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.
As we commemorate the Foundation’s 40th anniversary, we do so with the unbreakable spirit that we will one day end NF.

— Annette Bakker, PhD
Throughout 2018, we held a yearlong celebration of the 40th anniversary of the Children’s Tumor Foundation (CTF), expressing our gratitude to those who have come before us to establish this strong organization, built upon an important mission. Over the years this Foundation has momentously contributed to the body of knowledge about NF, and is impacting and improving the lives of the millions of people living with neurofibromatosis (NF).

I am amazed to think of what it must have been like for the Foundation’s first President, Lynne Ann Courtemanche, who established this organization along with Allan Rubenstein, MD and Joel Hirschritt, Esq. In 1978, few doctors even knew what neurofibromatosis was, and the gene mutations that cause the various forms of NF were completely unknown.

Thanks to the trailblazing efforts of NF researchers, a dedicated Board, and most importantly you, as supporters of the Foundation, we have seen previously unimaginable advances in NF research and monumental growth in our Foundation. It is because of the participation of a focused NF community that we now live in a time of great promise. NF treatment options that were unheard of in the past are now on the horizon because of the accomplishments of the Foundation and its supporters.

We are accelerating the drug discovery process and leading the way in NF research. Synodos for NF2 completed its third year with a significant data release and a promising NF2 clinical candidate. Our first industry partnership is a reality, and our NF Conference in November was the largest ever, with over 800 experts in attendance.

Even more exciting, we received the incredible news that the MEK inhibitor selumetinib has attained orphan drug status from the US Food and Drug Administration (FDA) and the European Medicines Agency (EMA). This drug discovery is a result of CTF’s multi-million dollar investment in the NF Preclinical Consortium. Your generous support of the Children’s Tumor Foundation also provided funding for the first in-human study of selumetinib. Thanks to the contributions of our family of donors throughout the years, we are now closer than ever to the first FDA-approved treatment for NF!

I am inspired by CTF’s accomplishments and energized by a calling to carry this momentum forward. Our vision to end NF continues with ever-increasing resolve. We have come so far, and I am confident that we will fulfill our mission. It is because we bind ourselves together as a team of researchers, volunteers, parents, donors, and patients, that the future is brighter than ever for all those living with NF.

Gratefully,

Annette Bakker, PhD, President
Celebrating 40 Years of Ending NF

Forty years ago, a small group of committed individuals joined together to build an organization dedicated to the search for treatments and a cure for a then little-known disorder called neurofibromatosis, or NF. That group – an NF patient named Lynne Ann Courtemanche, her physician Allan Rubenstein, and the attorney Joel Hirschtritt – established the National Neurofibromatosis Foundation, now known as the Children’s Tumor Foundation.

Throughout 2018, Children’s Tumor Foundation supporters gathered for festive fundraising events and galas across the country in celebration of the Foundation’s 40th anniversary year.

Held at the historic American Museum of Natural History in New York City, the Ruby Anniversary Gala paid homage to the origins of the Children’s Tumor Foundation, and raised $1.6 million for NF research.

Those closest to the Foundation enjoyed a walk down memory lane during a springtime 40th Anniversary Cocktail Party.
Francis S. Collins, MD, PhD, Director of the National Institutes of Health (NIH) was presented with a CTF Humanitarian Award at the Foundation’s Ruby Anniversary Gala in New York City. Dr. Collins is a renowned physician-geneticist noted for his landmark discoveries of disease genes – including the NF gene – and for his leadership of the Human Genome Project.

The Children’s Tumor Foundation is all about action, and we at the NIH, we’re all about action. Together, we can conquer NF.

— Francis S. Collins, MD, PhD, Director of the National Institutes of Health (NIH)
1882
Neurofibromatosis was first described by German pathologist Friedrich Daniel von Recklinghausen. Today NF1 is sometimes still referred to as “von Recklinghausen syndrome.”

1978
The National Neurofibromatosis Foundation (NNFF) was founded by Lynne Ann Courtemanche, RN, her physician Allan E. Rubenstein, MD, and Joel S. Hirschritt, Esq.

1982
Just after Joan Engel became the NNFF president, the first national research program on NF was originated. Grants totaling $40,000 were awarded.

1984
The first meeting addressing the need for NF clinics and standards of patient care was held in Toronto, Canada.

1985
The Foundation convened the first major international scientific conference on NF. This landmark gathering in New York was the precursor to today’s NF Conference.

1988
In May, the NNFF held its first annual meeting of healthcare professionals.

1990
On July 12, the discovery of the NFI gene in the labs of Francis S. Collins, MD, PhD and Raymond White, PhD made headlines. Two Young Investigator Awardees, Dave Viskochil, MD, PhD and Peggy Wallace, PhD played an instrumental role in that work.

1992
The Foundation began a legislative initiative within the federal government’s Congressionally Directed Medical Research Program (CDMRP). As a result, the Neurofibromatosis Research Program (NFRP) was established in 1996.

1993
Two teams independently announced the discovery of the NF2 gene, both having received funding from the NNFF. One team was led by James Gusella, PhD, and the other was led by Dr. Guy Rouleau, MD, PhD.

Over the past 40 years, there have been tremendous advancements in neurofibromatosis research, advocacy, awareness efforts, and patient care as a result of Children’s Tumor Foundation initiatives. From the very beginning, this Foundation has achieved a great deal for patients and families affected by NF.

The Children’s Tumor Foundation
40 Years of Progress
The NNFF created the first-ever website focused on NF. That site evolved into www.ctf.org, which today receives over a million visits each year.

The first annual meeting of NF Clinic Coordinators took place in October.

The NNFF changed its name to the Children’s Tumor Foundation (CTF).

The second edition of “Neurofibromatosis: A Handbook for Patients, Families, and Healthcare Professionals” was published and included information about schwannomatosis.
The Drug Discovery Initiative Awards were launched to fund NF drug testing in the lab.

Schwannomatosis was added to the Foundation’s mission upon discovery of the first schwannomatosis gene, *SMARCB1*.

The Clinical Research Awards Program was initiated.

LZTR1 was identified as a key gene in schwannomatosis by CTF Young Investigator Awardee Arkadiusz Piotrowski in the lab of Ludwine Messiaen, PhD.

In August, the CTF Biobank was established to collect tissue from patients for use in NF research, and 200 tissue samples were collected.

The REiNS (Response Evaluation in Neurofibromatosis and Schwannomatosis) collaboration was established by NF clinicians at the NF Conference to achieve consensus about diagnostic and clinical care.

CTF launched a collaborative research model, NF Preclinical Consortium, which went on to prove that MEK inhibitors decrease tumor volume in mice.

The first NF Registry was launched at the NF Forum.

A year of growth: the NF Clinic Network grew to serve over 10,000 patients per year; the Drug Discovery Initiative pipeline reached 44 projects; and the NFPC reached over 40 preclinical trials.

In May, CTF launched the “I Know a Fighter” campaign, a rally cry for the NF community that captured the remarkable spirit of those living with NF.
2016
Synodos for NF1 was launched on January 21, when investigators of the two Clinical Acceleration groups convened, followed by a February 28 meeting of the Low Grade Gioma group.

On October 2, the first Synodos Network Meeting was held to bring together the individual groups that make up all Synodos collaborations.

2017
On May 1, investigators that make up Synodos for Schwannomatosis convened for the first time.

The NF Registry grew to almost 8,000 participants from 89 countries.

On May 17, World NF Awareness Day, Niagara Falls glowed blue and green for the first time, kicking off an international awareness campaign called Shine a Light on NF. Hundreds of buildings, bridges, and monuments around the world light up each May.

CTF formed a partnership with pharmaceutical company SpringWorks Therapeutics.

2018
Synodos for NF2 concluded, with data yielding a promising clinical candidate.

AstraZeneca and Merck announced that the MEK inhibitor selumetinib was granted Orphan Drug Designation by the FDA for NF1.

The Children’s Tumor Foundation goes global and celebrates 40 years of driving research, expanding knowledge, and advancing care for the NF community.
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 malignant 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 patients. Join us as we revolutionize how treatments are developed for those who need them most.

**TRADITIONAL RARE DISEASE MODEL**

- **Why it takes so long and costs so much?**
  - Patient manifestations unclear
  - Clinical trial recruitment can be slow
  - Disconnect between discovery and treatment
  - Silos mean that experts are isolated
  - Time delays in reporting

**CTF RESEARCH MODEL**

- **Why are we faster?**
  - NF patient registry accelerates patient recruitment
  - Team science connects discovery to treatment
  - Open NF datahub for real-time data release
  - Preclinical platform speeds up drug testing
  - Key opinion leader network speeds up decision making
MEK makes a difference

CTF has funded ground-breaking preclinical work and early clinical studies that have moved forward into treatment trials, and now the first FDA-approved Orphan Drug Designation for NF1.

— Nicole Ullrich, MD, PhD, Harvard Medical School

NF HERO: Philip Moss
BEFORE  AFTER
57% shrinkage

NF HERO: Paige Doane
BEFORE  AFTER
32% shrinkage

NF HERO: Ryker Bennett
BEFORE  AFTER
42% shrinkage

NF HERO: Jane Constable
BEFORE  AFTER
30% shrinkage
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 NF.

**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 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 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 teams of scientists working on this problem?**

**CTF’S SYNODOS TEAM SCIENCE INITIATIVES**

Designed and managed by CTF, a diverse team of experts collaborate, participate, and immediately share all raw data in an NF Data Portal. By working together instead of in silos, we increase the efficiency of solving complex NF problems.
How can we standardize the endpoints of clinical trials?

THE REiNS CONSORTIUM
(Response Evaluation in NF and Schwannomatosis)

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

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.

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.

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.
Driving Collaboration

The Children’s Tumor Foundation’s team science projects are leading the way in NF research and accelerating the drug development process.

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 complex problems faced by NF patients, who drive the topic of research. 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

Synodos for NF2 was launched in 2014 in order to provide clarity to patients about available drug options and identify new ones. 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 Brigatinib (a Takeda drug) for the treatment of NF2. This successful three-year, $3 million program completed its work in April of 2018.
MEK Inhibitor Selumetinib Registration Trial

Over 70% of the patient participants in a clinical trial of the MEK inhibitor selumetinib have seen a reduction of 20-55% 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 have a massive result on 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.

Orphan Drug Status

The Food and Drug Administration (FDA) has granted Orphan Drug Designation for selumetinib, an MEK inhibitor, for the treatment of NF1 in February 2018, and by the European Medicines Agency (EMA) in August 2018. The news that selumetinib has been granted Orphan Drug Designation illustrates not only the potential of this treatment but provides further incentives for drug companies to invest in NF-related trials.

NF Preclinical Initiative

The NF Preclinical Initiative (NFPI) began in 2008 as the NF Preclinical Consortium (NFPC), a five-year 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 Initiatives 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 underway—one of those clinical trials is the MEK inhibitor selumetinib registration trial, in which patients are seeing significant shrinkage in the size of their tumors (read more below).

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.

I think it’s my responsibility—as a grandparent of a child affected by NF—to do everything I am capable of doing. And I know that CTF needs my support. It’s vital. It’s just so important.
—Carol Harrison Kalagher, Synodos for NF2 Benefactor
CTF funding of NF research leads the way to better diagnostic criteria and improved clinical care.

Testing Concepts
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. In 2018 the Foundation awarded one Clinical Research Award for a study of L-Carnitine safety and effects on muscle.

Learning More
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, and to bring young researchers into the NF field. This award program is one reason the understanding of NF has grown so rapidly during CTF’s 40-year history. Many of the Foundation’s past YIA awardees have gone on to pursue lifelong careers in the field of NF research. Two post-doctoral and three pre-doctoral students were awarded YIAs in 2018, two of which were co-funded by the NF Research Initiative (NFRI), which is made possible by an anonymous donation to the Boston Children’s Hospital.

Scientific Transparency
Drug Discovery Initiative Registered Reports (DDI-RR)
Through a 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, guaranteeing its awardees with an in-principle acceptance to publication, regardless of study outcome. This award evolved from the Foundation’s classic Drug Discovery Initiative Award program. In 2018 CTF awarded three investigators with DDI-RR awards to fund projects in NF2 tumors and NF1 muscle weakness.

“...I have worked with CTF for over a decade and have seen firsthand how their support of NF research has translated into effective treatments for my patients with NF.

—Tena Rosser, MD, Children’s Hospital of Los Angeles
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 NF 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. Although rarely life-threatening, these tumors can cause significant health issues, including vision loss, disfiguring bulging of the eye, and early puberty.

NF Animal Model Workshop

On October 4-5, 2018, the Children’s Tumor Foundation hosted the second Neurofibromatosis Animal Model Workshop in Palm Springs, California. More than 20 animal models were presented at the United States and Canadian Academy of Pathology (USCAP) learning center. Pathology slices of murine lesions were carefully evaluated by a group of 10 pathologists to create a single, universal pathological classification. Since our research community has developed a number of models that recapitulate many aspects of NF1, NF2, and schwannomatosis, it was necessary to classify those models based on their histopathological features by expert pathologists. This was important for the validation of the models, for their analysis and comparison with other models, and for their future effective use in preclinical treatment trials.

BIOBANK
Body and Tissue Donation Program

Originally set up to collect dermal neurofibroma surgical samples, the CTF Biobank has broadened its scope to collect tumors, nerves, bones, and other tissues post-mortem from NF1, NF2, or schwannomatosis patients. The tissue comes from people who previously requested that CTF arrange for them to donate their bodies to research after death. CTF’s procedure for body donation will ensure that NF1, NF2, and schwannomatosis tissue be made widely available, promising to speed up treatment development.
Joint Global NF Conference

The Children’s Tumor Foundation’s annual NF Conference took place in Paris from November 2-6 at the Joint Global NF Conference.

The support and planning of this particular conference was historic in that CTF, for the first time, combined forces with the European Neurofibromatosis Group, Association Neurofibromatoses et Recklinghausen, and the NF2/Schwannomatosis State of the Art group, to form the most comprehensive agenda and largest gathering of NF researchers, clinicians, patients, and patient advocates.

With more than 800 NF researchers and clinicians across a wide range of scientific disciplines attending from around the world, it was the largest NF meeting in history. Experts gathered to share the latest in NF research, to meet and collaborate with colleagues, and to advance NF research.

The NF Conference is recognized as the premier annual scholarly gathering of international NF researchers and physicians, and is considered a critical venue for the presentation and integration of basic science discovery, translational data, and clinical trial outcomes, to both enhance the quality of ongoing research and improve clinical care.

The planning committee worked with CTF leadership to design a broad-ranging and comprehensive agenda which spanned five days. Topics that are foremost in the NF community were included to provide education about best clinical practices for the neurofibromatoses, opportunities to share major advances in research, and reinforce the growth of new investigators. The conference was further enhanced by a number of satellite meetings and workshops, which allowed particular groups, including the NF Clinic Network, time for networking and information sharing.

This year’s conference presented nine plenary sessions and seven parallel sessions, along with the bi-annual NF2/Schwannomatosis State of the Art meeting which ran in parallel on days three and four. Renowned keynote speakers from outside the NF community served to stimulate fresh discussions and promote the development of new collaborations.
The Children’s Tumor Foundation announced the formation of the new European-based medical research NGO, called Children’s Tumor Foundation Europe, which will serve 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. This new organization will further strengthen bonds between experts and research opportunities worldwide, in line with CTF’s emphasis on open collaboration and open data.

As a research catalyzer, CTF organizes the largest international NF meeting in the world. In our 40th anniversary year, CTF partnered with European NF groups to organize the 2018 Joint Global NF conference in Paris.

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 will be to further build out 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.

The Foundation envisions a day when NF patients can live their lives free of the pain and difficulties that come with NF, and 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.

The Children’s Tumor Foundation hosted the inaugural launch event for Children’s Tumor Foundation Europe on November 9, 2018 at the Musical Instruments Museum in Brussels. Magda Chlebus, Executive Director, Science Policy and Regulatory Affairs, European Federation of Pharmaceutical Industries and Associations (EFPIA) served as the keynote speaker.

“It’s not a surprise that you chose the Museum of Music for the place to launch Children’s Tumor Foundation Europe. Because a team is like an orchestra that needs a conductor, and I hope CTF will be that conductor.”

— Magda Chlebus, Executive Director, Science Policy and Regulatory Affairs, European Federation of Pharmaceutical Industries and Associations
Sustaining Hope

Patient Engagement
CTF’s Patient Representative Training Program graduated its first class of “Patient Advocates” in May 2018. This Patient Engagement initiative is 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. In 2018, the NF Clinic Network grew to 52 clinics that serve approximately 14,000 patients. Clinics are invited to join the NFCN based on many factors, including expertise in NF care, access to specialists, number of patients seen, and commitment to educating colleagues and patients about the latest developments.

NF Forum
The Children’s Tumor Foundation’s NF Forum took place in Atlanta from May 4-6, 2018. 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. The Foundation was awarded a prestigious PCORI grant (Patient-Centered Outcomes Research Institute) for the 2018 NF Forum.
NF Camp
Over 100 youth attended the 22nd 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.

NF Registry
By the end of 2018, more than 9,000 individuals had joined the NF Registry, making it the largest patient-centered database of people with NF, and the only one designed to be available to 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. Over 18 different studies and clinical trials have used the NF Registry to notify individuals who fit certain trial or study criteria.

The Volunteer Leadership Training Conference
In celebration of the Foundation’s 40th Anniversary, 62 registered members of the Volunteer Leadership Council (VLC), our most active and dedicated volunteers, gathered for their annual Leadership Training Conference in Atlanta, Georgia. The conference allows VLC members the opportunity to have face-to-face interactions with staff and one another. They gain new insights about the latest scientific research, CTF program enhancements and marketing initiatives, as well as have time to share with and learn from each other. 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 Camp is the highlight of my year! It is so much fun hanging out with people who have the same challenges as me and helps me feel like I am not alone in what I go through on a daily basis." —Kala Schvaneveldt, Utah
Raising Awareness

The Foundation’s marketing and communications efforts are committed to broadening knowledge of neurofibromatosis worldwide by providing the most up-to-date information about NF on our website and in the Foundation’s publications. 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 in newspapers across the country. A growing number of TV and radio stations broadcast segments that feature stories of dedicated volunteers, NF walkers and endurance athletes, and NF Heroes and their families.

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, bringing the 2018 total to 205 landmarks spanning 11 countries.

“Through marketing, PR, and grassroots campaigns we have not just raised global awareness for NF but have educated and inspired so many. Relentless efforts such as these are helping to bring us ever closer to achieving our collective dream of ending NF.”

— Gwen Coverdale, CTF volunteer and NF mom
The Foundation’s annual NF Awareness Month campaign drew attention from 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.

With the “This is NF” photo series, we told a side of the NF story that isn’t often shared—that of the passion that adults living with NF bring to their careers. Professionals living with NF shared a side of their story that often goes unnoticed, demonstrating that living with NF doesn’t mean letting NF define you.

Proclamations were issued in 31 state houses and 40 city halls across the country recognizing NF awareness month. CTF 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, glow sticks, and face painting bring bubbling energy from start to finish.

**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.

**Fight NF Your Way**

CTF volunteers across the country organize one-of-a-kind fundraising events, including comedy nights, fashion shows, and sweet tea stands, to help fund NF research. These events are held throughout the year and work to connect communities with our nationwide team of volunteers.
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.

“I decided ‘doing nothing’ for my son was not an option.”

—Diane Owens
Endurance Athlete and NF Mom
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 2019 Defense and Labor, Health, and Human Services Appropriations conference report into law on September 28, 2018. 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.
Frankie and Olyviah Moriguchi were born in Eugene, Oregon. Both have NF1.

Frankie seemed to be a healthy baby until he started having seizures at five months old. When tested, the doctors discovered two tumors in his brain: a small pea-sized tumor and a tumor on the optic nerve. The optic tumor grew and eventually caused the need for multiple surgeries including the removal of his eye at the age of four.

Now age 23, despite all of the complications of NF, Frankie is a fun-loving young man. He likes Spongebob Squarepants, Word Girl, and Sesame Street. He enjoys traveling, especially by train. He would love to work for a railroad company keeping people safe, but will settle for working for the local bus station. Frankie is a great friend and a wonderful big brother.

Frankie’s sister, Olyviah, was an extremely curious child. Often, she would climb as high as she could without the fear of falling. Now age 19, she has had six surgeries. Her most recent was to repair her pectus, as her sternum was half an inch from touching her spine.

Olyviah never lets her complications from NF stand in the way of pursuing her goals and dreams. She often fights for the underdog, and understands that life isn’t fair. However, she doesn’t see that as an excuse for people to be unkind. Olyviah is fluent in Japanese as she began studying the language in kindergarten. She plans to use her language skills in her career, working internationally.
Financial Summary

Expenses 2018

- 84% Research & Medical
- 64% Public Education & Patient Support
- 7% Fundraising
- 9% Management

ANNUAL REPORT 2018
## Operating support and revenue

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions – individuals</td>
<td>$6,932,165</td>
<td>$5,382,209</td>
<td>$2,839,870</td>
</tr>
<tr>
<td>Contributions – corporations and foundations</td>
<td>$3,165,403</td>
<td>$3,285,858</td>
<td>$3,204,939</td>
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<tr>
<td>Bequests</td>
<td>$581,164</td>
<td>$10,016</td>
<td>$102,522</td>
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<tr>
<td>Contributed goods</td>
<td>$51,337</td>
<td>$80,418</td>
<td>$763,721</td>
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<tr>
<td>Other income</td>
<td>$495,656</td>
<td>$491,993</td>
<td>$851,491</td>
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<tr>
<td><strong>CONTRIBUTIONS AND OTHER INCOME</strong></td>
<td><strong>$11,225,725</strong></td>
<td><strong>$9,250,494</strong></td>
<td><strong>$7,762,543</strong></td>
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## Operating expenses

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<tr>
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<th>2016</th>
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<tbody>
<tr>
<td>Research and medical</td>
<td>$8,045,453</td>
<td>$8,215,708</td>
<td>$7,618,638</td>
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<tr>
<td>Public education and patient support</td>
<td>$2,517,210</td>
<td>$2,116,742</td>
<td>$4,667,514</td>
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<tr>
<td><strong>TOTAL PROGRAM SERVICES</strong></td>
<td><strong>$10,562,663</strong></td>
<td><strong>$10,332,450</strong></td>
<td><strong>$12,286,152</strong></td>
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<tr>
<td>Management and general</td>
<td>$1,086,755</td>
<td>$968,659</td>
<td>$1,039,689</td>
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<tr>
<td>Fundraising</td>
<td>$842,082</td>
<td>$1,419,382</td>
<td>$1,862,625</td>
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<tr>
<td><strong>TOTAL SUPPORT SERVICES</strong></td>
<td><strong>$1,928,837</strong></td>
<td><strong>$2,388,041</strong></td>
<td><strong>$2,902,314</strong></td>
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<td><strong>TOTAL OPERATING EXPENSES</strong></td>
<td><strong>$12,491,500</strong></td>
<td><strong>$12,720,491</strong></td>
<td><strong>$15,188,466</strong></td>
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## Change in Net Assets from Operations

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<th>2018</th>
<th>2017</th>
<th>2016</th>
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<tr>
<td></td>
<td>-58,269</td>
<td>-1,330,765</td>
<td>$262,363</td>
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## Other changes

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<th>2018</th>
<th>2017</th>
<th>2016</th>
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<tr>
<td><strong>NON-OPERATING REVENUE</strong></td>
<td>($128,565.00)</td>
<td>$565,099</td>
<td>($304,524)</td>
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## Change in Net Assets

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<tr>
<td></td>
<td>($186,834)</td>
<td>($765,666)</td>
<td>$721,833</td>
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<tr>
<th></th>
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<tbody>
<tr>
<td>Net Assets, beginning of year</td>
<td>$10,699,146</td>
<td>$11,464,812</td>
<td>$10,438,455</td>
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<tr>
<td>Net Assets, end of year</td>
<td>$10,512,312</td>
<td>$10,699,146</td>
<td>$11,464,812</td>
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</table>
The Children’s Tumor Foundation is grateful for the continued support of many individuals, corporations, foundations, and communities that have joined us in the fight against NF. Thank you for your help in advancing the Foundation’s mission.

### Distinguished Donors

<table>
<thead>
<tr>
<th>DISTINGUISHED BENEFACTORS</th>
<th>$1,000,000+</th>
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<tbody>
<tr>
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### Fundraisers

<table>
<thead>
<tr>
<th>SPECIAL EVENTS RAISING MORE THAN $50,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caddies for Colin - Colin’s Courageous Bay Hill Golf Tournament</td>
</tr>
<tr>
<td>Dancing with Our Stars</td>
</tr>
<tr>
<td>New England Gala</td>
</tr>
<tr>
<td>NYC Poker Tournament</td>
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<table>
<thead>
<tr>
<th>NF WALKS RAISING MORE THAN $45,000</th>
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</thead>
<tbody>
<tr>
<td>Los Angeles NF Glow Walk and 5K Run</td>
</tr>
<tr>
<td>NF Walk Boston</td>
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<tr>
<td>NF Walk Cincinnati</td>
</tr>
<tr>
<td>NF Walk Houston</td>
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<tr>
<td>NF Walk Rochester</td>
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<tr>
<td>NF Walk Seattle</td>
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<tr>
<td>NF Walk South Florida</td>
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<table>
<thead>
<tr>
<th>DIY EVENTS RAISING MORE THAN $10,000</th>
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<tbody>
<tr>
<td>Halloween Bash</td>
</tr>
<tr>
<td>Staten Island Family Fun Day</td>
</tr>
<tr>
<td>5th Annual #EndNF with Travis Classic Charity Golf Tournament</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FUNDRAISING TEAMS RAISING MORE THAN $10,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angela Marie (Los Angeles NF Glow Walk and 5K Run, Buffkin)</td>
</tr>
<tr>
<td>Aubri’s Avengers (NF Walk Chicago, Raymond)</td>
</tr>
<tr>
<td>Ava’s Army (NF Endurance California International Marathon, Lowell)</td>
</tr>
<tr>
<td>Camille’s Tumor Fighting Superheroes (Halloween Bash, Thoms)</td>
</tr>
<tr>
<td>Catalaya’s Crusade (NF Walk Seattle, Castanon)</td>
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</tbody>
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<thead>
<tr>
<th>CHAFING THE DREAM - CHICAGO4</th>
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<tbody>
<tr>
<td>Connor (NF Endurance Bank of America Chicago Marathon, Brennan)</td>
</tr>
<tr>
<td>Cluck NF (NF Endurance NYC Marathon, Moore)</td>
</tr>
<tr>
<td>Colin Courageous (NF Endurance United Airlines NYC Half, Cashell)</td>
</tr>
<tr>
<td>DeLilah’s Dream Team (NF Walk Kansas City, Bigham)</td>
</tr>
<tr>
<td>Dominick’s Dinosaurs (NF Walk New York City, Merlucci)</td>
</tr>
<tr>
<td>Dreaming for Danielle (NF Walk Houston, Clayton)</td>
</tr>
<tr>
<td>Kendall’s Crew (NF Walk Cincinnati, amphibian)</td>
</tr>
<tr>
<td>Kendall’s Warriors (NF Endurance I Know A Fighter Boston, D’Arcy)</td>
</tr>
<tr>
<td>Leyla (NF Walk Seattle, Ghassemi)</td>
</tr>
<tr>
<td>Mighty Meeks (NF Walk Chicagoland, Meek)</td>
</tr>
<tr>
<td>NF Luminators (NF Endurance TCS New York City Marathon, Ferruggiar)</td>
</tr>
<tr>
<td>NFE Team Garrett (NF Endurance America’s Finest Half Marathon &amp; 5K, Baumann)</td>
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<tr>
<td>Parker’s Posse (NF Walk Houston, Bell)</td>
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<tr>
<td>The George T. Lewis, Jr. 2001 Foundation</td>
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<tr>
<td>The Jin Hua Foundation</td>
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<tr>
<td>The Wireless Zone Foundation for Giving, Inc.</td>
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<tr>
<td>Nicole &amp; Roland Thoms</td>
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<td>Richard Wilpon</td>
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<tr>
<th>INSTITUTIONAL GIVING</th>
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<tbody>
<tr>
<td>National Institutes of Health</td>
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<tr>
<td>Neurofibromatosis Research Initiative</td>
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<tr>
<td>Neurofibromatosis Therapeutic Acceleration Program</td>
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<tr>
<td>The Patient-Centered Outcomes Research Institute</td>
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One of the things that has struck me over the years is just how constant this Foundation has been for the NF community. From its nascent days as the National Neurofibromatosis Foundation, to today’s Children’s Tumor Foundation, this has been the place that people turn to for answers to the difficult questions. And that, ultimately, is what this foundation is all about - finding the answers to this demanding and challenging disease.

— Richard Horvitz, CTF Board Chair, speaking at the 40th Anniversary Gala in New York City
Volunteer Walk Organizer Jessica Samblanet once again exceeded expectations at the 2018 NF Walk in Cincinnati, OH. Jessica and her family stepped into an active planning role for the Cincinnati Walk in 2015 and became the primary organizers in 2017. They have worked hard to grow it into one of CTF’s largest signature fundraising events. Her hard work and dedication to finding a cure is a year-round commitment, as is evident in the growth of this amazing event, which not only raised more than $75,000, but also honored many local NF Heroes. Jessica created the top fundraising team Kendall’s Crew in honor of her daughter Kendall, who has NF1. She is one of many determined NF Moms who will do everything they can to help CTF find effective treatments for NF.

Anne Trussell has been involved with the Children’s Tumor Foundation in many ways: as a member of the NF Endurance team where she completed 50 half-marathons and 7 full marathons in the last seven years. She has also shown her support of CTF as a member of the Arkansas Advisory Board since 2014, as a member of Volunteer Leadership Council and organizer of the “Wine and Art” fundraiser (which has raised more than $75,000 to date), and most recently as a Star at 2018’s Dancing with Our Stars event, where she won the coveted Mirror Ball Trophy due to her extraordinary fundraising and dedication to our mission.
The Foundation was developed with the knowledge that at last there were doctors interested in neurofibromatosis and eager to work with us in promoting research into the cause, prevention, and cure of this devastating disease....We know that by sharing our ideas, hopes, and fears, those of us with the disease, and those close to us, will have a feeling of togetherness rather than isolation. The key is working together, and for that we need your support.

— Lynne Ann Courtemanche, in the first Foundation newsletter, 1978

Fundraiser Highlight: Eddie Purtell

Eddie Purtell participated in Rock ‘n’ Roll Denver Marathon Series as a Choose Your Own Challenge athlete, and raised more than $20,000. Eddie was diagnosed with NF at birth with a tumor on his optic nerve. When he was three years old he lost his left eye due to complications with NF. Throughout his life, Eddie has had more than 20 surgeries. Despite all of this, he has done seven half marathons and one full marathon, raising more than $75,000 for the Children’s Tumor Foundation. In 2018, Eddie lost his Papa (Ted Purtell) and has since dedicated his racing and fundraising in his honor. Eddie is a member of our Volunteer Leadership Council, and is a valuable fundraiser for the NF Endurance team every year.
With Thanks

Fundraiser Highlight: The Fashion for NF Models

Eleven local NF Heroes strutted the runway in donated outfits by various designers at the 2018 Fashion for NF event in Los Angeles, California. Actor Brendan Robinson (Pretty Little Liars) emceed the event, which raised more than $13,000 from ticket sales, a silent auction, and a live auction of the models’ artwork.

Florida Hospital Medical Center
Daniel & Debra Fontaine
Miles & Christine Forman
Francis M. Fine Jewelry
Joshua Freitas
Mary Ann & Thomas Freye
Julie & Jonathan Fritz
Kevin & Susan Funke
G-III Apparel Group, Ltd.
Ginger Gahr
Galley Support Innovations
Leon and Doris Galloway
Thomas & Rosemary Gangel
Janet Ganio
Felix & Lilliam Garcia
GE United Way Campaign
Geico Philanthropic Foundation
Marilyn Gelder
Gibson, Dunn & Crutcher LLP
Laura Gildersleeve
Kenneth Gilman
Eric & Lisa Gioia
Mary Rose & Paul Gisch
Bernard & Brenda Gilkin
Give With Liberty - Employee Donations
Ellen Gilmer
Gary & Jeanne Glodek
Sanghamitra Gogoi
Philip Goldfarb
Goldman, Sachs, & Co.
Matching Gift Program
Mary Goldsmith
Van Golemis
Carl Golub
Susie Gonzalez
Jorge Gonzalez
Matthew Goode
Google Matching Gifts Program
Margaret Gordon
Grand Council of Cryptic Masons of the State of New York
Patrick & Eileen Grasso
Chad Graves
Greater Texas Federal Credit Union
Michael Greco
Pamela Greening
Revathi Greenwood
Robert & Dana Greenwood
Lisa Griffith
Dr. and Mrs. Horacio Groisman
Harley & Rochelle Gross
Barbara Gross
Hillev & Ruth Hachlii
Amy Hall
David Hamack
Adam Handwerker
Donald M. Hanigan
Nathan & Elaine Hanke
Michael & Pamela Hanley
Mark Hanna
William & Lenore Harris
Harris and Eliza Kemper Fund
William & Leslie Soltz
Joseph Hawk
David & Sheila Heal
Robert Hendrickson
Ira Hersch
Maurice & Jacqueline Herz
Marcus Hill Hester
Herren & Susan Hickingbotham
Barbara K. Hicks
Elaine Hill
Tony Hillbruner
Hillcrest High School
Cindy Hipp
L. Lee & Carole Hodges
Jeff Hoen
John & Michele Holbrook
Adam & Carol Holzhauer
Elizabeth Hoopes
Sharon Hope
Michael & Mary Horlick
Reid Horovitz
Michael Weiner & Danielle Horvitz-Weiner
Horvitz Family Fund
Hotels for Hope
Jane Howland
Jerry & Maureen Hunter
Mark & LaDeana Huyler
I.U.O.E. Local 12 Charitable Golf Committee, Inc.
If It’s Water, Inc.
Ent. Inc.
Instinet Incorporated
International Union of Operating Engineers Local 12
Munmun Islam
Joshua Izumigawa
J.P. Morgan Charitable Trust Matching Gift Program
Carmen & Shannon Jacobson
Richard & Amanda Jaffa
Joe Jaffa
Greg & Suzanne Bloom
John & Sally Jarboe
Jean Bates & Associates
Timothy & Walda Jefferson
Jesse & Tyler Jenner
Brian & Heidi Jensen
José Jiménez
JJ Twig’s
Jo-Ro Realty Corporation
Jerry J. Jusek
Robert Kane
Kansas City Southern Matching Gifts Fund
Yvette & Jon Kanter
Danielle Karr
Alex Kates & April Ondis
Aubrey & ROLEEN Katz
Jenny & Jared Kearschner
Joseph & Linda Keller
Allen & Vickie Kelley
Khali Center for Bariatric Care Foundation
Timothy Kiefel
Brett Kilty
Yoori Kim
Kinecta Federal Credit Union
Susan Kingsolver
Michael Kitlas
Kiwanis Club of Midlothian - Chesterfield
Michelle Klieger
Wayne & Carol Kryal
Michael Koegele
Jamie Kohen
George & Jutta Kohn
Andrew Kokkino
John & Jacqueline Konechna

We started Flashes of Hope as a way to encourage and inspire children who are suffering with chronic illness. Each year our Big Shots and Little Stars event gives these kids a night to remember, and CTF gives them hope for the future.

— Allison Clarke, who founded Flashes of Hope along with her husband Kip. Their organization contributed more than $600,000 to the Children’s Tumor Foundation in 2018
In 2015, Jeff Owens organized the first Orange Hills Golf Tournament as a fundraising event in honor of his son, Alex Owens. Diagnosed with NF when he was 4 months old, Jeff and his wife Diane began their CTF involvement by building a team to run the 2014 Tower of Terror 10-Miler with NF Endurance. While Jeff hosts this annual tournament, Diane has continued to race as an NFE athlete and actively participates in the Volunteer Leadership Council. The golf tournament raised over $30,000 in 2018, and over four years has raised almost $100,000. Additionally, Diane's personal fundraising as well as big brother Justy's racing efforts have raised over $70,000, bringing this family’s fundraising efforts to more than $170,000.

Leslie Kates and her husband, Richard, initiated grassroots efforts for CTF in Boston over 30 years ago, and have been a driving force behind the New England Gala for more than 25 years. Over that time, the Boston event has raised nearly $2 million for the Children’s Tumor Foundation. Their daughter, Stacey, is an adult living with NF1, and significant donations from their efforts have been directed toward CTF’s Synodos for NF1 program. Mrs. Kates has been instrumental in helping build CTF’s New England presence through advocacy, patient support, and fundraising to assist the research efforts of the National Office.

Fundraiser Highlight: Leslie & Richard Kates

Leslie Matlin
Suzanne Matz
Benjamin & Krista Maxwell
David & Beth McAlexander
Bartlett McCartin
Stephen & Kate McCurdy
Peter & Elaine McCusker
John & Nancy McFeeley
Edward McGough
Pat & Nina McKay
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Bridget McKeon
MCO Cartage, Inc.
Murray & Mary Ann
McQueen
Megan C. MacNeil
Josh Meier
Paul & Lili Meilink

Rodrigo & Luz Mejia
Merced Elks Lodge #1240
Meridian Realty Advisors, LP
Meriden Energy, LLC
Richard Midlach
Microsoft Matching Gift Program
Phyllis Midlarsky
John & June Miley
Richard & Margaret Miller
Erika & Kelley Millet
Joann Miyamoto
Jonathan Mok
Robert Moler
Monde Group, LLC
James & Cathy Moore
Christine Moore
Stephen Morey

Fundraiser Highlight: Jeff & Diane Owens
Carolanne Owenby and Tara Rogers hosted their 6th annual Little Heroes 5K of North Georgia in February 2018. Carolanne and Tara are the founders of our Little Heroes 5K program, and they hold a race each year in honor of Carolanne’s son Robert, and for all the other NF Heroes in the Gainesville, Georgia community. In 2018, the event raised over $35,000. Year after year the Gainesville community rallies around Robert and the Owenby family. They have set the bar for what a Little Heroes 5K should look like and how it can make such an impact in raising funds to support the mission of the Foundation. Carolanne also continues to be our top individual fundraiser, and in 2018 raised more than $29,000 for CTF through her participation in the Rock ‘n’ Roll Vegas Marathon.

**Fundraiser Highlight:** run 4 robert
The 26th Annual Children’s Tumor Foundation Golf Scramble was held on October 8, 2018 at Arnold Palmer’s Bay Hill Club and Lodge, home of the PGA tour event, The Arnold Palmer Invitational. This event has been hosted over the last 19 years by the Ehrli family in honor of their son Joe, who has NF1, and is also an Eagle Scout and attends the University of Central Florida. With the long-time Title Sponsorship by the Wireless Zone Foundation for Giving, they have been able to raise close to $750,000 over years. At the awards luncheon Brian Murtari, President of the Wireless Zone, and Dave Staszewski, Executive Vice President of the Wireless Zone, presented the Children’s Tumor Foundation with a check for an additional $25,000 to sponsor next year’s event. This year MLB All Star and World Series Champion Johnny Damon helped welcome the guests.

The Foundation presented a Humanitarian Award to Carol Harrison Kalagher, a philanthropist from Fort Lauderdale, Florida at the 40th Anniversary Gala in New York City. Carol is a primary benefactor of CTF’s Synodos for NF2 project, and an NF advocate. Inspired by her grandson Hunter, and focused on helping all who live with NF, Ms. Kalagher’s vision to provide funding for the Foundation’s Synodos for NF2 team science initiative has resulted in promising treatment candidates for those living with NF2. Carol has committed more than $500,000 towards this initiative; her support has been instrumental to the project’s success. Carol has committed more than $500,000 toward NF2 research, support that has been instrumental in the search for treatments for NF2.

The Fredecker Family Foundation
The Joseph & Drenda Vijuk Foundation
The Martin Andersen-Gracia Andersen Foundation, Inc.
The Mary Jane Harlow Charitable Trust
The MHE Foundation, Inc.
The Thompson Foundation
The Vana Family Foundation
The Wawa Foundation, Inc.

Steven L. Landers
Chrysler
Dodge
Jeep

Edward Stiker
Judith & James Stillwell
Martin & Mary Ann Stone
Leanne Story
Stephen & Christine Stout
John Striker & Eda
Modesta
Suffolk Transportation Service, Inc.
Thanks to CTF volunteer Kristy Evans, Sherwood Elementary hosted the first Classrooms That Care NF Experience event, and it was a huge success. A series of interactive exercises were brought into the Islip, New York school to educate students (and teachers!) about some of the many manifestations of NF. Students walked with a yoga block on one shoe to show bone discrepancies. Others wore garden gloves and raced to tie their shoes, to help demonstrate issues with fine motor skills. Lastly, some students wore blurry or blocked glasses while reading a book to show vision issues. After the school learned about NF, they set off on a mission to collect spare change and raise funds for research. The Sherwood Elementary students raised more than $1,500 toward our mission to end NF.

Two Counties One Cause is a high school basketball tournament benefiting CTF, matching up rival teams from Westchester and Rockland counties in New York. 2018 was its third year and raised more than $14,000. George Gaine, a physical education teacher and head coach for Tappan High School boys basketball, created the tournament to raise funds and awareness in honor of his daughter Brielle one year after he ran the NYC Marathon for NF Endurance with Team Brielle.
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.

“I’m thankful for all the NF research that CTF is funding, and I’m proud to encourage you to leave a bequest to the Foundation in your will, as I have. My planned gift will keep that progress moving forward for generations to come, and I’m grateful that I can be a part of that future.”

—Stuart Match Suna, CTF Board of Directors Member

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.
Synodos Continues to Deliver. This tremendous investment in open science is bringing results quicker. This year alone Synodos teams identified a promising clinical candidate for NF2; animal models that replicate NF1 in pigs are generating new, applicable knowledge; optic glioma teams are identifying treatment opportunities; and pain mechanisms are being discovered to help schwannomatosis patients.

A very energetic and largest ever NF Conference in NF history was held in Paris, with nearly 900 attendees from across numerous disciplines, demonstrating the growing significance of NF research, and setting the stage for the 2019 NF Conference in San Francisco.

The Foundation’s considerable investment in genotype/phenotype studies generated results that improve the predictability of NF in patients, by connecting specific gene mutations to their associated symptoms. Our goal is to replace “watch and wait” with “here’s what you can do.”

Each day we learn more about NF, and Key Workshops were convened by CTF to update NF diagnostic criteria – so doctors know what to look for when seeing patients. CTF also convened a major animal model workshop – from which patients will see better treatment options.

Innovation is in our DNA, and the pharmaceutical industry is noticing. Growing interactions with major pharma are bringing attention to NF, and growing NF’s critical importance into other disease areas as well.

Patients are at the center of everything we do, and CTF generated the tools to increase ‘patient power’ through our first Patient Engagement program, in which 20 new patient advocates graduated – their leadership will increase the patient voice in research priorities.

We are all one team, and CTF is a catalyzer of both NF research and NF relationships, bringing both public and private NF funders and organizations together in successful new partnerships which will expand the landscape of NF research. We’re driving research – for example, new cell lines – and also advancing care, with better-quality expertise for caregiver and patient support.

CTF leads the way with the creation of the NF Open Science Initiative and the NF Data Portal in partnership with NTAP and Sage, growing the ability of researchers to access the most current NF knowledge and research results. Our Key Opinion Leader Network brings the best people together in an open source environment, so that we get to a cure for NF faster.

MEK is making more of a difference than ever before, as the MEK inhibitor selumetinib was given Orphan Drug Designation by both the Federal Drug Administration (FDA) and the European Medicines Agency (EMA). Patients are seeing reduced tumor sizes, and most importantly, their lives are improving dramatically.
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*Lists on this page as of July 2018