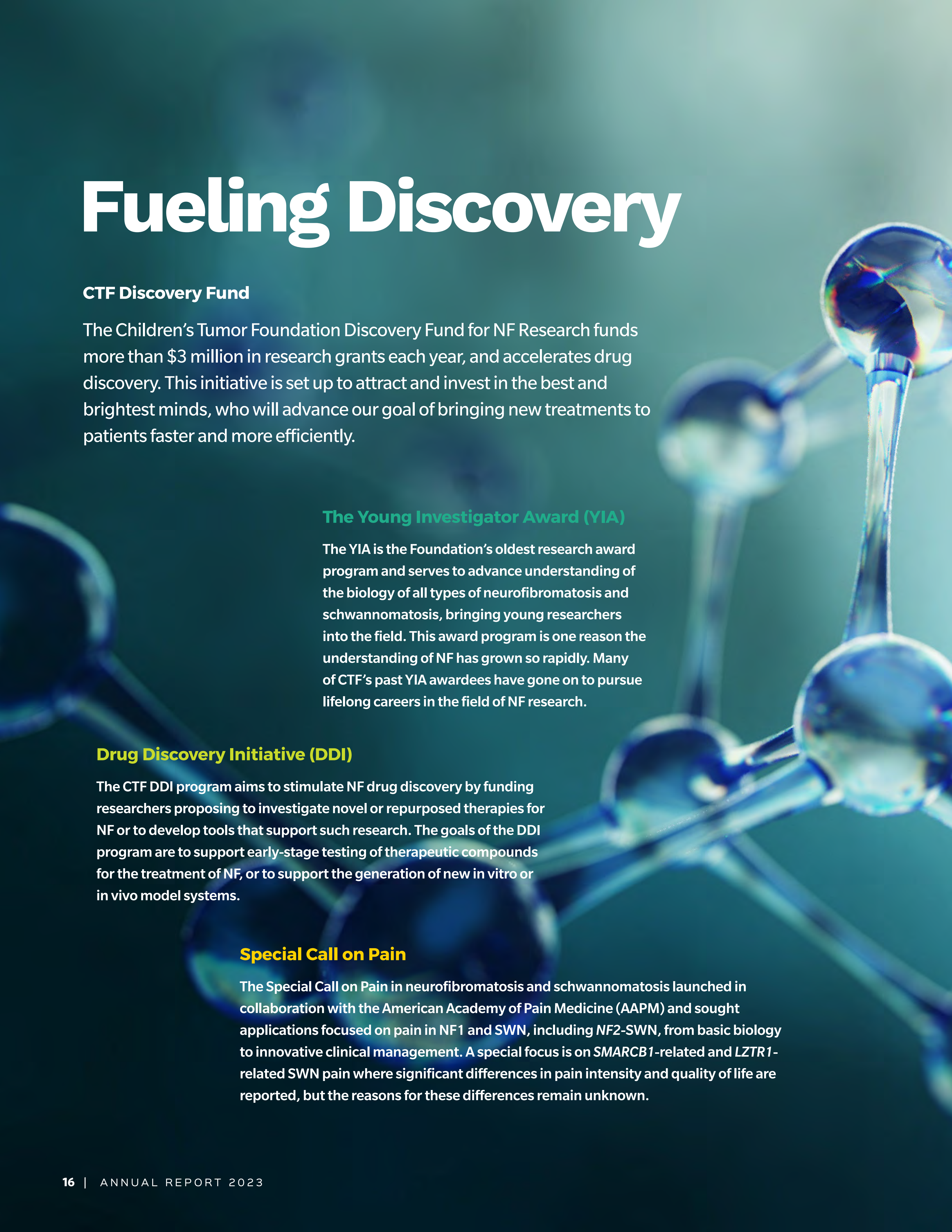
The Focused Ultrasound Foundation and CTF have established a partnership to advance innovative, noninvasive treatments in pediatrics. For more than 15 years, the Focused Ultrasound Foundation has been dedicated to advancing the development and adoption of focused ultrasound. The organizations are co-funding an early-stage laboratory study to investigate focused ultrasound's role in addressing *NF2*-SWN.

NF Diagnostic Criteria

In 2017, a group of NF investigators reached out to CTF to sponsor a revision of the NF diagnostic criteria, sparking a multi-year process that involved more than 90 leading NF experts from around the globe. In May of 2021, an update to the diagnostic criteria for NF1 was published, and an update to the diagnostic criteria and nomenclature for NF2 and schwannomatosis was announced in early 2022. These updates reflect the tremendous increase in knowledge about these conditions, and will allow for earlier and more accurate diagnoses for patients.

The BRIDGE Initiative

CTF has joined forces with the Milken Institute's FasterCures and CureSearch for Children's Cancer in a collaborative effort called the BRIDGE Initiative, which aims to convince pharmaceutical and biotech companies to release discontinued but valuable medicines. The BRIDGE Initiative is committed to unlocking these drugs for intended or new indications, such as for NF.



Fueling Discovery

CTF Discovery Fund

The Children's Tumor Foundation Discovery Fund for NF Research funds more than $3 million in research grants each year, and accelerates drug discovery. This initiative is set up to attract and invest in the best and brightest minds, who will advance our goal of bringing new treatments to patients faster and more efficiently.

The Young Investigator Award (YIA)

The YIA is the Foundation's oldest research award program and serves to advance understanding of the biology of all types of neurofibromatosis and schwannomatosis, bringing young researchers into the field. This award program is one reason the understanding of NF has grown so rapidly. Many of CTF's past YIA awardees have gone on to pursue lifelong careers in the field of NF research.

Drug Discovery Initiative (DDI)

The CTF DDI program aims to stimulate NF drug discovery by funding researchers proposing to investigate novel or repurposed therapies for NF or to develop tools that support such research. The goals of the DDI program are to support early-stage testing of therapeutic compounds for the treatment of NF, or to support the generation of new in vitro or in vivo model systems.

Special Call on Pain

The Special Call on Pain in neurofibromatosis and schwannomatosis launched in collaboration with the American Academy of Pain Medicine (AAPM) and sought applications focused on pain in NF1 and SWN, including *NF2*-SWN, from basic biology to innovative clinical management. A special focus is on *SMARCB1*-related and *LZTR1*-related SWN pain where significant differences in pain intensity and quality of life are reported, but the reasons for these differences remain unknown.

Clinical Research Award (CRA)

The Foundation's Clinical Research Award program supports early-stage NF research involving human subjects. These awards encourage studies of candidate therapeutics or other interventions and treatments; clinical-trial-enabling or ancillary studies; natural history studies; and investigations into clinical care in NF.

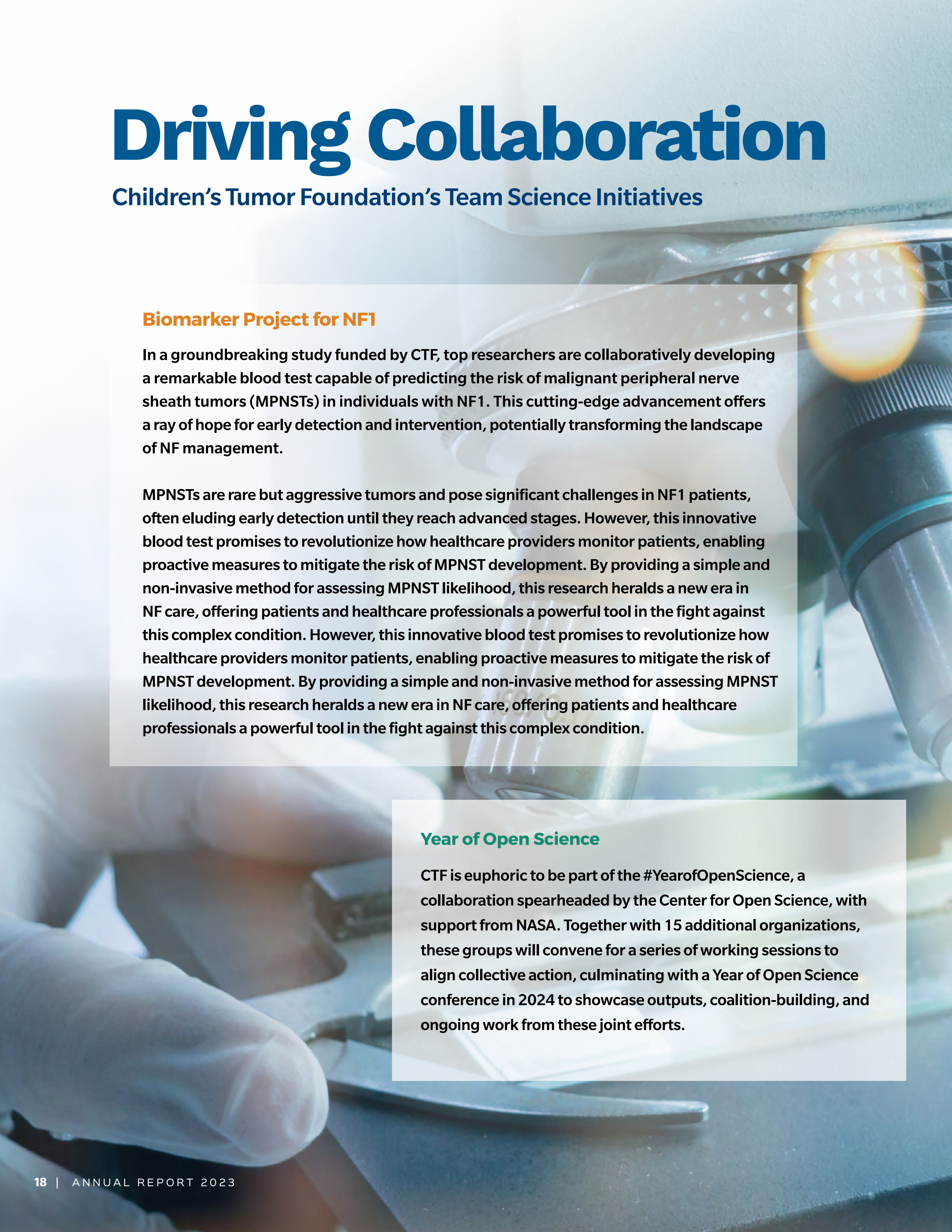
NF1 Gene Therapy Initiative

The NF1 Gene Therapy Initiative has the objective of exploring the feasibility of gene editing as a potential therapeutic strategy for NF1. This initiative aims to support proof of principle in vitro studies to investigate the feasibility of genome editing techniques, including but not limited to those based on CRISPR-Cas9, to correct pathogenic mutations in the *NF1* gene.

Contract Awards

The Contract Awards are special awards that the Foundation assigns to academic researchers or for-profit entities to run specific projects. The Contract Award is not a typical award but rather an objective and task-oriented project that allows the recipient to access funding otherwise not obtainable through other grant mechanisms.

> “We would again like to thank you and all those who donated to CTF, for believing in our projects and funding our CRAs. We are proud that our CTF awards have now produced over $5 million in federal research grants.”
>
> **— Drs. Rob Avery, Michael Fisher, and Gena Heidary**



Driving Collaboration

Children's Tumor Foundation's Team Science Initiatives

Biomarker Project for NF1

In a groundbreaking study funded by CTF, top researchers are collaboratively developing a remarkable blood test capable of predicting the risk of malignant peripheral nerve sheath tumors (MPNSTs) in individuals with NF1. This cutting-edge advancement offers a ray of hope for early detection and intervention, potentially transforming the landscape of NF management.

MPNSTs are rare but aggressive tumors and pose significant challenges in NF1 patients, often eluding early detection until they reach advanced stages. However, this innovative blood test promises to revolutionize how healthcare providers monitor patients, enabling proactive measures to mitigate the risk of MPNST development. By providing a simple and non-invasive method for assessing MPNST likelihood, this research heralds a new era in NF care, offering patients and healthcare professionals a powerful tool in the fight against this complex condition. However, this innovative blood test promises to revolutionize how healthcare providers monitor patients, enabling proactive measures to mitigate the risk of MPNST development. By providing a simple and non-invasive method for assessing MPNST likelihood, this research heralds a new era in NF care, offering patients and healthcare professionals a powerful tool in the fight against this complex condition.

Year of Open Science

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.

Optic Pathway Glioma Multicenter Study

CTF and the Children's Hospital of Philadelphia (CHOP) renewed their five-year study of optic pathway glioma (OPG) in children with NF1. The study involves 25 NF clinics, and aims to provide clinicians with clear criteria that will help them decide when a patient should be treated, and when treatment (such as chemotherapy) should be avoided. OPG develops in 15%-20% of children with NF1, and can cause significant health issues. The study has been renamed to memorialize late CTF ambassador Jeffrey Owen Hanson, who suffered from OPG.

NF Variant Curation Panel

CTF funded a ClinGen (Clinical Genome Resource)-driven initiative to build a central resource that defines the clinical relevance for all NF gene variants (*NF1, NF2, SMARCB1, LZTR1, SPRED1*) for use in precision medicine and research. The panel is composed of 25 experts, including molecular and clinical geneticists and NF specialists, from 9 countries and 18 institutions.

NF Conference

The annual NF Conference attracts clinicians, researchers, industry representatives, and patient advocates, in person and virtually, who are interested in hearing about the most recent advancements in research and clinical care for neurofibromatosis and schwannomatosis. 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.

In 2023 the NF Conference convened in Scottsdale, Arizona, and more than 600 attendees were presented with the best and latest research and clinical care practices. In addition to the core agenda, attendees were able to view poster presentations while a panel of judges selected the top three submissions from clinical and basic science entries.

The meeting concluded with the presentation of the 2023 Friedrich von Recklinghausen Award, awarded to Margaret Wallace, PhD. Dr. Margaret Wallace (aka Peggy) is a cornerstone NF field researcher. While she was a postdoctoral Young Investigators Award (YIA) fellow in the lab of Dr. Francis Collins at the University of Michigan, she played a vital role in cloning the *NF1* gene in 1990.

CTF Europe

Children's Tumor Foundation Europe (CTF Europe) is a medical research NGO that serves as a partner organization to CTF in the United States. Throughout its history, CTF has funded the best and most promising research globally, regardless of location, and as a result, many European laboratories and clinicians have benefited from CTF support. CTF Europe strengthens the bonds between experts and research opportunities worldwide, which is in line with CTF's emphasis on collaboration and open data.

The focus of CTF Europe is to raise awareness of NF at the European level, and build relationships with European agencies and partners, including the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Medicines Agency (EMA), the European equivalent of the FDA, while maintaining its commitment to funding and driving innovative research worldwide that will result in effective treatments for NF.

CTF Europe is further focused on consolidating European clinic networks, organizing and planning International NF Educational Resources (INFER) master classes for healthcare providers, providing travel grants to medical professionals for their training in European NF excellence centers, and training European researchers to allow them to successfully apply for grants issued by US funding bodies. CTF Europe also promotes the NF Registry in Europe in partnership with national patient associations.

CTF and 35 other organizations joined together in a project called EU Patient-cEntric clinicAl tRial pLatforms (EU-PEARL), a unique public-private strategic partnership funded by the IHI to conceptualize and lead the design of integrated research platforms, enabling a more efficient and patient-centric drug development in Europe. Collaborating with the Global Coalition for Adaptive Research (GCAR), plans are underway to operationalize a first-of-its-kind clinical trial for patients with NF initially designed through the EU-PEARL initiative.

INFER
INTERNATIONAL
NF
EDUCATIONAL
RESOURCES

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

Sustaining Hope

Empowering Stakeholders

NF Summit

The NF Summit is an educational and networking conference that evolved from CTF's annual NF Forum and Volunteer Leadership Conferences, which have taken place for over a decade. The 2023 Scottsdale, Arizona, meeting was a dynamic, inclusive event created for anyone with a connection to NF. The NF Summit brought together multidisciplinary speakers covering a wide range of content, including chronic pain, hearing loss, and using social media to raise awareness and build community. Community recognition awards (The Make NF Visible Community Awards) were presented to volunteers, clinicians, researchers, corporate partners, and community members who strive to make NF visible in various ways and who are true champions of CTF and the NF cause.

Patient Engagement: CTF Engage

CTF Engage is the Foundation's patient engagement initiative, designed to prepare individuals with NF and their families to participate as advocates in NF research. Patient representatives are trained to work with stakeholders such as researchers, the pharmaceutical industry, and the U.S. Food and Drug Administration to add their perspectives during all phases of the research process. CTF continues to build on the success of the past several years with this newly designed patient engagement initiative, which promises to elevate the patient voice in research in even more impactful ways.

NF Registry

More than 11,000 individuals have joined CTF's NF Registry, making it the largest patient-entered database of people with NF, and the only one designed to be available to all interested investigators. The Registry has proven to be a valid and useful tool for both patients and researchers. Not only are thousands of patients from all over the world contributing their data online at nfregistry.org, but the data is being actively used—and appreciated—by researchers working on all forms of NF, as well as attracting the attention of pharmaceutical companies. The Registry is now available in multiple languages, further increasing participation.

NF Clinic Network (NFCN)

The NFCN was established by CTF to standardize and raise the level of NF clinical care, and to integrate research into clinical care practices. The NFCN has grown to more than 70 clinics in the US and Canada that serve approximately 20,000 patients each year. Clinics may apply to join the NFCN and are evaluated based on several factors, including NF expertise, patient volume, multidisciplinary approach, commitment to NF education and training, research activities, and connections with the Foundation.

> "Over the decades, this organization has done more to advance care of families with NF than any other U.S. organization...CTF truly enhances my care of families dealing with all issues related to NF."
>
> **— David Viskochil, MD, PhD, University of Utah**

Spreading Awareness

CTF's marketing and communications efforts support patients and their families no matter where they are on their NF journey. Whether newly diagnosed, in the midst of a treatment regimen, or engaging with the broader community to improve awareness and understanding, patients and families can rely on CTF for the latest information about all types of NF.

All too often the patient journey starts with an online search that leads to inaccurate or outdated information, and so CTF prides itself on being a safe haven for all who need direction and support. We provide up-to-date NF knowledge on our website and in our patient brochures, newsletters, webinars, and videos. We also drive a dynamic and engaging presence on social media, connecting patients and families worldwide. Our goal is to ensure that those who don't have NF support in their community can find it through the global CTF family.

In a world that runs 24/7, the Foundation breaks through with impressive media outreach and public relations efforts. Our multichannel approach in print, digital, TV, and radio results in hundreds of media pickups each year, and brings the NF story to hundreds of millions of people worldwide.

While NF is a serious condition, the Foundation creates inspirational and engaging tools that patients can use to share their NF story in a personal way. From "I Know a Fighter" to "Shine a Light on NF" to "Make NF Visible," we make sure that everyone knows our driving passion: to END NF.

The Foundation's "Make NF Visible" campaign draws attention across the globe to those living with NF.

Make NF Visible
Children's Tumor Foundation

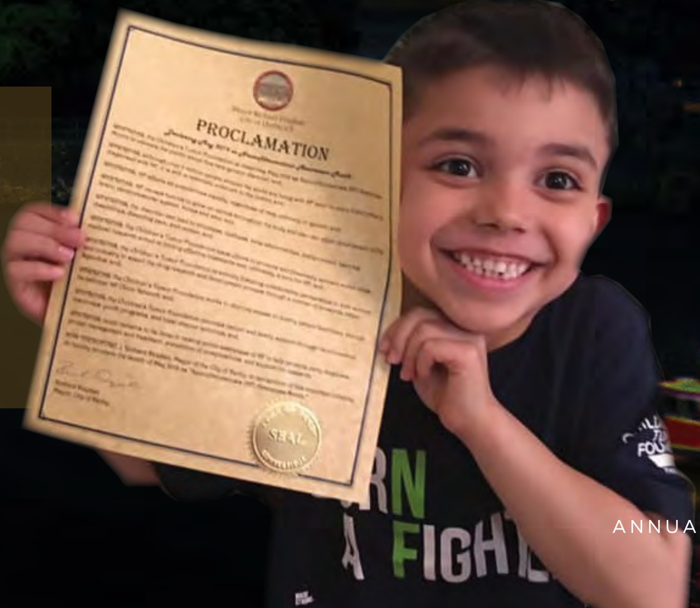
> "I want to show others that just because I have *NF2*-SWN and I've had 28 surgeries…I'm still pursuing my dreams. Right now, I'm in grad school, and I hope to pursue my PhD in the future. I'm not letting NF stop me."
>
> **— Christine, who lives with *NF2*-SWN**

The "Shine a Light on NF" initiative cast a blue-and-green glow on hundreds of buildings, bridges, monuments, and family residences across the country and around the globe.


Empire State Building

On May 17, World NF Awareness Day was celebrated across the country, and to mark the occasion, CTF produced two new short documentary films featuring young people living with NF and their families.

Proclamations were issued in state houses and city halls across the country recognizing "NF Awareness Month." CTF volunteers engaged with their local leaders and helped ensure that more people in office know about NF and how it affects their constituents.



Raising Funds

Special Events

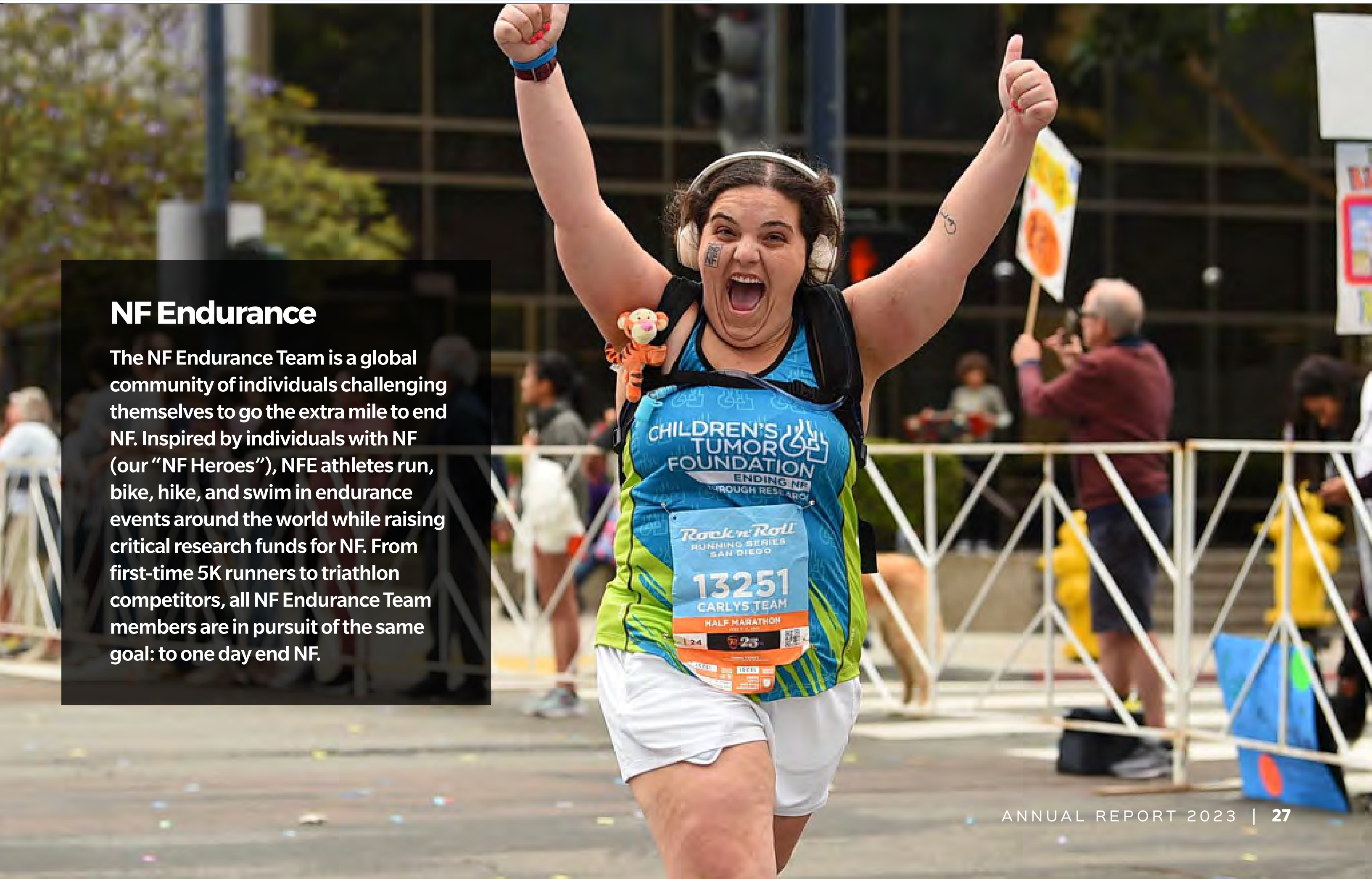
The Children's Tumor Foundation hosts a wide array of special events, collaborating with volunteer committees across the country to organize unforgettable experiences to support NF research. Meanwhile, through our "Fight NF Your Way" program, volunteers receive important tools and resources that help them create unique fundraising activities and community-building events.

Shine a Light NF Walk

Shine a Light NF Walk is the signature fundraising program of the Children's Tumor Foundation, bringing NF out of the shadows and inspiring the community to come together to raise critical funds for NF research. At these fun and inspirational events held across the country, communities rally around local families affected by NF. Frequent appearances of costumed characters, balloon animals, and face painting bring bubbling energy from start to finish.

Cupid's Undie Run

Cupid's Undie Run is a mile(ish) fun run in which brightly adorned, underwear-clad team members run outdoors for NF awareness and to raise funds for NF research. The first Cupid's Undie Run took place in 2010 in Washington, D.C. What started as a unique "let's put hilarity into charity" twist on traditional charity walks/runs turned into a national phenomenon attracting wide attention and increased funding for NF. In the decade since, Cupid's Undie Run has raised millions of dollars for CTF-funded NF research.



NF Endurance

The NF Endurance Team is a global community of individuals challenging themselves to go the extra mile to end NF. Inspired by individuals with NF (our "NF Heroes"), NFE athletes run, bike, hike, and swim in endurance events around the world while raising critical research funds for NF. From first-time 5K runners to triathlon competitors, all NF Endurance Team members are in pursuit of the same goal: to one day end NF.

Advocacy

From the earliest days of the Foundation, CTF staff and volunteers have advocated relentlessly for continual federal funding of NF research, with frequent and highly strategic visits to Capitol Hill and Member District Offices. The CTF Government Affairs Team continually expands the breadth of its advocacy and profile-building efforts with the guidance of outside counsel Squire Patton Boggs. We are also actively engaged with the Defense Health Research Consortium. This consortium is composed of over 50 organizations dedicated to the preservation of annual funding levels for Congressionally Directed Medical Research Programs (CDMRP) within the Department of Defense.

We are making a difference! In 2023, thanks to the continued strong advocacy work from CTF and the NF community, bipartisan leadership in Washington, D.C., secured $25 million for NF research through the CDMRP for fiscal year 2024. This funding will allow us to further develop scientific data, break through barriers, and forge a pathway to end NF.

National Ambassador

Kevin Martin

Kevin Martin was honored as the 2024 National NF Ambassador on November 13, 2023, in New York City, during the Children's Tumor Foundation 45th Anniversary National Gala. This award is bestowed upon an individual with NF to recognize their courage in living with the condition, and their personal efforts to further the Foundation's goals of research, public awareness, and patient support.

“I've always known about my NF. I was diagnosed at age 2, and I was actually with my brother when we went to our pediatrician. He was getting a strep throat test and I was just tagging along and the doctor noticed my head was a bit bigger than it should have been. She was concerned and sent me for a scan. And that's how my NF was discovered.

My parents were always open and honest about what NF was, and what it meant to have it. So having NF is all I've ever known. Even at such a young age, my parents would answer any questions I had about NF, even the tough ones to tell a child about surgery or even death.

My scariest moment of living with NF came last year, when my largest tumor, which stretches from my cheek down to my lung, was growing rapidly and showed signs of turning malignant. A follow-up PET MRI only made things scarier for me, as my doctors ordered a biopsy immediately after. The waiting and unknowing were the most scared I've ever felt in my life, but once the results came back and showed there was no cause for alarm, a wave of relief came over me like I've never felt before.

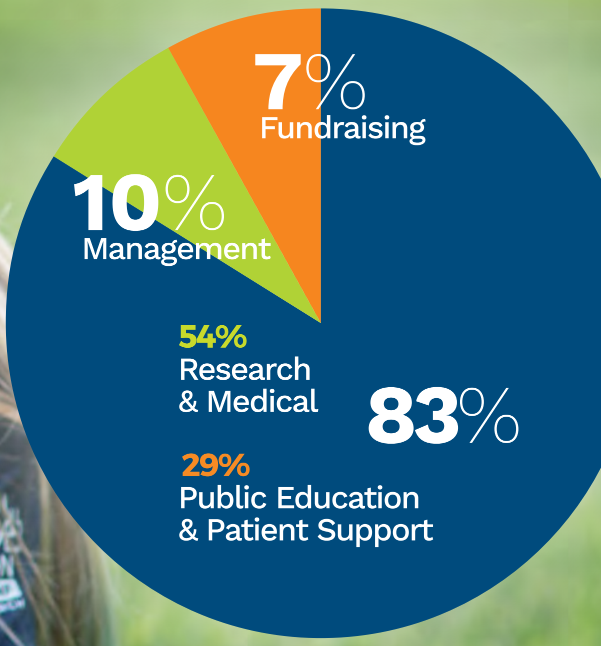
My mother has been involved with CTF ever since I was diagnosed. Over the years she's had numerous roles on the Board of Directors, and I would often tag along to board meetings and events. I'm still with CTF because while we have made significant progress in NF research, like the first FDA-approved drug for NF, there is still plenty of work to be done.

I am now a member of CTF's Junior Board, a group of young professionals who want to be more involved with CTF. The Junior Board has hosted events such as happy hours, cooking classes, painting classes, and more.

One thing I would say to patients with NF is as scary as it can be, there's a whole group of people who are in this community who will have your back, who are going through the exact same thing. Meeting people at all these CTF events, I've had such a supportive group of friends that I've met who know exactly what I'm dealing with. And I wouldn't trade that for the world. It's been an amazing experience being involved with CTF. It's brought so many benefits to my life. As scary as it can be, there's also a positive side to it.”

Financial Summary

Expenses **2023**



Operating support and revenue

	2023	2022	2021
Contributions: individuals	$7,368,568	$8,136,795	$6,571,808
Contributions: corporations and foundations	$4,076,706	$3,951,038	$4,035,129
Bequests	$544,494	$306,122	$185,000
Contributed goods	$488,964	$226,605	$214,955
Other income	$158,890	$1,252,318	$1,539,709
Government grants	$178,253	$299,188	$1,077,026
Loss from disposition of property and equipment	$0	(9,445.00)	$0
CONTRIBUTIONS AND OTHER INCOME	**$12,815,875**	**$14,162,621**	**$13,623,627**

	2023	2022	2021
Special event revenue	$3,274,197	$2,970,370	$3,318,650
Less: direct benefits to donors	-$225,903	(222,968.00)	(40,000.00)
Special event revenue, net	$3,048,294	$2,747,402	$3,278,650
TOTAL OPERATING & SUPPORT REVENUE	**$15,864,169**	**$16,910,023**	**$16,902,277**

Operating expenses

Program Services	2023	2022	2021
Research and medical	$10,337,022	$9,468,471	$6,032,140
Public education and patient support	$5,650,326	$4,122,574	$2,720,523
TOTAL PROGRAM SERVICES	$15,987,348	$13,591,045	$8,752,663
Supporting Services			
Management and general	$1,884,548	$1,144,982	$945,320
Fundraising	$1,261,974	$1,266,163	$930,453
TOTAL SUPPORT SERVICES	$3,146,522	$2,411,145	$1,875,773
TOTAL OPERATING EXPENSES	**$19,133,870**	**$16,002,191**	**$10,628,436**

Change in Net Assets from Operations		$907,832	$6,273,841

Other changes

	2023	2022	2021
NON-OPERATING REVENUE	$1,438,619	(651,650.00)	$561,848

Change in Net Assets

	2023	2022	2021
Net Assets, beginning of year	$27,551,982	$27,295,800	$20,460,111
Net Assets, end of year	$25,720,900	$27,551,982	$27,295,800

With Thanks

The Children's Tumor Foundation is grateful for the continued support of the many individuals, corporations, foundations, and communities who have joined us in the fight against NF. Together, we are making enormous progress. Thank you for your partnership.

Architects of Impact

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Margaret Wallace
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Bonnie Young

*Denotes deceased

NF Legacy Society

As a supporter and friend of the Children's Tumor Foundation, you have been vital in building us up from a grassroots group with just a few members into the leading organization we are today, fully committed to finding treatments for all types of NF. 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.

Our vision is to end NF. We owe it to future generations of NF patients and families to see that vision become a reality. And as long as there is the Children's Tumor Foundation, there will always be an advocate fighting hard for the NF community.

By making a special legacy gift to the Children's Tumor Foundation, you will play an important role in ensuring that this work continues. Your planned gift is an investment in the long-term future of the organization, ensuring that CTF will continue to lead the way in the fight to end NF.

The Children's Tumor Foundation 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 in their estate plans.

To learn more about leaving a legacy and making a planned gift, please visit freewill.com/CTF, contact the Foundation at donorrelations@ctf.org, or call us directly at 1-800-323-7938.

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TOP TEN ADVANCEMENTS IN NF RESEARCH 2023

Anchored to our strategic plan and reflective of our mission, our Top Ten Advancements in NF Research are laying the groundwork to better the lives of the over 4 million people living with NF. These advancements are accelerating the path to approvals so that 2024 will be a time of abundant scientific exploration and research advancements.

CTF STRATEGIC PLAN

The Children's Tumor Foundation (CTF) 2023-2028 Strategic Plan is a blueprint for scientific discovery, fostering collaboration, and catalyzing advancements in NF. Our pledge is an unwavering commitment to pioneering research, innovative funding, and groundbreaking drug development for all types of neurofibromatosis or schwannomatosis. We're bringing the best minds in research and industry to NF, accelerating the pathway from discovery to treatment, and including the patient's voice at every step.

Read more at ctf.org/strategic.

1 CTF launches a new phase as an impact investor with a major investment in a cutaneous neurofibroma clinical trial.

2 Major platform trial design established in Europe that will accelerate the path to approved NF drugs.

3 *NF2*-SWN INTUITT Trial demonstrates promising first results for patients.

4 CTF launches Preclinical Hub to streamline access and guide potential treatments through a swift screening journey.

5 CTF partners with NASA for the Year of Open Science and a commitment to data sharing.

6 CTF and GCAR announce strategic alliance for NF platform trials.

7 CTF and AAPM partner to expand the field of NF pain studies.

8 CTF releases NF+SWN Diagnosis App for doctors/professionals and NF Care App for patients/families.

9 CTF releases new NF language, stats, and resources to reflect updated diagnostic criteria.

10 CTF's NF Conference "From Discovery to Treatments" is the largest gathering ever.

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CHILDREN'S TUMOR FOUNDATION
ENDING NF
THROUGH RESEARCH
BORN A FIGHTER.