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 national 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.
I really feel that NF patients are simply UN: UNdaunted in your UNcommon courage. UNbeatable in your UNsurpassed ability. UNbreakable in your spirits. And UNaccepting of the status quo. To end NF we need that UN attitude.

— Annette Bakker, PhD, upon accepting a 2017 Rare Champion of Hope Award from Global Genes for notable efforts in science
As 2017 came to an end, the Children’s Tumor Foundation entered its 40th anniversary year, and began a celebration of our history of progress, leading the way to find treatments for neurofibromatosis (NF). Through the relentless work that CTF researchers have been doing, those living with NF can look forward to a better life. In this report of CTF’s 2017 accomplishments, you will read of groundbreaking progress and vital new partnerships. My hope is that you will be inspired to believe along with me—we can end NF.

On so many fronts, CTF-funded research is making great strides for NF. Our focus is on promoting collaboration and breaking down the barriers that hamper progress, with a goal to shorten the length of time it takes to develop effective treatments. Synodos for NF2 completed its third year with a significant data release and an extremely promising treatment candidate for NF2. Our first industry partnership became a reality and we are expanding to many more.

Even more exciting, 70% of patients enrolled in the clinical trial of the MEK inhibitor selumetinib at the National Cancer Institute are seeing their tumors shrink by 20-50%. The images of the NF Heroes who are participating in this trial speak for themselves; their young lives have improved, both visibly and physically. The MEK trial has been revolutionary, and throughout 2017 and into our current year, our eyes are trained upon our bold goal of 100% tumor reduction in 100% of patients. We are overjoyed by the incredible news from AstraZeneca and Merck that selumetinib has attained orphan drug status from the FDA. We are closer than ever to the first FDA-approved treatment for NF!

The impact of your generosity is astounding. Your faith in the work we are doing propels us forward and fills us with purpose. Thank you to all those who support this fight in so many ways—through fundraising, volunteering, planning, donating, or advocating. Together we are changing the lives of NF patients, and the future of NF research.

Our vision to end NF continues with ever-increasing passion. We have come so far, and as we continue along this crucial path, I am confident that we will fulfill our mission. It is because we bind ourselves together as a united front of researchers, volunteers, parents, donors, and patients, that we will lead the way.

Gratefully,

— Annette Bakker, PhD, President and Chief Scientific Officer
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 that day is on the horizon because of our innovative team-based approach to drug development.

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**

**PATIENT**

**TREATMENT**

*Why it takes this 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

**COST:**
Hundreds of millions of dollars

**NEW CTF RESEARCH MODEL**

**PATIENT**

**TREATMENT**

*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

**GOAL:**
Double the speed for half the cost!
Over 70% of enrolled patients with plexiform neurofibromas saw decreased volume of at least 20-50% in these inoperable tumors, a first in NF research. This highly successful study is the result of the Children’s Tumor Foundation’s major investment in the team-science approach of the NF Preclinical Consortium. This MEK trial success has been published in the prestigious New England Journal of Medicine, and is on track to be NF’s first approved drug.
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.

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.

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.

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.

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.

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.
How can we standardize the endpoints of clinical trials?
The REINS Consortium (Response Evaluation in NF and Schwannomatosis) is establishing approval criteria. 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.

The Children’s Tumor Foundation [has a] knack for identifying and securing highly qualified participants with widely varied, but complementary, expertise. Even more remarkable is the commitment of each to the goal of developing cures in the shortest possible time.

— Webster Canevee, PhD
Director of Strategic Alliances in Central Nervous System Cancers, Ludwig Institute for Cancer Research
The Children’s Tumor Foundation’s team science projects are leading the way in NF research and accelerating the drug development process.

**Synodos: CTF’s Premier Research Model**
The Children’s Tumor Foundation assembles “dream teams” of doctors, scientists, and patients who work together to solve complex problems faced by NF patients, who drive the topic of Synodos collaborations. Data is analyzed by our partners at Sage Bionetworks, and then made available to all Synodos members, and shortly thereafter, to the rest of the world via CTF’s NF Data Portal. This approach is expanding interest in NF research to other research areas, including cancer.

**Synodos for NF2**
The first of the Synodos models established by CTF, Synodos for NF2 was launched in 2014 to provide clarity to patients about available drug options for NF2. This consortium of multidisciplinary investigators from 12 world class labs and medical centers performed rigorous drug testing that 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 met in Toronto, Canada in May of 2017 to officially launch Synodos for Schwannomatosis, 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.

**Synodos Network Meeting**
Over 70 researchers, clinicians, patients, staff, and other experts gathered in Florida for the first Synodos Network Meeting, hosted by CTF and supported by the Jin Hua Foundation. The theme of the meeting was Synodos: The Art of Ending NF, and included the vibrant artwork of Synodos patient advocate and former NF Ambassador Jeffrey Owen Hanson. This was the first joint gathering of key leaders from all Synodos initiatives, and it provided a unique opportunity to share research updates and exchange views on specific Synodos-related matters.

**Synodos for NF1**
CTF sought out feedback from NF1 patients when establishing Synodos for NF1 in the spring of 2016. Patient concerns for better treatment options for NF1, as well as the search for 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.
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 for a total cost of $11 million. The preclinical studies led to 16 clinical trials that are currently under way; 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).

After the [Synodos for Schwannomatosis] meeting today, I feel that we’ve assembled a total dream team of people who are highly dedicated to making something happen by working together.

—Richard A. Horvitz
CTF Board of Directors Chair and Synodos for Schwannomatosis Patient Advocate

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 20-50% in their inoperable plexiform neurofibromas. A registration trial such as this is the final step before FDA approval. 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 is the result of CTF’s NF Preclinical Initiative, which demonstrated that MEK inhibitors have a massive result on the volume of these tumors.

—Kristina Rath
Mother of NF Hero Jane

Orphan Drug Status
The Food and Drug Administration (FDA) has granted Orphan Drug Designation for selumetinib, a MEK inhibitor, for the treatment of NF1. The news that the FDA has provided orphan drug status illustrates not only the potential of this treatment, but provides further incentives for drug companies to invest in NF-related trials.
CTF funding of NF research leads the way to better diagnostic criteria and improved clinical care.

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 works 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. For the 2017 grant cycle, two YIAs were granted to postdoctoral students whose projects focus on NF1 tumors. The NF Research Initiative (NFRI) and David Miller, MD, PhD of Boston Children’s Hospital are funding the 2017 awardees.

TESTING CONCEPTS

Drug Discovery Initiative Award (DDI)
The DDI Award program supports in vitro (cell) and in vivo (animal) studies of early-stage testing of candidate drug therapies for the treatment of all forms of NF. Four DDI awards were granted in 2017, which include projects that target therapies for NF1-related malignant peripheral nerve sheath tumors (MPNST), neurofibroma growth, NF2-related schwannomas, and to screen drugs against NF1 and NF2 cell lines.

SCIENTIFIC TRANSPARENCY

Drug Discovery Initiative Registered Reports (DDI-RR)
In 2017, CTF introduced a rigorous new way of reviewing and funding projects. Through a collaboration with top scientific journal PLOS ONE, in a new process known as “Registered Reports,” awardees are offered financial support by CTF and in-principle acceptance for publication by the journal. This model will allow for more rigorous, reproducible, and transparent science, guaranteeing its awardees publication, regardless of study outcome.

DELIVERING TO PATIENTS

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 treatment interventions, clinical-trial-enabling or ancillary studies, natural history studies, and investigations into clinical care in NF.
I believe my work, supported by the YIA, will shed light on the cell-cell communication network within NF and MPNST, which will ultimately help in designing new therapeutic strategies against these devastating diseases.

—Lai Man (Natalie) Wu, PhD
Cincinnati Children’s Hospital Medical Center, 2017 Young Investigator Awardee

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, nerve, bone, and other tissues post-mortem from NF1, NF2, and schwannomatosis patients. The tissue comes from people who previously request 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.

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.
Doctors, clinicians, patients, and researchers gathered in downtown Washington, DC for CTF’s annual 2017 NF Conference. Approximately 400 people were in attendance, which is nearly 25% more than the previous year, making it the largest NF Conference thus far.

President of the Biden Cancer Initiative Greg Simon joined the 2017 NF Conference as Keynote Speaker at the Welcome Dinner, held at the historic National Press Club. Simon spoke on the important topics of research collaboration and breaking down barriers to research progress. Greg Simon’s relationship with the Foundation began when both he and CTF President Annette Bakker, PhD, attended the Cancer Moonshot Summit at the invitation of former Vice President Joe Biden. Simon was then serving as the executive director of the Cancer Moonshot Task Force.

“I’m here to thank you for getting it right and for getting it right so soon in your life as a Foundation. And to thank you for giving people hope. The kind of hope that says, we’re going to get it done . . . and take chances to cure NF. The kind of hope that’s backed up by years of work, by thousands of patients putting their lives on the line, and by . . . all the people in the Foundation who are willing to take the risk to help [those with NF] live a long and healthy life.”

— Greg Simon
President of the Biden Cancer Initiative, to the attendees of the NF Conference
If a genotype-phenotype correlation exists for a particular mutation, it will help these families have some perspective of what the future will bring, and it will help families cope with the disease.

“— Ludwine Messiaen, PhD of the University of Alabama
Throughout this journey, I have drawn strength and inspiration from the many NF families I have met. This has empowered me to contribute my knowledge and wisdom of living with NF to the NF research community. NF is too much for anyone to take on alone, and it is only through collaboration that we will find a way to end NF.

— Sarah Adsit
NF Mom

Patient Engagement

Patient engagement in research is increasingly recognized as an important component of the research process and promises to accelerate the development of new treatments, by focusing researchers on real-life issues that they may not have otherwise considered. As part of this initiative, CTF launched the Patient Representative Training Program, designed to prepare individuals with NF and their families to participate as advocates in NF research. Our goal is to help patients learn how to add their perspective during all phases of the research process – from the laboratory, to the clinic, to the community. Patient Representatives are trained to work with stakeholders such as researchers, research institutions, the pharmaceutical industry, the Food and Drug Administration, and patient advocacy organizations.

NF Symposium

An NF Medical Symposium is a one-day, local or regional conference to educate and support individuals affected by NF. Symposia are often hosted by NF clinics from around the country and audiences may include patients, family members, healthcare providers, and educators. Additionally, CTF sponsors the NF Forum, a gathering where NF patients and families can learn more about NF research, and enjoy social activities to connect with other members of the NF community. In 2017, CTF was awarded a coveted grant from PCORI (Patient-Centered Outcomes Research Initiative) to support patient training at the 2018 NF Forum.

Neurofibromatosis Clinic Network (NFCN)

The Neurofibromatosis Clinic Network was established to standardize and raise the level of neurofibromatosis clinical care nationally, and to integrate research into clinical care practices. In 2017, 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 Registry

By the end of 2017, over 8,000 individuals 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* in June 2017. Not only are thousands of patients from all over the world contributing their data online at nfregistry.org, 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.

NF Camp

Over 100 youth attended the 21st annual NF Camp, which expanded from two to three July sessions in 2017. NF Camp is a weeklong adventure held at the beautiful Camp Kostopulos in Emigration Canyon, Utah. Campers enjoy 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.

The Volunteer Leadership Training Conference

The Volunteer Leadership Training Conference took place in April 2017 in Seattle, Washington, just before the Seattle NF Symposium. The gathering provides an opportunity for our active volunteers to learn how to grow their events, become more effective fundraisers, connect with each other, and learn more about the many programs the Foundation offers.

“I seriously wish I could talk to every parent of a kid with NF and tell them what a positive, motivational, encouraging, life-changing experience NF Camp is.”

— Kathleen Sullivan
mom to NF Campers Mark and Aaron
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 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 stories of NF Heroes and their families.

Proclamations were issued in 26 state houses and 30 city halls across the country recognizing NF awareness month. CTF engaged local leaders and helped ensure that more people in office know about NF and how it affects their constituents.

The Shine a Light on NF initiative cast a blue and green glow on buildings, bridges, and monuments around the country and across the globe, bringing the 2017 total to 159 landmarks spanning 9 countries.

The I-35W Mississippi River Bridge in Minneapolis, Minnesota
With the “This is NF” photo series, we told a side of the NF story that isn’t often told—that of the passion that adults living with NF bring to their careers. These professionals shared a side of their story that often goes unnoticed, demonstrating that living with NF doesn’t mean letting NF define you.

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.
NF Walks are non-competitive, relaxed, celebratory events designed to champion the individuals who live every day with the challenges of neurofibromatosis. 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.

Do-It-Yourself Events

With the help of our regional staff, individuals across the country organize one-of-a-kind fundraising events, including comedy nights, fashion shows, and Sweet Tea for Sophie stands, to help fund NF research. These events are held throughout the year and work to connect communities with our nationwide team of volunteers.

“Instead of presents this year, I want donations for my NF Walk. I want everyone to come for the Walk so we can raise money to find a cure for NF.” — Evelyn Frias

NF Hero, age 9

NF Walk

Instead of presents this year, I want donations for my NF Walk. I want everyone to come for the Walk so we can raise money to find a cure for NF.

— Evelyn Frias

NF Hero, age 9
NF Endurance

The NF Endurance Team gives participants the opportunity to run, bike, swim, and compete in endurance events across the country and internationally. Comprised of a broad spectrum of athletes, from those who are running in a 5K for the first time, to courageous triathlon competitors, our Endurance Team goes the extra mile to end NF, and gains inspiration from NF Heroes (individuals with NF).

“ I take strength and inspiration from the children and adults suffering from NF on a daily basis – this is the driving force that will push me to endure more hardship as the race progresses. I can only hope that my small effort helps to make a difference and raise money for the research needed to find a cure for NF.

— Craig Noble
NF Endurance Athlete
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 Congressional Member District Offices. We are pleased that $15 million in dedicated NF research funding was again secured in the Fiscal Year 2017 congressional funding cycle. The recipients of these federal grants are conducting research that is of immense value to NF researchers around the world.

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.

Without collaboration among the government, industry, academia, and foundations, we won’t get there. It is a team sport. . . . Your repository, your tissue bank, meetings like this where you reinforce the notion not to duplicate what’s going on…but to chase the risky, to chase the immediate, to chase the urgent. . . . I’m here to thank you for getting it right.

— Greg Simon
president of the Biden Cancer Initiative in his address to the CTF NF Conference attendees at the National Press Club in Washington, DC
Sarah Rodbell

Sarah Rodbell was honored as the 2017 Children’s Tumor Foundation NF Ambassador, an award bestowed upon a young person with NF to recognize courage living with the disorder, and personal efforts to further the Foundation’s goals of research, public awareness, and patient support.

The daughter of Liz and Mitchell Rodbell, Sarah was diagnosed with NF1 when she was 10 years old. When her mother was brushing her hair she found a bump. Later, after a biopsy, they found out it was a cancerous tumor. Thankfully, after two surgeries, she has been cancer free since 2009.

Sarah started fundraising for CTF when she was 11 years old and hasn’t stopped. Sarah helped plan and organize the NYC NF Walk, held a bake sale at her school, and she and her uncle raised funds for the Children’s Tumor Foundation through his participation in the IRONMAN Mont Tremblant. Sarah pushes herself every day and tries to make each day memorable.

She loves photography and spent her year as CTF’s NF Ambassador taking photographs, including a photo series for National Geographic, which was on display at CTF’s New York Gala.
Only 2% of the charities we rate have received 8 consecutive 4-star evaluations, indicating that Children’s Tumor Foundation outperforms most other charities in America. This ‘exceptional’ designation from Charity Navigator differentiates Children’s Tumor Foundation from its peers and demonstrates to the public it is worthy of their trust.

— Michael Thatcher
Charity Navigator
President & CEO
### Change in Net Assets from Operations

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### Other changes

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### Change in Net Assets

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<td>(765,666)</td>
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### Net Assets, beginning of year

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<td>Net Assets, end of year</td>
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with thanks

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.

**CHAMPIONS $1,000,000+**
- Cupid’s Charity
- Gilbert Family Foundation
- Richard Horvitz and Erica Hartman-Horvitz Foundation

**STEWARDS $500,000+**
- Flashes of Hope/Kick It

**PARTNERS $200,000+**
- Anonymous
- Sally Gottesman
- Rachel B. Tiven & Seth M. Marin

**LEADERS $100,000+**
- CureNFwithJack
- Frank & Shelley Haughton

**PATRONS $50,000+**
- Interblock USA L.C.
- Irving Berlin Charitable Fund, Inc.
- Stuart Match Suna
- The Paul E. Singer Foundation
- Michael & Kelly Peterson
- RBC Foundation USA
- The Spiegel Family Foundation
- Roland & Nicole Thoms
- UBS Business Solutions US LLC

**BENEFACTORS $25,000+**
- Assurant Foundation
- Barton Malow
- Ellen & Stephen Carpenter
- David & Michelle Carroll
- Jason Colodne
- The Derfner Foundation
- DTE Energy Foundation
- William & Marlene Emerson
- Brian & Luisa Ferruggiari
- The Forbes Company, LLC
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- ICAP Services North America LLC
- The Jin Hua Foundation
- The Kettering Family Foundation
- Lear Corporation
- Little Heroes of North Georgia LLC
- The MakeSense Foundation
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- Kevin & Elizabeth McMeen
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- Peerless Clothing International
- Patricia Spencer
- Strategic Staffing Solutions
- Wallbridge
- Robert D. Walters, Jr.
- The Wireless Zone
- Foundation for Giving, Inc.

**SPONSORS $10,000+**
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- Daniel & Robin Altman
- Jeffrey Apple
- Barry & Seward, PLLC
- Brian & Kelly Behrens
- Belfor USA Group Inc.
- Belkin Burden Wenig & Goldman, LLP
- Bernard Financial Group
- Timothy Birkmeier & Malyka Degoa
- Black Knight Financial Services
- Blue Team Restoration
- Bob’s Discount Furniture
- Charitable Foundation, Inc.
- Robert Brainin & Nicola Kean Brainin
- The Broder Family Foundation Inc.
- The Brown Foundation
- Tricia Brown-Fowler
- Colin & Sarah Bryan
- Caffee, Halter & Griswold LLP
- Cantor Fitzgerald Relief Fund
- Citizens Commercial Banking
- Clear Capital
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- Colasanti Construction Service Inc.
- The Collingwood Group LLC
- Matt Cullen
- Benjamin Davey
- Ian & Chelsey Desmond
- Donald H. Baltzer Trust
- Eileen B. Baltzer Trust
- Elite Fire Safety, Inc.
- Emily Anne Weikert Charitable Foundation
- Equifax Foundation
- FCA US LLC
- Fifth Third Bank - Eastern Michigan
- John & Marcy Fikany Forest City Enterprises, Inc.
- Gable A Visual Solutions Company
- The Gallagher Family Foundation
- Mark & Tracy Galloway
- The George T. Lewis, Jr. 2001 Foundation
- Gertrude and William C. Wardlaw Fund
- Shirley Gilbert
- John & Stephanie Gofinos
- Goodwin Procter LLP
- The Gordon and Llura Gund Foundation
- Stephen & Myrna Greenberg
- Greenberg Traurig, LLP
- Nicholas & Kristin Guehlstorf
- Heritage Optical Center Inc.
- The Huntington National Bank
- Ilitch Holdings, Inc.
- Image One Corporation
- Jones Day
- Andrew & Frances Kallman
- Kenwal Steel Corporation
- Kilpatrick Townsend & Stockton, LLP
- LaBelle Electric
- Alan & Linda Landis
- Mark & Andrea Light
- Todd Lunsford
- Peter & Jacqueline McKenna
- Medical College Of Wisconsin
- Microsoft Matching Gift Program
- Stephen & Eve Milstein
- National Basketball Association
- National Institutes of Health
- New Orleans Firemen’s Federal Credit Union
- Anita & Charles Newberg
- Jerry & Frances Newberg
- Nomad Framing, LLC
- Nomadic Expeditions, Inc.
- Michael & Sara Orlando
- Jeffrey & Diane Owens
- Jeff Perry
- Plante Moran
- Kevin & Kathryn Prokop
- RAM Construction Services
- RateMarketPlace
- Richard and Jane Manoogian Foundation
- Andrea Rockefeller
- Natalie & Win Rockefeller
- Jean Rothschild
- Kenneth C. Rudd, Esq.
- Janet H. Shaver
- Win Sheridan
- Gary & Lisa Shiffman
- SHoP Architects
- Philip & Judith Shwachman
- Jonathan Staver & Rachel Winer

**LEADERS $100,000+**
- CureNFwithJack
- Frank & Shelley Haughton

Seattle NF Walk

On Saturday, September 23, 2017, hundreds gathered at Owen Beach in Tacoma, Washington for the fourth annual Seattle NF Walk and raised more than $89,000. NF Hero Natalie Denham was in the spotlight at this Walk, as were many other NF Heroes who enjoyed a day full of fun, food, and laughter. Special thanks to Christo Costamon and Michele McMillin, Walk co-chairs, and to Matthew and Kate Riley of Team Isla, who raised more than $50,000 for NF research.
Our mission is to find a cure for NF in Isla’s lifetime. With the love and help from everyone on Team Isla, and in thanks to all of the amazing teams across the country, we will do this. We will end NF.

— Matt Riley, Isla’s dad and Team Isla Captain
The stunning Dancing With Our Stars annual benefit was held on September 7, 2017. At this 10th Anniversary Spectacular, Arkansas celebrities showed off their dance moves as they competed for the coveted mirror-ball trophy. The first Dancing With Our Stars was held in 2007 and raised $25,000. The event has grown tremendously and this year raised more than $200,000, bringing the ten-year total to over $1 million for NF research. Our gratitude goes out to Lesley Oslica and the DWOS Committee for their continuing work on this wonderful event.
DONOR SPOTLIGHT

Since it was founded in Cleveland in 2001, Flashes of Hope has photographed close to 60,000 children fighting cancer to help them look and feel attractive and invigorated, boosting their confidence as they cope with the depths of the disease. “Big Shots & Little Stars” is the charity’s most impactful annual fundraiser, raising money for research to accelerate a cure for children’s cancer. The night culminates with a strut down a fashion runway spanning the floor of the Quicken Loans Arena. Cleveland-area business leaders, civic leaders, and Cavalier basketball players partner with the children and escort each of them down the runway for a moment in the spotlight. Thanks to this event, Flashes of Hope made a 2017 donation of $750,000. The Children’s Tumor Foundation extends our utmost thanks to Flashes of Hope and its founders, Kip and Allison Clarke, for their continued support in funding NF research.
Cocktails for a Cure

Cocktails for a Cure was held on October 22, 2017 at the Brookville Country Club in Long Island, New York. It was a beautiful evening filled with delicious hors d’oeuvres and flowing champagne. Thank you to all of the attendees and donors, and to the wonderful event committee: Laura Perfetti, Cristina Spoto, Lisa Arena, Jill Hannity, Pam Blank, Kristen Kalenderian, Meg Blank, and Marietta Perfetti. The evening raised more than $108,000 to support the mission of the Foundation, thanks to a silent auction, a raffle, and a live auction in honor of NF Heroes Julia Perfetti and Charlotte Spoto.
Maxine and Stuart Frankel Foundation
Benjamin & Krista Maxwell
John & Nancy McFeeley
Robert & Jamie McGrath
Kaye McGregor
Bridget McKeon
McKnight Title Escrow
Michael & Lori McLaughlin
Fred & Elizabeth McLeod
Shawn & Erin McLevige
Tim & Micheile McMillin
John McNamara
MCO Cartage
Debbie Means
Paul & Lili Meilink
Rodrigo & Luz Mejia
Jason Merchant
The Merck Foundation
Merritt, Inc.
Dominick & Melissa Mertucci
The MHE Foundation, Inc.
Steven Middleton
Flora Migyanka
John & June Miley
J. Scott & Susan Miller
Mark Miller
Richard & Margaret Miller
Thomas & Janice Milone
Guo Min
Patricia & Donald Mintmire
Luis Miranda
Mello & Mary Jo Mitchell
Joan Miyamoto
James & Laurède Moffett
Frederick & Shelley Molineux
Stewart Monday
Michael Montanaro
Mark & Blanca Montella
Darlene Monzo
James & Cathy Moore
Moos & Cabot, Inc.
Christine Morrison
Mike & Darlene Morton
Philip & Renie Moss
William Moyssiadis
Kerry & Steve Muller
David Mullet
Kelly Mullins
Kevin & Stacey Mullins
Chip & Cindy Murphy
Lisa Murphy & Cindy Bourgeault
Rick & Windsor Naething
Neeb-Kearney & Co., LLC
David & Shanna Nelson
Renee Nelson
Scott & Tara Nelson
Barbara Nessim
Brian & Ym Neugeboren
Neumann/Smith
Architecture
Paul & Nicole Nevitt
Michael & Judy Newell
NewGen Strategies & Solutions, LLC
Newmont USA Limited
Jon Nichols
Cristina Nicoara
Leo Nicollini
Soniee Noack
Jeffrey & Constance Noiva
Mariam Noland & James Kelly
Northwell Health
David Norton
Irving & Barbara Nusbaum
Karen & Dennis O’Keefe
Terence & Kay O’Neill
Edward O’Shea
Kevin & Susan O’Shea
R. Wayne & Emily Ogozaly
Richard & Caroline Olgee
Gabriel Oliveri
June Oller-Moya & Jeffrey Moya
John & Cathy Olszewski
Otis Elevator Company
Thomas Oven
Wesley & Carolanne Owenby
George & Sandra Pace
Jason & Kristin Pace
Cherie Page & Chris Petiprin
Pak’s Karate Academy of Mandarin
Chelsey Paksi
Bobby & Carol Palmer
Matthew Parker
Glenn Pasch & Mayra Bracer Pasch
Pat Covelli Foundation
Jagruti Patel
Robert & Patti Patent
Patricia M. Hynes & Roy L. Reardon Foundation
Andrae Patterson
Brian Payne
Edward Pearson
Pentastar Aviation
Lisa Perchedouk
Paul & Karen Perella
Alfonso & Doris Perez
Anthony & Laura Perfetti
Francisco Javier Peris Felipo
Leigh Perkins
The Perkins Charitable Foundation
Perkins Coie LLP
Douglas & Colleen Perry
Lora Perry
Peter Basso Associates
Melissa Peters
Bruce Peterson
Mary Peterson
Paul & Tricia Pfeifer
Roy & Rose Pfeifer
Pfizer Foundation Matching Gifts Program
Robin & Erik Phelps
Richard Petch
Margaret Phill
Starr Piner
Zach & Michelle Piner
Charles & Patricia Pittman
Gordon & Denise Pitzman
Pledgeling, LLC
Kristine Poirier
Kenneth R. Pomeroy Jr.
John Power
Paul & Angel Price
Professional Movers
Prosperity Bank
Tony Pulice
Hattie & Ted Purcell
R.D. White Co. Inc.
Rachel Hardester
LeAnn’s Jewelry

Cupid’s Charities

February of 2017 marked the eighth consecutive Cupid’s Undie Run to benefit the Children’s Tumor Foundation. Everyone’s favorite Valentine’s Day-themed party has shown us yet again what an inspired group of generous people can do to spread awareness and raise money for NF. Cupid’s has grown by leaps and bounds since the first undie run in 2010 with 300 participants, to more than 89,000 all-time undie runners! Cupid’s Undie Run brings together individuals directly affected by NF and people who are unaffected for a unique and fun event to end NF. Thank you to all the undie runners, volunteers, and staff for the ongoing support from Cupid’s Charities to the CTF mission!

Howard and Mara Rachlin
Frederic Raguchi
Randall-Paulson
Architects, Inc.
Eric & Abby Randolph
Albert & Audrey Ratner
Brian & Pat Ratner
Rayonier Operating Company LLC
Jason & Stacey Raznick
Realtime Data Team
Donald & Judith Rechler
Daniel & Lisa Reck
Steve Reddy

She does not understand all the aspects of NF1 yet, but she knows that it is a part of who she is and that it makes her stronger inside and out.

— Hillary Adams, mom to NF Hero Julia
CureNFwithJack

CureNFwithJack continues to graciously support the Children’s Tumor Foundation through golf tournaments and events around the country. The 6th Annual DC Golf Classic was held in October of 2017 and drew participants and donors who have generously contributed for years. In addition to the Washington, DC event, CureNFwithJack hosted two golf tournaments in Atlanta, Georgia, as well as a fundraiser through the Atlanta Charity Clays.

CureNFwithJack was founded by Jake and Beth Burke, who rally around the NF cause in support of their son Jack, who is now thirteen and lives with NF1. In 2017, CureNFwithJack made a generous $150,000 donation to support NF research. Our utmost thanks to the Board of Directors of CureNFwithJack (who are all volunteers and not directly affected by NF) and the entire Burke family, Jake, Beth, Jack, Luke, and Grace for your ongoing support. You are providing hope for millions who live with NF.

The New York City Poker Tournament

The 2017 New York City Poker Tournament was held on June 7th and hosted over 135 players. The annual event brought in more than $100,000 to support NF research. We extend a huge thank you to CTF Board Member Dan Altman and the rest of the planning committee for, once again, going all in for CTF!
Sally Gottesman

Sally Gottesman became involved with CTF after her oldest daughter was diagnosed with NF1 over a decade ago. In 2017 she made a generous multi-year commitment to the Foundation to support CTF’s fundraising strategy and advancement, support that will have significant impact upon the future of the Foundation. Sally is a donor-activist and has committed herself to increasing funding and catalyzing research for NF. A graduate of Wellesley College and the Yale School of Management, Sally says “I am motivated to use my time, my money, and my education to help my daughter and all people and families who have NF. I hope that everyone touched by this disease will join me by generously giving of their resources because I am confident that collaboration is the breakthrough ingredient to solve this problem.” In addition to her commitment to NF research, Sally serves as the Chair of Encounter, which brings American Jewish leaders to the West Band and East Jerusalem on immersive educational experiences so that they can more constructively engage with the most critical issues at the heart of the Israeli-Palestinian conflict. Our thanks to Sally for extending her expertise and support with such gracious enthusiasm.
IAN DESMOND
When baseball player Ian Desmond was playing for the Washington Nationals in 2012, he befriended South Carolina native Ethan Brown, who had been diagnosed with neurofibromatosis. Ian began interacting with Ethan via Twitter and invited him to a game in Atlanta later that year. Since then, the two have continued to correspond and Ian, who now plays for the Colorado Rockies, has become a champion for NF awareness and the Children’s Tumor Foundation.

In 2016, Ian and his family pledged to donate $1,000 to the Children’s Tumor Foundation for every run he hit during the month of May for NF Awareness Month, resulting in a $20,000 donation.

In May of 2017, Ian released a special edition T-shirt featuring his profile and our End NF message, with the proceeds from sales coming to CTF. In June, nearly 200 members of the CTF community from Colorado watched the Rockies play at the third annual NF Night at the Rockies, which aims to raise funds for CTF and gather local NF families together to enjoy a great evening of baseball. The Desmond family presented a check for $16,000 to CTF which represented $1,000 for every run he scored in May.

We are especially grateful to Ian and Chelsey Desmond for being so passionate and generous in their continued efforts to help find a cure for NF.

JONATHAN SADOWSKI
Actor and producer Jonathan Sadowski competed for the Children’s Tumor Foundation in the celebrity edition of the cooking show Chopped in April of 2017. He won the episode, and then moved on to compete for the Foundation in the celebrity final! Best known for his role as “Josh Kaminski” on the Freeform sitcom, Young & Hungry, Jonathan has been a valued friend of the Foundation for years. He has been an active participant and spokesperson for CTF’s Los Angeles NF Walk, and can be seen in a PSA promoting the NF Walk program. Jonathan also makes frequent appearances at events around the country, including Kids Fashion for NF and the NY Gala. He volunteers his time to meet with NF patients and families. Thank you, Jonathan, for your vibrant energy and ongoing support!
In 2017, CTF announced the NF Legacy Society. These esteemed individuals have taken the extra initiative to ensure the future of NF research, by including the Children’s Tumor Foundation as a beneficiary in their will or trust, retirement account, or life insurance policy.

To learn more about making a planned gift, please reach out to Melissa Sosa-Longo, VP of Major Gifts, at msosa-longo@ctf.org or 646-738-8549.