FROM PROCESS ANNUAL REPORT 2016 TO PROGRESS

CHILDREN’S TUMOR FOUNDATION ENDING NF THROUGH RESEARCH
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.

What is NF?

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.
ON THE COVER
This picture of Lucy, our outgoing five-year-old, was taken at the 2016 NF Walk in Washington, DC. It was a rainy day, so she wore one of our extra adult T-shirts to keep warm. Lucy was diagnosed with NF1 when she was six months old through a blood test after we noticed many café au lait spots. Lucy doesn't let her diagnosis stop her. Despite many doctor appointments, she knows how to enjoy life!

After her diagnosis we felt completely helpless, so we scoured the internet looking for a way to unite with other NF families and to help fund research, which led us to the Children's Tumor Foundation. Since finding CTF, our family has attended three NF Forums and helped plan two local NF Walks. We are grateful for the connections we have made and are proud to be part of the CTF family!

— Lisa, Lucy's mom
“Patients are at the heart of everything we do.”

— Annette Bakker, PhD, President and Chief Scientific Officer
Dear friends,

At the Children’s Tumor Foundation—from the early days of the NF Preclinical Consortium, to our current Synodos Consortia focused on NF1, NF2, and schwannomatosis—collaboration has been our guiding principle. Clinicians, scientists, patients, family members, caregivers, volunteers, donors, fundraisers, industry members, and advocates work together to fulfill our vision: Ending NF.

This approach—a team science approach focusing on issues chosen by patients—is revolutionizing NF research. We are filling the clinical drug development pipeline and delivering real results for NF patients, as evidenced in a 2016 clinical trial at the National Institutes of Health (NIH) for the MEK inhibitor selumetinib.

The images of NF Hero Philip Moss speak for themselves (see pg. 7). The plexiform tumor in his neck has shrunk an incredible 50% since his participation in the MEK clinical trial. While this is not yet a cure, Philip’s life has improved, both visibly and physically, with his enhanced mobility and better health.

The seeds of this progress were planted in 2008, when the Children’s Tumor Foundation made a major investment in the NF Preclinical Consortium. Just nine years later, we are witnessing the impact of the NFPC’s trailblazing work, which demonstrated that MEK inhibitors have significant impact on tumor size in animal models, and informed a subsequent Clinical Research Award, in which the drug was used in an NF patient for the first time. This early funding paved the way to the selumetinib clinical trial and the incredible results we are seeing. Our collaborative process has led to substantial progress that benefits the patient.

Philip is not alone. Over 70% of the participants in this particular trial have seen tumors reduce in size by at least 20%. The NF research field has not seen anything like this before.

But as amazing as that is, we want 100%. Our goal is 100% tumor reduction in 100% of patients. A bold goal, but your support will help make it a reality.

There is much work to do. In the pages that follow, you will read about the Foundation’s strategic research plan for the next five years. This work enhances our guiding principles of collaboration, open data access, and accelerated timelines for drug development. With the first-ever drug approval for NF on the horizon, it is now more important than ever that all join together to support NF research. Together, we can ensure the opportunity for better lives for all who live with NF.

— Annette Bakker, PhD, President and Chief Scientific Officer
“I don't know what my future holds or what my boys will have to face, but we will not give up. We will continue to do all that we can to increase NF awareness, raise funds for neurofibromatosis research, and help find a cure!”

Leticia Leano, an NF Hero
With CTF’s mission to “drive research, expand knowledge, and advance care for the NF community” firmly in mind, a number of important strategies for the future were defined.

The Children’s Tumor Foundation Is Uniquely Suited To:

1. **Catalyze** and support collaborative, cutting-edge research initiatives.
2. **Develop** transformative therapies in partnership with government entities, research funders, and industry.
3. **Integrate** communities with an interest in NF, including patients, clinicians, researchers, and funders.
4. **Attract** and retain outstanding investigators to focus on NF.

Neurofibromatosis Research Needs Include:

1. **Identification of New Therapeutic Targets.** A better understanding of the cause of loss of function of the NF genes, and the resulting symptoms of NF, will identify additional therapeutic targets.
2. **Development of Innovative Therapeutic Approaches.** There is a need for increased capacity for robust preclinical studies of individual drugs and combinations of therapeutic agents. Innovative approaches will be needed to expand the capacity of both preclinical testing and clinical trials.
3. **Development of Approaches to Early Diagnosis and Prediction of Specific Manifestations.** Best practices for patient care need to be established to enable appropriate and efficient diagnostic testing and initiation of treatment. The discovery and development of biomarkers, studies of patient outcomes, and analysis of tissue specimens are essential for advancing individualized patient care.

Children’s Tumor Foundation Funding Priorities:

- The global NF Conference and NF-related workshops as flagship events for the exchange of ideas and consensus building.
- Promising early-stage investigators.
- Synodos model of team science.
- Preclinical Consortium and pursuit of opportunities for collaboration with pharmaceutical companies to provide a pipeline for clinical trials.
- Enable and enrich clinical trials.
- Engage partners to:
  - Support tissue collection and biobanking initiatives.
  - Develop biomarkers for manifestations of NF.
- Develop innovative approaches to grow the NF Registry and promote patient engagement.
- Implement and fund a two-tier system to support NF centers of excellence and grow the number of NF clinics nationwide that support the CTF mission.

The Children’s Tumor Foundation is strategically integrating our investments to fill critical gaps in NF research in order to ensure a future in which there are approved treatments available for those living with NF.

Strategic Plan

The Children's Tumor Foundation held a strategic planning meeting in September 2016 to refine the Foundation’s research goals for the next five years. Key opinion leaders from the NF research and clinical communities came together, along with representatives from federal research funding agencies, the pharmaceutical industry, venture capital, and other NF organizations.
Fostering COLLABORATION

The Children’s Tumor Foundation’s team science approach is revolutionizing NF research and filling the clinical drug development pipeline.

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. Their goal is to speed the drug discovery process through innovative research methods, collective knowledge, and data shared openly through CTF’s NF Data Hub. 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, expanding interest in NF to other fields, including cancer.

Synodos for NF2

The first of the Synodos models established by CTF, Synodos for NF2 was launched in 2014 in order to provide clarity to patients about available drug options for NF2. This consortium brings together multidisciplinary investigators from a host of centers of excellence who collaborate and share their data in real time. Principal Investigators from eight institutions presented the findings of their work from the first year of this three-year, $3 million collaboration in late 2015. In the spring of 2016, the first dataset from this collaboration was released to the public through CTF’s NF Data Hub, with additional results released throughout the year.

Synodos for Schwannomatosis

In 2016, the Children’s Tumor Foundation responded again to the voice of the patient and prepared for the launch of a new Synodos for Schwannomatosis initiative, which will work toward developing effective treatments for schwannomatosis pain. This project will be multi-tiered, bringing together basic, translational, and clinical researchers, based on the Foundation’s current Synodos consortia models for NF1 and NF2. Schwannomatosis is the rarest and least studied form of neurofibromatosis. Incomplete understanding of the molecular basis of the disease and the absence of well-characterized preclinical tools have been the primary roadblocks to therapeutic advancements. A team of collaborators will work toward specific solutions to these problems.

Synodos for NF1

When establishing Synodos for NF1, which kicked off in the spring of 2016, CTF responded to what concerns NF1 patients most—better treatment options for NF1, as well as answers for low grade glioma patients, who have previously only been told to “watch and wait.” Synodos for NF1 is made up of three separate consortia that bring together 24 investigators from eight leading institutions and two companies. Two teams form the Preclinical Acceleration component, and each will focus on the development of swine models that will closely resemble a human’s response to a potential treatment, providing better development of clinical trials in humans. 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.
The Neurofibromatosis Therapeutic Consortium (NFTC) This successful research collaborative project brought together four labs to find novel targets for clinical trials. The three-year, $4 million collaboration was co-funded with NTAP (Neurofibromatosis Therapeutic Acceleration Program) and was an extension of the Neurofibromatosis Preclinical Consortium (NFPC), a five-year, $7 million program that concluded in 2013.

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 CTF Preclinical Platform is clear: the team 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 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.

Progress: MEK Inhibitor Clinical Trial
By the end of 2016, over 70% of enrolled patients with plexiform neurofibromas (PNs) saw decreased volume in these inoperable tumors. Brigitte Widemann, MD, of the National Cancer Institute, reported that response data in this trial for children and young adults is showing meaningful decreases in tumor volume.

This highly successful clinical study is the result of CTF’s major investment in the NF Preclinical Consortium, wherein Nancy Ratner, PhD and D. Wade Clapp, MD demonstrated that MEK inhibitors (MEKi) have a massive result on PN tumor volume in mice. The drug was first tested in a human subject as part of a Children’s Tumor Foundation Clinical Research Award granted to Michael J. Fisher, MD in 2011.

The MEK trial success was published in the prestigious New England Journal of Medicine. Over 70% of trial participants have seen tumor reduction in size of at least 20%, a first in NF research.

“...The first picture was taken in June of 2015, two months after Philip was discontinued from [the drug ] Gleevec after eight months of tumor growth. We were sent home with no other option. When I asked his oncologist about other chemotherapies, she shook her head, took my hand and said, ‘We are not going to treat your son like a pin cushion.’ We walked out of her office with no hope, facing an uncertain future. The second picture is from September 2016, after a year on selumetinib (AZD6244). MIRACLE! You all are our miracle workers. ”

Renie Moss, mom to Philip, who lives with NF
Progress is being made in NF research that furthers the understanding of neurofibromatosis, leading the way to better diagnostic criteria, earlier diagnosis, and improved clinical care.

**TO PROVIDE THE TISSUE TO STUDY**

**Biobank: Body and Tissue Donation Program**

Originally set up to collect dermal neurofibroma surgical samples, the CTF Biobank was broadened to collect tumors, nerve, bone, and other NF1 tissues post-mortem. The tissue comes from people who previously requested that CTF arrange for them to donate their bodies to research after death. Late in 2015, the Foundation received approval to begin banking tissue from people with either NF2 or schwannomatosis. CTF’s procedure for body donation will ensure that NF1, NF2, and schwannomatosis tissue be made widely available, promising to speed up treatment development.

**TO UNDERSTAND**

**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. The Children’s Tumor Foundation is pleased to have funded four Young Investigator Awards (YIA) for 2016, including one pre-doctoral student and three postdoctoral fellows who are doing basic NF research. These young scientists will be funded through this award for two years. Many of the Foundation’s past YIA awardees have gone on to pursue lifelong careers in the field of NF research, and have furthered the basic understanding of NF biology.

**TO TEST THE CONCEPT**

**Drug Discovery Initiative Award (DDI)**

The DDI award funds early stage research that allows researchers to quickly screen high-risk/high-potential compounds in both cell and animal models. CTF awarded four Drug Discovery Initiative awards in 2016. Three of these awards will target novel therapies for NF1-related tumors, and one will target an NF2-related schwannoma therapy.

**TO BRING 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 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 2016, two CRAs were awarded: one for a phase two trial on bone mass in adults with NF1, and one to survey cognitive outcome tools in NF1.

“...my hope is that the work I am doing now will lay the foundation for new therapies for NF patients and grant us greater insights into NF. I consider it an honor to be dedicating my efforts to better the lives of others, and especially to a group of individuals who have demonstrated that they can overcome any obstacle that life presents to them.”

**Stephanie J. Bouley, 2016 Young Investigator Award Recipient**

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Progress: OPG Multicenter Study

The Children’s Tumor Foundation and the Gilbert Family Neurofibromatosis Institute launched a five-year collaboration, involving 25 NF clinics in a study of optic pathway glioma (OPG) in children with neurofibromatosis type 1. The goal is to provide NF clinicians with clear criteria that will help them decide when a patient should be treated, and when treatment should be avoided because of harsh side effects.

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. A nagging question in the NF research community has been when or whether to treat OPG. Chemotherapy is the only treatment, so it is vital to know when this is necessary or when it can be safely avoided.

“...We are moving closer to treatments for all forms of neurofibromatosis because of the work of the Children's Tumor Foundation. It takes passionate volunteers, strong families, generous donors, and dedicated scientists working together to detect, diagnose, treat, and defeat diseases like NF.”

NF Conference

More than 300 individuals from the NF research and clinical communities were joined by representatives from industry, government, and other allied patient groups at the Children's Tumor Foundation NF Conference in Austin, Texas. This annual gathering is the only place that NF professionals from many different disciplines and backgrounds come together. The core agenda of this four-day event is to present the latest findings in NF basic research, clinical research, and clinical care. Additionally, multiple satellite meetings are organized to take advantage of the broad attendance at the event. Together with attendees from the NF Forum, a special dinner event kicked off the Conference, featuring Texas Governor Greg Abbott as the keynote speaker.

Texas Governor Greg Abbott, to the attendees of the NF Forum and NF Conference Joint Dinner
The Neurofibromatosis Clinic Network (NFCN) 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 2016, the NF Clinic Network grew to 50 clinics that serve approximately 10,000 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 NF Forum is a national patient education and family gathering, hosted in different cities across the United States. The NF Forum originated out of a desire to bring NF patients, families, caregivers, and friends together in an inviting atmosphere of education and fellowship. In 2016, nearly 300 people gathered in Austin, Texas to be inspired, to learn, and to unite as one large NF family.

NF Registry
The NF Registry is a patient-centered database that allows those living with any form of NF to contribute to research and stay up-to-date on studies of potential treatments. Participating is safe, easy, and secure, and everything can be done online at nfregistry.org. The NF Registry has already been shown to speed clinical trial recruitment. By the end of 2016, over 7,000 individuals joined and 18 clinical trials found participants through the NF Registry.

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Sustaining HOPE
“By attending the different breakout sessions, I learned a great deal of information about the research that is being conducted that not only benefits children with NF, but adults as well. I loved meeting the other NF adults that are active with CTF and the different fundraisers. But the best part of the Forum is the hope it gave me for the future, and hope for the end of NF.”

Tera Millecker-Willhelm, adult living with NF
**The Volunteer Leadership Training Conference**
The Volunteer Leadership Training Conference took place in June 2016 in Austin, Texas, just before the NF Forum. 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.

“...It’s amazing how the spirit and drive to end NF forces you out of your comfort zone at every turn... This shows that we will always be better together, and that one day we will end NF.”

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**NF Camp**
This year marked the 20th anniversary of CTF’s NF Camp, a week-long opportunity for teens and young adults ages 12 to 22 to meet others who are living with NF1, NF2, or schwannomatosis. Upon arrival at NF Camp, a new world opens. Often for the first time, campers can talk freely about NF, share their experiences, and make lasting friendships. NF Camp is a chance for young people to get away from it all, have fun, and enjoy life. NF Camp takes place at Camp Kostopulos (Camp K) in Emigration Canyon, Utah on 25 beautiful acres in the canyons outside Salt Lake City. This campground caters to individuals with special needs and provides a wide array of recreational activities accommodating all ages and abilities.

“I love NF Camp because, in this huge world that we live in, I don’t feel so alone or different from the rest.”

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**Karyn Santovito, Vice Chair of the Volunteer Leadership Council**

**Hunter Jackson, Camper**
The Children’s Tumor Foundation proudly launched a new website in 2016 (ctf.org), an up-to-date destination for news, information, events, and the latest in NF research. This new platform makes it easier than ever to get involved in the fight to end NF.

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 new 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.
The Children’s Tumor Foundation celebrated NF Awareness Month in May by expanding upon its “I KNOW A FIGHTER” theme, which draws attention to uplifting stories of those living with NF. Members of the NF community take the lead in this nationwide campaign by promoting NF awareness through local city or state proclamations, community fundraisers, and personal stories they share online. NF Awareness Month got the attention of local and national media with coverage of fundraising events, proclamations, and the Foundation’s “Shine a Light on NF” campaign, through which 146 landmarks spanning across 8 countries lit up in blue and green during the month of May to spread NF awareness.

“I get very enthusiastic about NF Awareness Month. I obtained a proclamation of NF Awareness Day in Rochester last year, and had two buildings light up in tribute—all the while taking care of our own NF specialist visits, chemo treatments, and now autism education. Everyone asks me how do you do it? How do I NOT do it—it’s my son’s life!”

Michelle Lampman, mom to Ryan, an NF Hero
NF Walk
At an NF Walk, communities rally around individuals and families affected by NF. NF Walks are non-competitive, relaxed, celebratory events designed to champion the individuals who live every day with the challenges of neurofibromatosis. 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.

“Brady was officially diagnosed with NF1 when he was three years old. For the second year, our community has pulled together to host a fundraiser for our NF Walk Team, Brady’s Buddies, and we are hoping this event will be bigger and better than ever. Brady’s engaging personality makes it easy to raise awareness for NF, and we will continue to be involved until we help find a cure!”

Erin Ward, Brady’s mother
Regional 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 lemonade stands, to help fund NF research. These events are held throughout the year and work to connect communities with our nationwide team of volunteers.

NF Endurance
The NF Endurance Team is a group of athletes that run, bike, compete, and swim in 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 Tough Mudder competitors, our Endurance Team goes the extra mile to end NF.
Staff and volunteers at CTF advocate relentlessly for continual federal funding of NF research, with frequent and highly strategic visits to Capitol Hill and Member District Offices. We are pleased that $15 million in dedicated NF research funding was again secured in the Fiscal Year 2016 congressional funding cycle. The recipients of these federal grants are conducting research that is of immense value to NF researchers around the world.

With the guidance of outside counsel Squire Patton Boggs, the CTF Government Affairs Team continued to expand the breadth of its advocacy and profile-building efforts in 2016, including active engagement with the Defense Health Research Consortium. This Consortium is now 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.

Cancer Moonshot
At the invitation of former Vice President Joseph Biden, Children’s Tumor Foundation President and Chief Scientific Officer Annette Bakker, PhD, attended the Cancer Moonshot Summit in Washington, DC. This meeting of esteemed scientific leaders was dedicated to shortening the length of time it takes to develop effective treatments for cancer in particular, and disease in general. The first-of-its-kind summit was focused on promoting collaboration among researchers, industry, and patients, and to breaking down the barriers that hamper progress. CTF’s collaborative research model is a successful example of this approach, and Dr. Bakker has been sharing CTF’s experience at subsequent Cancer Moonshot gatherings as well as other meetings, highlighting CTF’s business model as applicable to other rare disease areas as well as cancer.

The Children’s Tumor Foundation’s innovative business model is a prototype for other rare disease areas, as well as for cancer.
Corinne Moffett, daughter of admired CTF patrons Jim Bob and Laurée Moffett, was honored as the 2016 Children’s Tumor Foundation Ambassador, an award bestowed upon an individual 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.

Corinne demonstrates great courage in dealing with obstacles that arise when living with NF, and speaks about her disorder with an admirable openness, including speeches to sororities in the Austin area in hopes of having a chapter adopt CTF as one of their charities. Along with her mother Laurée, Corinne hosted the Foundation’s Volunteer Leadership Council at their Texas home during the Volunteer Leadership Training Conference in June. This kindness and generosity of spirit exemplifies Corinne in everything she does, and reflects her tenure as the Foundation’s Ambassador.

Corinne will enter her freshman year at the University of Texas at Austin in the fall of 2017, where she will major in textiles and apparel. She loves photography and created “Eyes of Austin,” a portrait series capturing a number of individuals in her hometown.

“I have learned to find my voice and speak openly about having NF, and to bring as much awareness as I can to the battle of ending NF.”

Corinne Moffett, NF Ambassador
Financial SUMMARY

“Only 2% of the charities we rate have received at least 7 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 and CEO

2016 was the seventh year in a row that the Children’s Tumor Foundation was honored with a 4-star rating from Charity Navigator, America’s largest independent evaluator of philanthropies. The Foundation is also accredited by the Better Business Bureau’s Wise Giving Alliance.
### Operating support and revenue

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<td>Contributions - corporations and foundations</td>
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<td>Bequests</td>
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### Operating expenses

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### 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><strong>$566,887</strong></td>
<td><strong>$89,933</strong></td>
<td><strong>$1,526,203</strong></td>
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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.
Dan & Jennifer Gilbert

On Saturday, November 19, 2016, Dan and Jennifer Gilbert hosted the beNeFit IV, “An Aquatic Affair to End NF” in downtown Detroit, where more than 1,700 guests helped raise $5.1 million for NF research. Dan and Jennifer are parents to NF Hero Nick Gilbert, and they created “The beNeFit” in 2013 as an inspirational annual extravaganza to raise funds and increase awareness of NF. The Gilberts’ hard work, dedication, and vision have translated into nearly $17 million raised in four years for the Children’s Tumor Foundation. Thank you, Dan and Jennifer for your unending support!
Dancing With Our Stars was a big hit in September in Little Rock, Arkansas. Local stars spent months rehearsing to perform at the event and competed to win the coveted mirror ball trophy. The 2016 winner was philanthropist and volunteer Susan Hickingbotham and the best performance trophy went to Win Rockefeller. The whole night was a win for the fight against NF, with $227,000 raised for NF research. Thank you to former CTF Board Member Lesley Oslica and the volunteer event committee for their drive, energy, passion and hard work in putting this event together.
Cupid’s Undie Run

February 2016 marked the seventh consecutive Cupid’s Undie Run to benefit the Children’s Tumor Foundation. Cupid’s has grown in leaps and bounds since 2010, when participants raised $10,000, to 2016, when they raised more than $3.8 million. Everyone’s favorite Valentine’s Day-themed party has shown what an amazing group of generous do-gooders can do for a cause they believe in. Cupid’s Undie Run is a fun and unique way to raise money specifically for NF research. The Children’s Tumor Foundation is thankful for Cupid’s adventurous spirit in the pursuit to find a cure for NF.
Cocktails for a Cure
was held in October at the Brookville Country Club in Long Island, New York. It was a beautiful evening hosted by Lisa Arena, CTF Board Member Laura Perfetti, Jill Hannity, and Cristina Spoto. More than $80,000 was raised to support the mission of the Foundation. A highlight was a live auction for two pumpkins decorated by NF Heroes, Julia Perfetti and Charlotte Spoto.
DONOR SPOTLIGHT

Richard A. Horvitz and Erica Hartman-Horvitz

Thanks to a generous $1 million donation from CTF Board Chair Richard A. Horvitz and his wife Erica Hartman-Horvitz, the Children’s Tumor Foundation will launch its newest consortium, Synodos for Schwannomatosis. The Horvitz family’s long-standing involvement with the Children’s Tumor Foundation demonstrates their passion and unwavering commitment to finding treatments for all forms of neurofibromatosis.

Never eager for public acclaim, Mr. Horvitz is a dedicated NF advocate, and has championed the work of the Children’s Tumor Foundation’s advocacy efforts, work that benefits the entire NF research field. His efforts were instrumental in helping secure increased federal funding for NF research. In 2012, Mr. Horvitz was honored with the Humanitarian Award for his meaningful work with the Children’s Tumor Foundation.

Mr. Horvitz was a longtime caregiver to his late wife, Marcy, who had schwannomatosis. He is married to Erica Hartman-Horvitz, who is also active with the Foundation and has given her time and treasure to advance our mission. Thank you Rick and Erica for your longstanding commitment, dedication, and investment in the Children’s Tumor Foundation.
WITH THANKS

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Bracer Pasch
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Sosnick Schwartz
Daniel & Roxanne Schwartz
Marc Schwartz & Emily
Camieni
Sandra & Alan Schwartz
Darla Scott

The New York City Poker Tournament
committee went “all in” planning the big event
this year. More than 135 guests raised more than
$115,000. Texas Hold’em–style poker was played, as
a new champion came forth. Congratulations Brian
Neugeboren for winning a seat at the World Series
of Poker. Thanks to Event Chair and CTF Board Member
Dan Altman and the event committee for putting all
their cards on the table to end NF!
Since it was founded in Cleveland in 2001, Flashes of Hope has photographed close to 60,000 kids fighting cancer to help them look and feel attractive and invigorated again using a still image as a confidence booster, while they cope with the depths of the disease.

“Big Shots and Little Stars” is the charity’s most impactful annual fundraiser, raising funds for research to accelerate a cure for children’s cancer. The night culminates with a strut on a fashion runway spanning the floor of the Quicken Loans Arena where the Cleveland Cavaliers court usually is, with players and other Cleveland-area civic and business leaders chaperoning the child they’re partnered up with for their moment in the spotlight.

Thanks to the Big Shots and Little Stars event, Flashes of Hope made a donation of $650,000 to the Children’s Tumor Foundation, which will go toward critical research into malignant peripheral nerve sheath tumors.

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.
WITH THANKS

Carey Tum
Turner Construction
Company Foundation
Adam & Sarah Turner
Alyssa & Marc Tushman
Herbert & Grace Tyler
John & Helen Tyrybon
Liang D. Tzeng
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Robert C. Zinnershine
Brad & Lisa Zorfas

“We are newer to the NF family than others. And when I say family, it has truly become a family. I have learned more from the people in our community than anywhere else.”

Rebecca Brooks, mom to Sloan, who lives with NF
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