

2019
ANNUAL
REPORT



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What is NF?

Neurofibromatosis (NF) is a term for three distinct genetic disorders: NF1, NF2, and schwannomatosis. NF affects 1 in every 3,000 people. It causes tumors to grow on nerves throughout the body and can lead to blindness, deafness, bone abnormalities, learning disabilities, disabling pain, and cancer. NF affects people of every population equally, and there is not yet a cure.



Founded in 1978,

the Children's Tumor Foundation (CTF) began as the first grassroots organization dedicated to finding treatments for NF. Today, CTF is a highly recognized global nonprofit foundation, the leading force in the fight to end NF, and a model for innovative research endeavors.

Our mission

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

Our vision

End NF.



**CHILDREN'S
TUMOR
FOUNDATION**
ENDING NF
THROUGH RESEARCH

2019

von Recklinghausen Award

For Contributions To
Neurofibromatosis Research and
Clinical Care

Presented To

Scott Plotkin, MD, PhD

*Annette Bakker with 2019
von Recklinghausen Award
winner Scott Plotkin*

Dear friends,

As we reflect on the past year here at the Children's Tumor Foundation (CTF), I am deeply grateful to all of you who have contributed to the important mission of this Foundation, thereby improving the lives of all those living with neurofibromatosis (NF). Because of you, we are breaking through the barriers and living in a time when FDA-approved treatments for NF are not just a hope - but a reality! This annual report details the events of 2019, a year in which we stood at the precipice of the 2020 announcement of the first-ever FDA-approved treatment for neurofibromatosis. This incredible moment is a direct result of you, our patients, donors, and volunteers, who have held on tightly to our mission to end NF.


Nowhere was the importance of your support more palpable than at the 2019 NF Conference, NF Forum, and NF Hackathon in San Francisco, California. Researchers, clinicians, and data experts from around the world gathered to share the latest findings in the field of NF. In the same San Francisco hotel, patients, volunteers, and caregivers came together to learn and encourage one another. I am tremendously proud to represent such a wonderful group of patients and families, and a group of experts so enthusiastic about serving them.

The NF community is full of passion for the work that we do at the Children's Tumor Foundation, and throughout the year many extraordinary events brought our donors together to fund research. At the National Gala in New York City, we celebrated the launch of the Discovery Fund, an \$8 million initiative supporting the Foundation's long-standing commitment to driving the most promising NF research. It was an honor to express our gratitude to the Founding Members of the Discovery Fund: Shelley and Frank Haughton, Richard Horvitz and Erica Hartman-Horvitz, and Jim Bob and Laurée Moffett.

The Children's Tumor Foundation's focus is on finding treatments for all types of neurofibromatosis: NF1, NF2, and schwannomatosis. The 2019 year marked the launch of the NF2 Accelerator Initiative, and in this annual report we are incredibly excited to share the tremendous progress that this effort has made toward treatments for NF2. My heartfelt thanks extends to the NF2 Accelerator Initiative supporters and their tremendous dedication to this important initiative.

NF has no boundaries and CTF's global activities are moving forward to help the 2.5 million people worldwide who are living with NF. When we can bring one drug for NF to the market, there can be a second. And a third. Now more than ever, we press on with renewed passion to find treatments for all symptoms and all types of NF. Thank you for joining us in this fight!

Gratefully,



Annette Bakker, PhD, President

Leading the Way

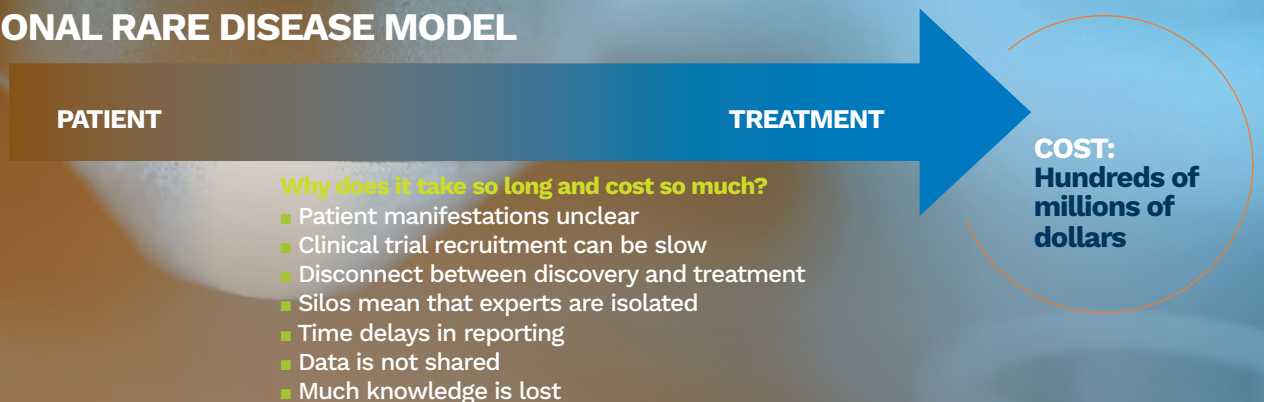
At the Children’s Tumor Foundation, we’re working to better the lives of over 2.5 million people who live with NF. And we’re doing so by focusing on the tagline in our name, Ending NF Through Research. We envision a day when NF patients can live their lives free of the pain and difficulties that come with NF, and our innovative team-based approach to drug development is making that vision a reality.

Patients are told to “watch and wait” to see if their tumors will grow, and determine later if it might impact their lives with devastating conditions such as cancer. We don’t think that’s fair, and we don’t think that’s necessary. By bringing together the brightest minds in research and industry, and revamping the systems that often slow the pathway to treatments, we can change “watch and wait” to “here’s what you can do.”

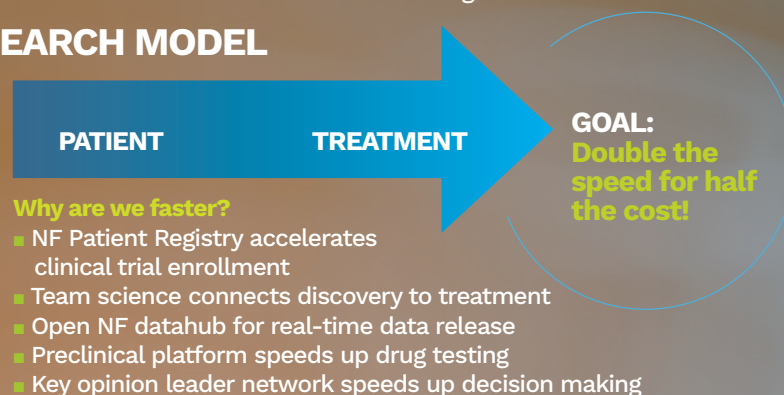
And the best part? CTF’s research model not only benefits NF patients, but also the millions of patients living with cancer, or one of the 7,000 rare diseases in existence.

We’re in a rush to find treatments for all manifestations in all types of NF. Join us as we revolutionize how treatments are developed for those who need them most.

TRADITIONAL RARE DISEASE MODEL



CTF RESEARCH MODEL



SELUMETINIB: The Path to Approval

CTF research discovery paved the way to the first FDA approval.

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 up to 16 years and costs hundreds of millions of dollars to translate a new discovery into one clinical treatment. The impact of the NF Preclinical Initiative is clear: these teams completed 116 preclinical trials in 8 years, at a total cost of \$11 million. The preclinical studies led to 16 clinical trials that are currently under way—one of those clinical trials included the MEK inhibitor selumetinib registration trial.

The Path to Approval

Selumetinib, a MEK inhibitor, was granted Breakthrough Therapy Designation by the U.S. Food and Drug Administration (FDA) in April 2019. The treatment was granted Orphan Drug Designation by the US FDA in February 2018 and by the European Medicines Agency (EMA) in August 2018. The news that selumetinib was granted these designations was a giant leap toward the thrilling April 2020 announcement that selumetinib had received FDA approval.

MEK Inhibitor Selumetinib...the road to the first approved drug for NF

Over 70% of the patient participants in a clinical trial of the MEK inhibitor selumetinib saw a reduction of 20-60% in their inoperable plexiform neurofibromas. Brigitte Widemann, MD, of the National Cancer Institute, reported at the Foundation's 2015 NF Conference that response data in this trial for children and young adults showed meaningful decreases in tumor volume. This highly successful clinical study was the result of CTF's NF Preclinical Initiatives, wherein Nancy Ratner, PhD and D. Wade Clapp, MD demonstrated that MEK inhibitors (MEKi) have a massive result on PN tumor volume in mice. The drug was first tested in a human subject as part of a Children's Tumor Foundation Clinical Research Award granted to Michael J. Fisher, MD in 2011.

“It was after conducting a number of clinical trials that we got to selumetinib, and this was the first one that actually worked...I knew then that very likely, selumetinib was different than all the other things I had tried before. And that was really an amazing feeling because it gave me, for the first time, the hope that we were really onto something that may help patients with NF1.”

— Brigitte Widemann, MD, National Cancer Institute, NIH

2019 Progress Leads to a 2020 Selu-bration

Koselugo announced as first FDA-approved treatment for NF.

The U.S. Food and Drug Administration (FDA) has approved Koselugo (selumetinib) for use in patients with inoperable plexiform neurofibromas, a common manifestation in neurofibromatosis type one (NF1). The FDA's approval of AstraZeneca's and MSD (Merck)'s submission is a major milestone for patients living with neurofibromatosis, a genetic disorder that causes tumors to grow on nerves throughout the body. Affecting 1 in 3,000 people of all populations equally, this announcement is the first ever approved treatment for NF, and portends the potential for the development of treatment options for all NF patients.

Announced in April of 2020, Koselugo's approval follows comprehensive clinical testing of the drug in patients at the National Cancer Institute (NCI), a division of the National Institutes of Health (NIH). In those clinical trials, over 70% of NF patients with inoperable plexiform neurofibromas saw tumor size reduction anywhere from 20-60% in size. In addition to both visible and actual tumor reduction, patients reported higher-quality physical function, reduced pain, improved mobility, and enhanced emotional and psychological status.

The first use of MEK inhibitors as a potential treatment for NF tumors came from early-stage discoveries by Children's Tumor Foundation-funded researchers, who showed that MEK inhibitors could significantly affect NF tumor size. Positive early clinical results were first reported at CTF's annual scientific NF Conference in 2015, as well as in subsequent publications in the *New England Journal of Medicine* in 2016 and 2020.

Collaborative efforts among the NCI, the NIH, the NFRP-CDMRP (Neurofibromatosis Research Program of the Congressionally Directed Medical Research Programs), NTAP (Neurofibromatosis Therapeutic Acceleration Program), and CTF ensured that this 'MEK Story' proceeded expeditiously through proactive and strategic coordination,

“CTF has funded groundbreaking preclinical work and early clinical studies that have moved forward into treatment trials, and ultimately led to the first FDA-approved drug for NF1.”

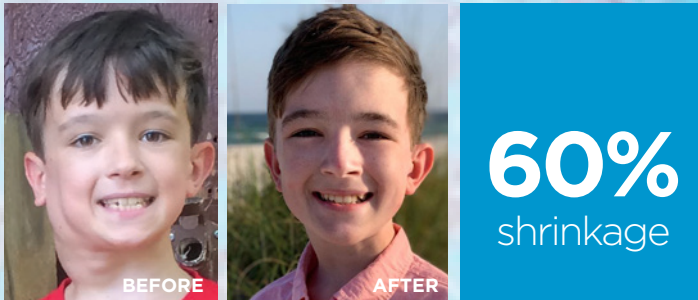
— Nicole Ullrich, MD, PhD, Boston Children's Hospital/Harvard Medical School

guaranteeing efficient use of donor/investor funding, and support from the federal government.

Another hallmark of this path to approval has been the inclusion of patients throughout the process, including the first ever 'NF listening session' held at the FDA in 2019. Many other MEK inhibitors are also now in clinical trials, including mirdametinib from SpringWorks Therapeutics, a company which the Children's Tumor Foundation helped spin off from Pfizer.

“We are so excited for the entire NF community today! This announcement from the FDA about Koselugo (selumetinib) is a tremendous step towards our ultimate dream – approved treatments for all forms of neurofibromatosis,” said Annette Bakker, PhD, President of the Children's Tumor Foundation. “We believe that FDA approval of this treatment helps not only a subset of NF1 patients, it opens the door to increased interest in all forms of NF by pharmaceutical companies. We are already experiencing it – the number of companies interested in NF1, NF2, and schwannomatosis is growing rapidly.”

Koselugo: Stories of the Road to Approval



“People don’t ask me what is wrong with my neck anymore. The drug does make me fatigued, which is tough since most kids my age are active in sports or physical activities that are challenging for me. But 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 getting ready to start high school and 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

“I am thankful for the Children’s Tumor Foundation’s enormous efforts to support the research that led to such a trial. Now that selumetinib has been approved as the first-ever FDA-approved treatment, I am thrilled that now other people with plexiform neurofibromas will have access to and can benefit from selumetinib; proud that Jane was one of the first 24 children in the world to take selumetinib. She has seen it through from a Phase I trial to FDA approval, and her experiences, both good and bad, with the medication have helped guide researchers on how best to use it. I am relieved that all of Jane’s hard work—all the trips to the NIH, all the blood draws and MRIs and other tests, all the side effects and uncertainty—has paid off and will benefit others.” — NF Hero Jane Constable, as told by her mom, Kristy



“We are so thankful that the Children’s Tumor Foundation invested in the science that made the clinical trial for selumetinib possible! We are incredibly thankful that all NF Heroes will now have access to the drug that changed Cooper’s life. We shudder to think of what would have happened if Cooper’s tumor had continued to grow. Before starting the drug, his tumor was nearly doubling in volume every 18 months. Since starting selumetinib, his tumor has not only stopped growing, it has shrunk 21%! Our hope is that it will be as life-changing for others as it has been for our family.”

— NF Hero Cooper, as told by Cooper’s mom, Kirsta

Attracting Pharma

The Children's Tumor Foundation provides answers to the questions that pharmaceutical companies are asking in order to invest in a rare disease such as neurofibromatosis.

Are teams of scientists working on this problem?

CTF'S SYNODOS TEAM SCIENCE INITIATIVES

Designed and managed by CTF, a diverse team of renowned experts collaborate, participate, and immediately share all raw data in an NF Data Portal. By working together instead of in silos, we greatly increase the efficiency of research into difficult NF problems that are too complex to be solved by individual scientists.

Where do we find experts?

CTF'S 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 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 working to standardize and improve NF patient care.

Are there patients engaged in the drug discovery process?

CTF PATIENT ENGAGEMENT PROGRAM

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

Where can we find the patients to participate in 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

Through our partnership with Sage Bionetworks, data is available and ready to use in the NF Data Portal. This centralized data repository is managed by specialists who collect, analyze, and release integrated data, accelerating the understanding of NF and the identification of "druggable" targets.

Is there enough tissue available for testing?

THE NF BIOBANK PROVIDES TISSUE FOR RESEARCH

In order 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, to support all aspects of drug research.

How can we standardize the endpoints of clinical trials?

THE REINS CONSORTIUM
(Response Evaluation in Neurofibromatosis and Schwannomatosis)

This worldwide consortium of NF clinicians and NF patients develops new clinical trial designs, and works with the FDA to establish drug approval criteria for NF.

Have these drugs been tested in animal models?

CTF'S NF PRECLINICAL INITIATIVE HAS ESTABLISHED NOVEL TARGETS FOR CLINICAL TRIALS

Because early testing of innovative concepts is vital, CTF has invested in teams of top laboratories with NF-relevant animal models, bringing promising drug treatments to the clinic quickly and efficiently.

Driving Collaboration

The Children's Tumor Foundation's Synodos Initiatives are team science projects that accelerate the drug development process and revolutionize NF research.

Synodos

Synodos is the premier collaborative research model of the Children's Tumor Foundation, and represents a significant financial commitment on the part of the Foundation. In each Synodos collaboration, CTF assembles "dream teams" of doctors, scientists, and patients who work together to solve problems that are too complex for any individual lab or researcher to solve. Our goal is to speed the drug discovery process through innovative research methods, collective knowledge, and data shared openly through CTF's NF Data Portal. This data is analyzed by our partners at Sage Bionetworks, and is then made available to all Synodos members, and shortly thereafter, to the rest of the world. This approach is expanding interest in NF research to additional fields, including cancer.

Synodos for NF1

CTF sought out the concerns of NF1 patients when establishing Synodos for NF1 in the spring of 2016. Patient concerns for better treatment options for NF1, as well as answers for low grade glioma patients, prompted CTF to initiate three separate consortia, bringing together 24 investigators from eight leading institutions and two companies. Two teams form a Preclinical Acceleration component, each focusing on the development of a swine model to closely resemble a human's response to a potential treatment. The third Synodos for NF1 team is working to develop treatments for low grade glioma, the most common childhood brain tumor affecting children with NF1.

Synodos for NF2

The first of the Synodos models established by CTF, Synodos for NF2 launched in 2014 to provide clarity to patients about available drug options, and completed its work in April of 2018. This consortium of multidisciplinary investigators from 12 world-class labs and medical centers, has performed rigorous drug testing that has laid the groundwork for clinical trials to test a promising new compound for the treatment of NF2.

Synodos for Schwannomatosis

An international consortium of clinicians and scientists from multiple disciplines make up the Synodos for Schwannomatosis team, another CTF consortium based on the successful Synodos model. The project is performing an extensive molecular analysis of schwannomatosis tumor samples to identify new therapeutic targets and advance the understanding and management of the disease, with a special focus on pain.

“There’s nothing more difficult than trying to live your life in terrible pain; pain that might even end your life, as I unfortunately experienced in my family. So by helping people get out of their chronic pain, and finding treatments that work, we’re making lives immeasurably better for the affected community.”

— Richard Horvitz, CTF Board Chair, and Synodos for Schwannomatosis Patient Advocate



CTF funding of NF research leads the way to better diagnostic criteria and improved clinical care.

Fueling Innovation

CTF Discovery Fund

In 2019, the Children's Tumor Foundation announced the Discovery Fund for NF Research, an \$8 million investment over 3-5 years that will fund a minimum of 45 new research studies, and accelerate drug discovery for neurofibromatosis. 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 NF1, NF2, and schwannomatosis, as well as bringing young researchers into the NF field. This award program is one reason the understanding of NF has grown so rapidly. Many of the Foundation's past YIA awardees have gone on to pursue lifelong careers in the field of NF research.

Drug Discovery Initiative Registered Reports (DDI-RR)

Through collaboration with a top scientific journal, *PLOS ONE*, in a process known as "Registered Reports," CTF awardees are offered the Foundation's financial support as well as in-principle acceptance for publication by the journal. This model will allow for more rigorous, reproducible, and transparent science, while guaranteeing its awardees an in-principle acceptance to publication regardless of study outcome. This award evolved from the Foundation's classic Drug Discovery Initiative Award program.



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.

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 for the treatment of NF1, NF2, or schwannomatosis; clinical-trial-enabling or ancillary studies; natural history studies; and investigations into clinical care in NF.



On behalf of my co-investigators, 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

NF2 Accelerator Initiative

The Children's Tumor Foundation has announced the establishment of a significant research initiative dedicated to finding effective treatments for NF2, along with a substantial investment of \$2.3 million in this bold new effort. Called the NF2 Accelerator Initiative, this three-year undertaking will bring active NF2 treatments to the clinic (and patients) by expanding the clinical drug pipeline for NF2, improving drug selection through the development of innovative testing models, and the development of gene therapy options that address the underlying genetic causes of NF2.

As a global leader of NF research, the Children's Tumor Foundation is dedicated to developing cures for all three forms of NF. The Foundation and its partners bolstered the NF2 research field through team science with Synodos for NF2, bringing together multidisciplinary scientists from 12 world-class labs. The Synodos teams shared information, datasets, and results in real-time at every step of research development and have since made that data freely available to all on the nfdataportal.org.

That collaborative effort resulted in the identification of promising new clinical candidates for NF2. The NF2 Accelerator Initiative leverages this new knowledge into a new and ambitious structure, with the goal of speeding up the drug discovery process.

The NF2 Accelerator Initiative will concentrate on opportunities in three areas:

- 1. Expand the Clinical Drug Pipeline for NF2:** This effort will focus on discovering novel therapeutic targets and the development of preliminary biomarkers to help validate existing therapeutic targets for NF2.
- 2. Improve Drug Selection for NF2:** This focus is on the development of animal models to improve drug testing and efficacy within NF2.
- 3. Gene Therapy for NF2:** CTF has invested in gene therapies in the past but has now received a very exciting gene therapy proposal with the potential to become a treatment option for patients with NF2.

We are so grateful to the following families for their incredible support of the NF2 Accelerator and believing in CTF's vision to end NF2.

Family Thoms Fund at the KBF Foundation Canada
The Galloway Family
RB & Susan Harrison
Carol & Steven Kallagher
Nicola Kean & Rob Brainin
John & Beth Morris
The Wonder Fund

Ongoing CTF Research

OPG Multicenter Study

The Children's Tumor Foundation and the Gilbert Family Neurofibromatosis Institute have collaborated on a 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 to 20% of children with NF1, and can cause significant health issues.

Genotype-Phenotype

New research, funded by the Children's Tumor Foundation's Isaac and Sadie Fuchs Genotype-Phenotype Grant, found that certain NF1 genotypes can help predict phenotypes. Led by Ludwine Messiaen, PhD, of the University of Alabama at Birmingham, this discovery of genotype-phenotype correlation can impact counseling and management of more than 10% of the NF1 population.

NF1 Gene Therapy Initiative

CTF announced the NF1 gene therapy initiative in 2018, with the objective of exploring the feasibility of gene editing as a potential therapeutic strategy for NF1. The first phase of this initiative is focused on proof-of-principle *in vitro* targeting of Schwann cells to correct pathogenic mutations in the *NF1* gene. Two independent groups were awarded funding under this initiative, each for \$240,000 for a total duration of two years.

NF Diagnostic Criteria Workshops

The diagnostic criteria for NF1 and NF2 were established at the National Institutes of Health (NIH) consensus meeting in 1987, and the diagnostic criteria for schwannomatosis in 2005. Since that time, there has been a tremendous increase in knowledge about these genetic disorders. In 2017, a group of NF investigators reached out to CTF to sponsor a revision of the diagnostic criteria, sparking a multi-year process that has involved more than 70 leading NF experts from around the globe. The results will be shared in an upcoming publication and will have far-reaching impact.

Biobank: Body and Tissue Donation Program

The CTF Biobank contains tumors, nerves, bones, and other tissues post-mortem from NF1, NF2, or schwannomatosis patients. These body and tissue donations can be divided and shared among several different labs to support multiple research studies, promising to speed up treatment development.

Volumetric Analysis

The Children's Tumor Foundation supported an important study for the completion of prospective clinical trial comparative validation between the National Cancer Institute (NCI) and Massachusetts General Hospital (MGH). This study used volumetric analysis techniques for plexiform neurofibromas to homogenize the methods by which these tumors are measured across the country and provide an unambiguous tool to monitor tumor progression.

2019 NF Conference

The Children's Tumor Foundation (CTF) had a monumental presence in San Francisco, California as neurofibromatosis patients, clinicians, researchers, families, caregivers, volunteers, and data experts came together for a series of educational and inspiring events. The NF Conference was held in conjunction with the NF Forum at the Hyatt Regency Hotel in San Francisco from September 20 – 24, 2019. Nearly 500 clinicians, researchers, pharma representatives, patient advocates, and other healthcare professionals attended the NF Conference.

The Conference's three-and-a-half-day agenda was packed with sessions covering a vast array of important topics. With a nod to our opening keynote speaker Stephen Groft, PharmD, of the National Center for Advancing Translational Science, and borrowing from the title of his talk, one could say the theme of the 2019 NF Conference was, "From Challenge to Challenge - and a whole lot in between."

NF Hackathon

The week prior to the annual NF Conference, the second NF Hackathon brought together more than 75 data specialists, engineers, and artificial intelligence experts. Held at the Google Developers Launchpad Space in San Francisco, these experts explored vast amounts of data from the NF Data Portal (the collaboration of the Children's Tumor Foundation, Sage Bionetworks (Sage), and the Neurofibromatosis Therapeutic Acceleration Program (NTAP)). The high-energy Hackathon participants broke up into 10 teams, and four teams were selected to present their findings at the NF Conference. The Hackathon was managed by SVAI (Silicon Valley Artificial Intelligence), with the participants focused on three core areas: Imaging, Preclinical Drug Modeling, and Genomics.





CTF Europe

The Children's Tumor Foundation has formed a European-based medical research NGO, called Children's Tumor Foundation Europe, which 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. Children's Tumor Foundation Europe is further strengthening the bonds between experts and research opportunities worldwide, in line with CTF's emphasis on open collaboration and open data.

The Children's Tumor Foundation is also an associated partner of the Innovative Medicines Initiative (IMI), as well as the NF package lead for the IMI Integrated Research Platforms call, focused on the design of innovative clinical trials. This call's focus on NF is serving as a test case for other rare diseases as well.

The focus of Children's Tumor Foundation Europe is to raise awareness of NF at the European level, and build relationships with European agencies and partners, including EFPIA (European Federation of Pharmaceutical Industries and Associations), while maintaining its commitment to funding and driving innovative research worldwide that will result in effective treatments for NF. CTF Europe is set on building global networks of clinicians and patients, united to end NF.

In December of 2019, the Children's Tumor Foundation 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

“The Children's Tumor Foundation brings the strong NF know-how and has vast patient, clinical, and academic networks. This is where the magic can happen!”

— Simone Manso, Chair,
Children's Tumor Foundation
Europe

Innovative Medicines Initiative to conceptualize and lead the design of an integrated research platform, enabling patient-centric drug development in Europe. CTF is the co-leader of the neurofibromatosis package of this exciting project, which you can read more about at eu-pearl.eu.

The Foundation envisions a day when NF patients can live their lives free of the pain and difficulties that come with NF, and now that day is on the horizon because of its innovative team-based approach, and its nonprofit-enabling platform aimed at accelerating research and development. CTF aims to advance cures not only for NF but expand their approach to other rare disease areas as well.

Sustaining Hope

NF Forum

The Children's Tumor Foundation's NF Forum took place in San Francisco, California in September of 2019, in conjunction with the NF Conference. This national patient education and family gathering allows those living with NF and their families to connect, support, and learn from each other. Families and patients learn together while attending seminars on relevant topics pertaining to neurofibromatosis and have the opportunity to meet NF researchers and medical professionals in attendance at the NF Conference.

Patient Engagement

CTF's Patient Representative Training Program is the Foundation's Patient Engagement initiative, designed to prepare individuals with NF and their families to participate as advocates in NF research. Through online and in-person learning, the program's goal is to show patients how to add their perspective during all phases of the research process. Patient Advocates are trained to work with stakeholders such as researchers, research institutions, the pharmaceutical industry, the Food and Drug Administration, and patient advocacy organizations.

Neurofibromatosis Clinic Network (NFCN)

The Neurofibromatosis Clinic Network was established by the Children's Tumor Foundation to standardize and raise the level of neurofibromatosis clinical care nationally, and to integrate research into clinical care practices. By the end of 2019, the NF Clinic Network had grown to 54 clinics that serve approximately 15,000 patients. Clinics may apply to join the NFCN and are evaluated based on many factors, including expertise in NF care, access to specialists, number of patients seen, and commitment to educating healthcare providers and patients about the diagnosis of and treatments for NF.

NF Camp

Over 100 youth attended the 23rd Annual NF Camp in July, which was held in three week-long sessions. NF Camp takes place at the beautiful Camp Kostopulos in Emigration Canyon, Utah. Campers enjoyed horseback riding, rope courses, and day trips to local theme parks. At NF Camp, often for the first time, campers can talk freely about NF, share their experiences, and make lasting friendships.

Volunteer Leadership Council

Members of the Volunteer Leadership Council (VLC), our most active and dedicated volunteers, gathered for their annual Leadership Training Conference in San Francisco in conjunction with the NF Forum. This gathering allowed VLC members the opportunity to have face-to-face interactions with staff and one another. They gained new insights about the latest scientific research, CTF program enhancements, and marketing initiatives, and spent time sharing and learning. Volunteer Recognition Awards (VRAs) were presented to volunteers to celebrate the contributions of Volunteer Leaders in several categories from our newest up-and-comers to our most tried and true champions.

NF Registry

Nearly 10,000 have joined the Foundation's NF Registry, making it the largest patient-centered 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, according to an analysis published in the journal *PLOS ONE*. 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. The Registry recently moved to the OpenApp platform, which will allow easier use, availability in multiple languages, and additional enhancements to further increase participation.

“

Over the decades, this organization has done more to advance care of families with the neurofibromatoses than any other US organization, and it has not lost sight of the importance of interactions between individuals with these conditions, as exemplified at NF Camp. CTF truly enhances my care of families dealing with all issues related to NF.

— David Viskochil, MD, PhD, University of Utah

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Raising Awareness

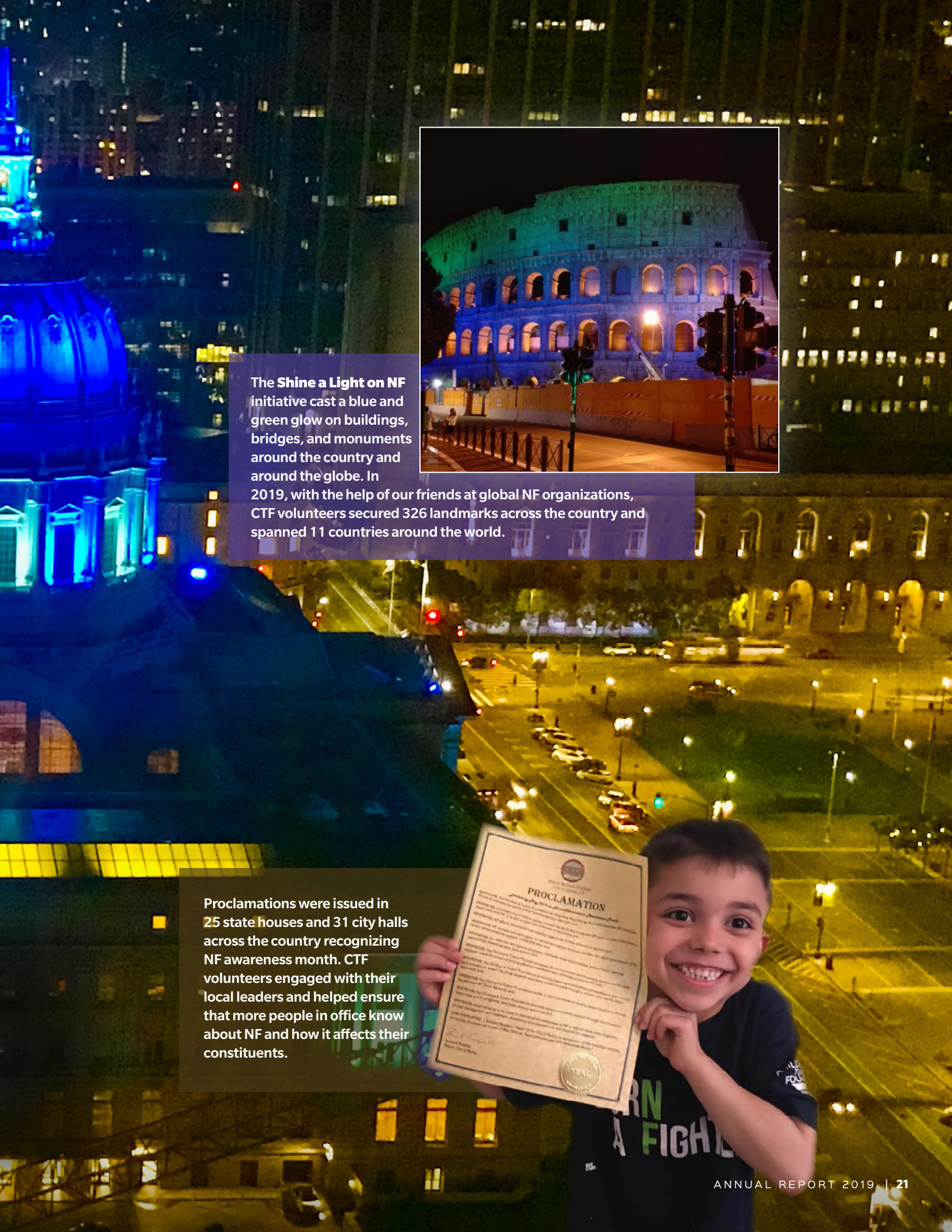
The Foundation's marketing and communications efforts are committed to broadening knowledge of neurofibromatosis, by providing the most up-to-date information about NF on our website and in our patient brochures, newsletters, webinars, and videos. With a dynamic presence on social media, CTF is connecting NF families and spreading CTF's vision to those without an immediate NF connection.

The Foundation's media outreach efforts continue to grow, with countless articles online and in newspapers across the country. A number of TV and radio stations broadcast segments that feature stories of dedicated volunteers, Shine A Light NF Walks, NF Endurance athletes, and NF Heroes and their families.

The Foundation's annual NF Awareness Month campaign drew attention across the globe to neurofibromatosis and those living with this disorder. The I KNOW A FIGHTER theme permeated numerous events held during the month of May, as members of the NF community took the lead in promoting NF awareness and the mission of the Foundation.

“The most important part of my involvement with CTF is that I was very well supported on my journey. Now that's what I'm trying to do for others. I want to be that person that helps in any way that I can.”

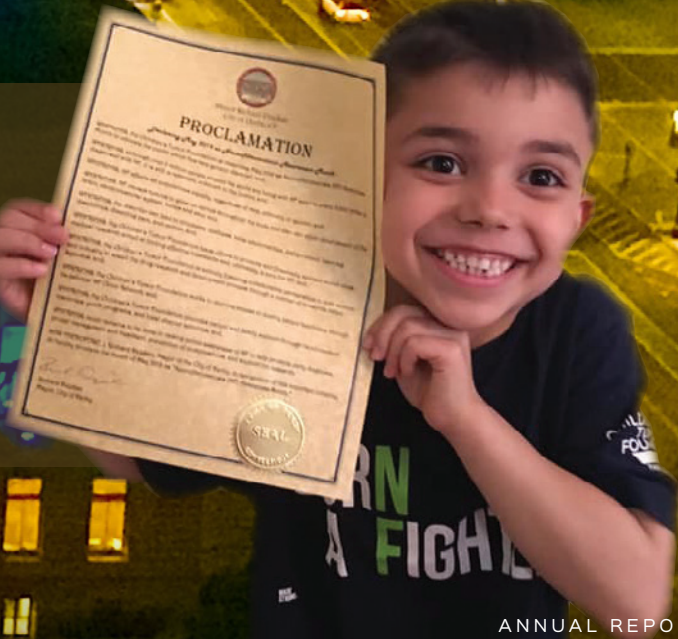
— **Stephanie Jaramillo, NF Mom and NF Awareness Month volunteer**



The **Shine a Light on NF** initiative cast a blue and green glow on buildings, bridges, and monuments around the country and around the globe. In 2019, with the help of our friends at global NF organizations, CTF volunteers secured 326 landmarks across the country and spanned 11 countries around the world.



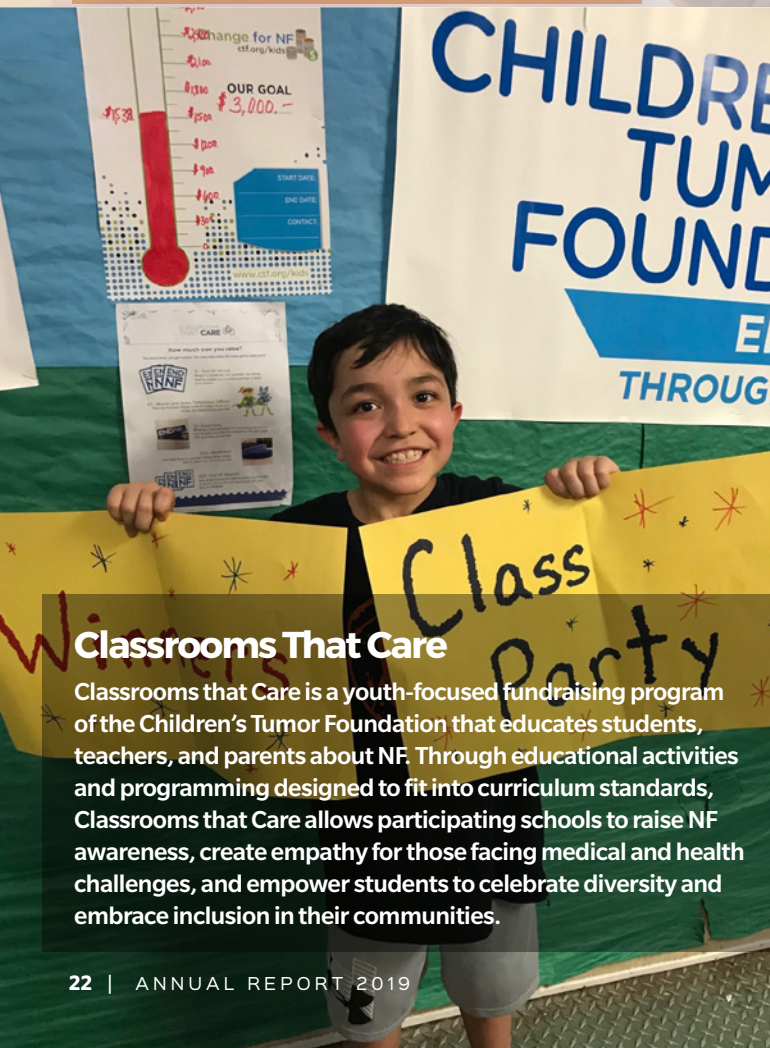
Proclamations were issued in 25 state houses and 31 city halls across the country recognizing NF awareness month. CTF volunteers engaged with their local leaders and helped ensure that more people in office know about NF and how it affects their constituents.



Raising Funds

Shine A Light NF Walk

Shine a Light NF Walk is the signature fundraising event of the Children's Tumor Foundation, bringing neurofibromatosis 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. Each event is as unique as the location in which it is held.



Classrooms That Care

Classrooms that Care is a youth-focused fundraising program of the Children's Tumor Foundation that educates students, teachers, and parents about NF. Through educational activities and programming designed to fit into curriculum standards, Classrooms that Care allows participating schools to raise NF awareness, create empathy for those facing medical and health challenges, and empower students to celebrate diversity and embrace inclusion in their communities.

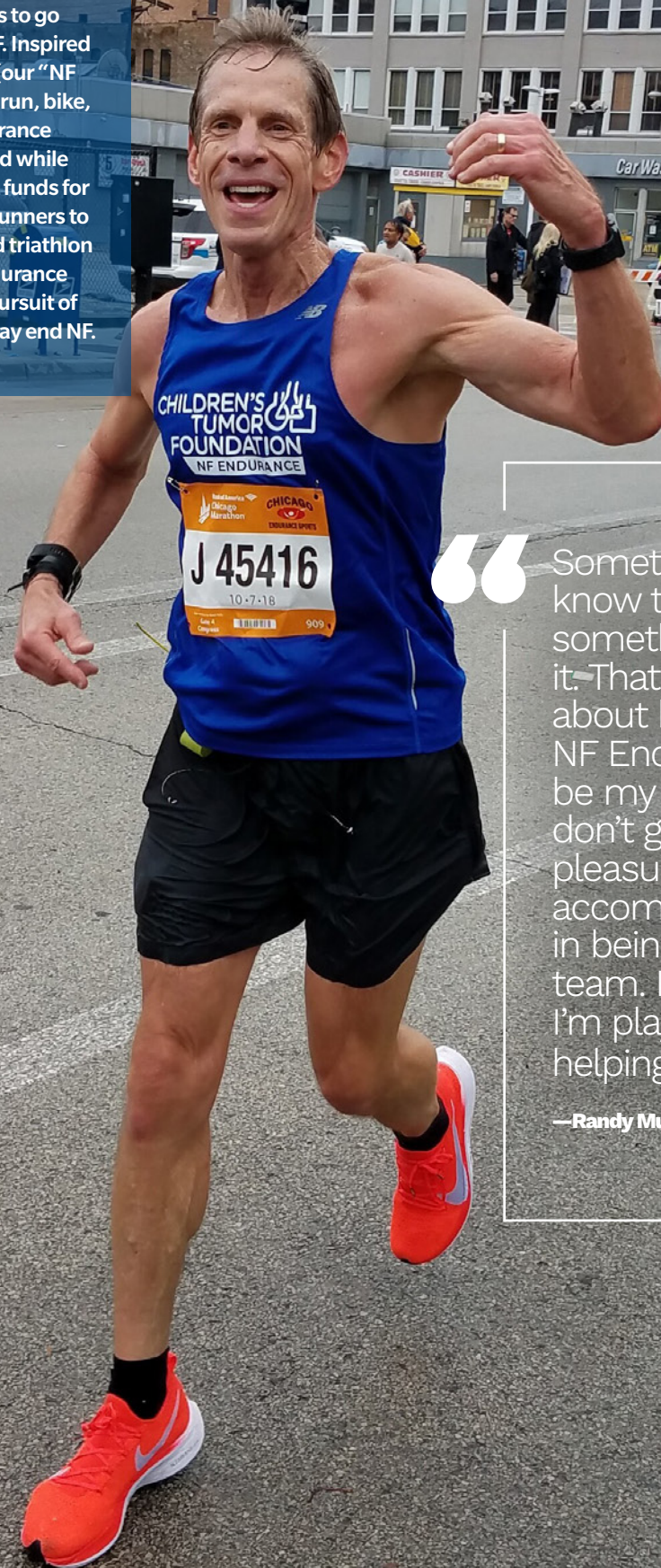


Special Events

The CTF Special Events team works with volunteer committees across the country to organize festive fundraising galas, golfing tournaments, cocktail parties, and Dancing With Our Stars events (pictured). Meanwhile, "Fight NF Your Way" volunteers organize one-of-a-kind fundraising events, including comedy nights, fashion shows, and sweet tea stands that help fund 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 seasoned mud race and triathlon competitors, all NF Endurance team members are in pursuit of the same goal: to one day end NF.



“ Sometimes you don't know that you're missing something until you find it. That's the way I feel about being a part of NF Endurance. This will be my sixth marathon. I don't get nearly as much pleasure out of my own accomplishments as I do in being a part of a bigger team. It is great to know I'm playing a small part in helping people with NF.

—Randy Mullis, NF Endurance athlete

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 actively engaged with the Defense Health Research Consortium. This Consortium is comprised of over 50 organizations dedicated to the preservation of annual funding levels for Congressionally Directed Medical Research Programs (CDMRP) within the Department of Defense.

After receiving approval from both chambers of Congress, President Trump signed the FY 2020 Defense and Labor, Health, and Human Services Appropriations conference report into law. The conference report includes \$15 million in funding to support neurofibromatosis research and is vital to our fight to end NF. This funding will support strategic research through the Department of Defense's Neurofibromatosis Research Program (NFRP), resulting in new discoveries and better outcomes for NF patients and their families. This would not be a reality without the tireless work and advocacy done by the Children's Tumor Foundation, the NF Community, patients, and their families. This sustained federal funding will allow us to further develop scientific data, break through barriers, and forge a pathway to end NF.

The Children's Tumor Foundation's NF Accelerator model is a prototype for other rare disease areas, as well as for cancer.



NF Ambassador: McKinnon Galloway

McKinnon Galloway was diagnosed with NF2 at age 16 after a volleyball hit her in the head during a school match. The concussion that McKinnon sustained prompted a routine MRI, which ended up changing the course of her life dramatically. The doctors explained that she had two tumors in her brain and predicted that she would go deaf by the time she graduated high school. She and her family were in complete shock. One day, she was a normal, healthy teenage girl with a bright future and the next, an NF2 patient on an unforeseen path of uncertainty and fear.

Over the next 10 years, as she endured multiple medical challenges, McKinnon struggled privately with feelings of self-consciousness, depression, shame, and paralyzing fear. She buried her feelings and withheld the seriousness of her deteriorating condition from her family, her friends, and everyone she met. She hid behind a dazzling, but artificial, smile and forged ahead as the epitome of strength and courage when all she really wanted was to be “normal” or to disappear completely.

Eventually, McKinnon did lose hearing on one side, despite being enrolled in a phase I clinical trial for a chemotherapy drug and undergoing a second brain surgery. The surgery was successful in saving her smile from full facial paralysis, which was somewhat ironic because her desire to smile diminished as the depression continued to deepen and her resolve to not burden her loved ones grew stronger.

McKinnon’s parents scrambled to learn what they could about a diagnosis they had never before known. What they learned terrified them. They absorbed the very real possibilities of deafness, blindness, muteness, balance issues, seizures, and much more. They discovered that there is no cure which devastated them at first, but eventually became their motivation to get involved.

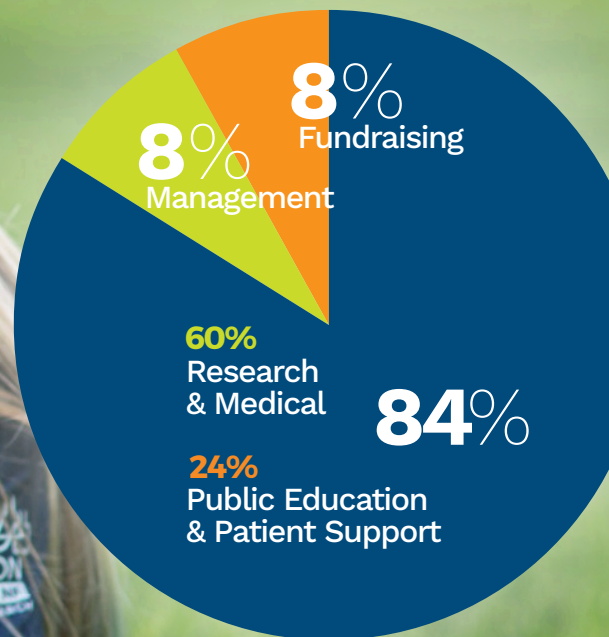
In her role as the CTF National Ambassador, McKinnon stopped trying to hide her diagnosis, and proclaimed her NF story as a strong and brave advocate for the Children’s Tumor Foundation and all those living with NF. She starred in a new CTF YouTube series called “Tumor Talk,” launched the Junior Board for the Foundation, educated children through Classrooms that Care, and traveled to Washington, DC to speak to the FDA, as well as speaking at CTF’s Joint Global NF Conference in Paris, France and at numerous fundraising events throughout the country. McKinnon’s ambassadorship was characterized by her authentic smile, beautiful spirit, exuberant ideas, and endless enthusiasm.



Financial Summary



Expenses 2019



Operating support and revenue			
	2019	2018	2017
Contributions – individuals	\$10,406,627	\$6,932,165	\$5,382,209
Contributions – corporations and foundations	\$4,132,732	\$3,165,403	\$3,285,858
Bequests	\$878,802	\$581,164	\$10,016
Contributed goods	\$23,581	\$51,337	\$80,418
Other income	\$1,582,275	\$495,656	\$491,993
CONTRIBUTIONS AND OTHER INCOME	\$17,024,017	\$11,225,725	\$9,250,494
	2019	2018	2017
Special event revenue	\$780,795	\$1,371,526	\$2,600,665
Less: direct benefits to donors	(\$107,115)	(\$164,020)	-\$461,433
Special event revenue, net	\$673,680	\$1,207,506	\$2,139,232
TOTAL OPERATING & SUPPORT REVENUE	\$17,697,697	\$12,433,231	\$11,389,726

Operating expenses			
	2019	2018	2017
Program Services			
Research and medical	\$6,807,928	\$8,045,453	\$8,215,708
Public education and patient support	\$2,691,715	\$2,517,210	\$2,116,742
TOTAL PROGRAM SERVICES	\$9,499,643	\$10,562,663	\$10,332,450
Supporting Services			
Management and general	\$946,277	\$1,086,755	\$968,659
Fundraising	\$877,648	\$842,082	\$1,419,382
TOTAL SUPPORT SERVICES	\$1,823,925	\$1,928,837	\$2,388,041
TOTAL OPERATING EXPENSES	\$11,323,568	\$12,491,500	\$12,720,491

Change in Net Assets from Operations	\$7,119,681	(\$186,834)	(\$765,666)
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Other changes	2019	2018	2017
NON-OPERATING REVENUE	\$745,552.00	(\$128,565.00)	\$565,099

Change in Net Assets	\$7,176,017	(\$186,834)	(\$765,666)
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	2019	2018	2017
Net Assets, beginning of year	\$10,512,312	\$10,699,146	\$11,464,812
Net Assets, end of year	\$17,631,993	\$10,512,312	\$10,699,146

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. Thank you for your help in advancing the Foundation's mission.

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Caddies for Colin
Cocktails for a Cure, Boston
Cocktails for a Cure, Long Island
Dancing With Our Stars
End NF with Ian Desmond

Firstronic Golf Outing
NYC Poker Tournament
The Children's Tumor Foundation |
2019 National Gala

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SHINE A LIGHT NF WALK,
Cincinnati
SHINE A LIGHT NF WALK,
Michigan
SHINE A LIGHT NF WALK,
Los Angeles

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Being at the Shine A Light Walk in Idaho was so inspiring. It was the first time we'd seen so many other families affected by NF, all gathered together, lending support, understanding, and just having fun together! It was such an incredible reminder that our little family is not alone, that we are all in this quest together to find a cure for NF. — Shine a Light on NF Walk participant, Evlyn

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Her big brothers wanted to find a way to raise funds and awareness for vital research being done by the Children’s Tumor Foundation. They found that selling sweet tea for their baby sister was a perfect way to do just that.



— Shanna Nelson, Sophie’s Mom; Sweet Tea for Sophie

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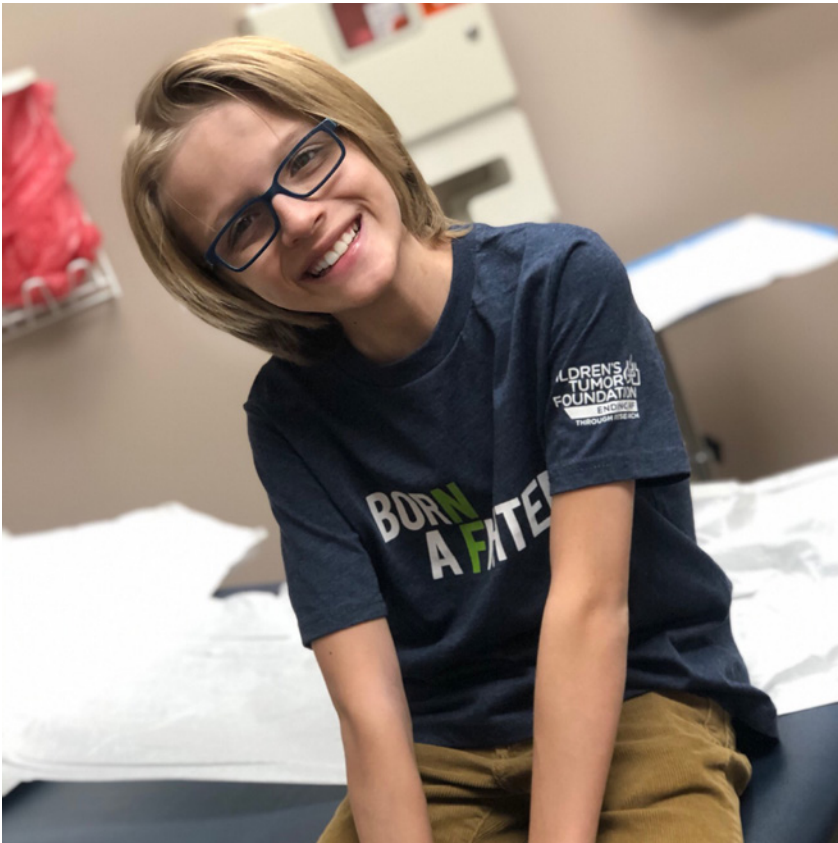
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“ Camille is a true warrior. She faces each day and challenge as it comes. Her balance is an issue, her eyesight and hearing are compromised, and yet she is so brave and strong. I would do anything I could to change things for her, but despite her challenges, she keeps on moving forward. ”

— Roland Thoms, father to Camille who lives with NF2, and along with his wife Nicole, organizer of the hugely successful Halloween Bash annual fundraiser



NF Legacy Society

As a supporter and friend of the Children's Tumor Foundation, you have been vital in building this Foundation from a grassroots group with just a few members into the leading organization it is today, fully committed to finding treatments for neurofibromatosis. 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 the Children's Tumor Foundation 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 contact the Foundation at info@ctf.org, or call us directly at 1-800-323-7938.

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