

CHILDREN'S TUMOR FOUNDATION

# ANNUAL REPORT 2020

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH





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## What is NF?

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





## Founded in 1978,

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

## Our mission

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

## Our vision

End NF.





CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

CTF President  
Annette Bakker



# Dear friends,

The year 2020 was notable, marked by the uncertainty of a global pandemic, but also by historic success in the field of NF research. Millions of lives were upended by COVID-19, while at the same time unprecedented scientific collaboration was formed to bring the world a vaccine. It is precisely this type of collaboration —focused, united, and defying boundaries — that the Children’s Tumor Foundation exemplifies in its mission to end NF.

In April of 2020 we reaped the rewards of more than 40 years of Children’s Tumor Foundation-funded research: the U.S. Food and Drug Administration (FDA) granted approval for the first-ever drug for NF, Koselugo (selumetinib). In clinical trials, more than 70% of patients with inoperable plexiform neurofibromas taking selumetinib saw tumor reduction anywhere from 20-60% in size. And now this life-saving drug is available to patients across the country. We are deeply grateful to all the patients, donors, volunteers, researchers, clinicians, and partners who made this long hope a reality.

Other important clinical trials began in 2020. The first NF2 patients were enrolled in a world-premier innovative platform trial; patients were recruited into the first-ever clinical trial for schwannomatosis pain; and a new trial studying the effects of a gel to treat cutaneous NF is showing promising results in tumor reduction. All of this was made possible because of YOU. Donors to the Children’s Tumor Foundation fund the best and most promising research. And that research is delivering results, tangibly improving the lives of the 2.5 million people around the world living with NF.

Though the pandemic lockdowns kept everyone at home and unable to celebrate these transformative achievements in person, the Children’s Tumor Foundation brought the NF community together in unique and creative ways, while NF patients and families once again exhibited resilience and dedication in the face of adversity. With the rallying theme that “Home is Where the Heart Is,” on World NF Day thousands around the world gathered virtually to watch the first-ever Zoomathon, raising hundreds of thousands of dollars for NF research and boosting the spirits of all who were sheltering at home. Though the event was virtual, the connection we felt was real, and the Zoomathon’s success gave us confidence to pursue other events in virtual formats: the NF Conference, the NF Forum, the Hackathon, and numerous special events, including the Halloween Bash and the Celebration Concert to End NF. CTF’s NF Camp, Shine A Light NF Walks, NF Endurance events adapted to virtual environments too, and I applaud the amazing Foundation staff for their ingenuity as we continually “pivoted” throughout 2020 to adapt to changing circumstances.

I am optimistic that the best is still to come. We are moving with lightning speed into a future filled with possibility, and CTF will continue its focus on securing the cooperation of drug companies to seek out potential treatments for patients with all types of NF, including NF1, NF2, and schwannomatosis. Because NF knows no borders, we will continue to strengthen our global activities throughout Europe, Latin America, Asia, and beyond.

Thank you to our NF researchers, government and industry partners, our dedicated Board, our fundraisers, donors, volunteers, and of course, our patients and their families and caregivers. If the year 2020 showed us anything, it is that we are in this together, and only together will we prevail.

Warmly and gratefully,



Annette Bakker, PhD, President



# 2020: The coronavirus pandemic

It goes without saying that 2020 was a year unlike any other, as the COVID-19 pandemic upended lives all over the world, shut down businesses and communities, and spread fear and uncertainty. Out of an abundance of caution, and in order to protect the CTF family of patients, volunteers, and staff, the Children's Tumor Foundation quickly pivoted to a virtual model in March 2020 and re-imagined how the fight to End NF could continue. With the characteristic support and resilience of the NF community, our mission continued unabated, bringing NF awareness and engagement with the Foundation's programs to growing audiences through new digital formats that made CTF initiatives even more accessible to all.

Early in the pandemic, the Foundation's community of researchers and clinicians made themselves available to the patient community through a series of CTF webinars that informed, guided, and assured NF patients and families with answers to questions that had arisen amidst the uncertainty. They spent the year studying the potential impacts of COVID-19 and supporting the use of telemedicine to assist patients who found themselves suddenly unable to visit their doctors in person.

As May approached, which is NF Awareness Month and a key time for the NF community to spread knowledge of neurofibromatosis, the Foundation pivoted to a "Home is Where the Heart Is" theme, in recognition of the new shelter-at-home reality, and offered the NF community ways to drive the End NF mission from the safety of their homes. This concept culminated in a World NF Day livestream called the Zoomathon, with over 50 celebrities announcing to the world that NF patients deserve to be seen for who they are, which is more than just their NF.

The success of this approach fueled more creative ideas, and the NF community rose to the occasion. Challenges like "how does one hold a virtual walk and still fundraise" to "how does one host a research symposium" were solved with originality and perseverance. Even as patients, volunteers, researchers, doctors, and CTF staff faced challenges related to working from home, and adjustments from juggling daycare, school, and family obligations, the NF community's energy shone through and

discovered new ways to communicate virtually. The year brought challenges, but also triumphs.

One of those triumphs was the approval of the first-ever drug for a form of neurofibromatosis by the U.S. Food and Drug Administration. That news in April fueled the belief year-round that our End NF mission was too important to put on pause, as the Foundation's pipeline of research leading to new clinical trials continues to grow for all forms of NF. That spirit of innovation carried through all facets of the Foundation's offerings, as in-person events became virtual – from research meetings to dance events to walk/runs to galas – keeping the NF community together, even as we had to stay apart.

Because of your participation in new and innovative ways, and your continued support, the Children's Tumor Foundation made it through 2020 as strong and unified as ever. Always together in heart, we continue the fight to end NF.





National Celebration Concert to End NF

CHILDREN'S TUMOR FOUNDATION #ENDNF

LEF / Leslie and Richard Kates / Vanessa Blomberg / Bob Opm emolo / Lee & Kathy B

— Virtual —  
*National Celebration*  
**CONCERT**  
 — to —  
**END NF**

WILL BEGIN IN 00:27

*Performers:*

EMHYLOU HARRIS GRAMMY AWARD-WINNING ARTIST	GAVIN DEGRAW MULTI-PLATINUM SINGER-SONGWRITER	DENISE BENTON TOWN-AWINGATED BROADWAY ACTRESS
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# Leading the Way

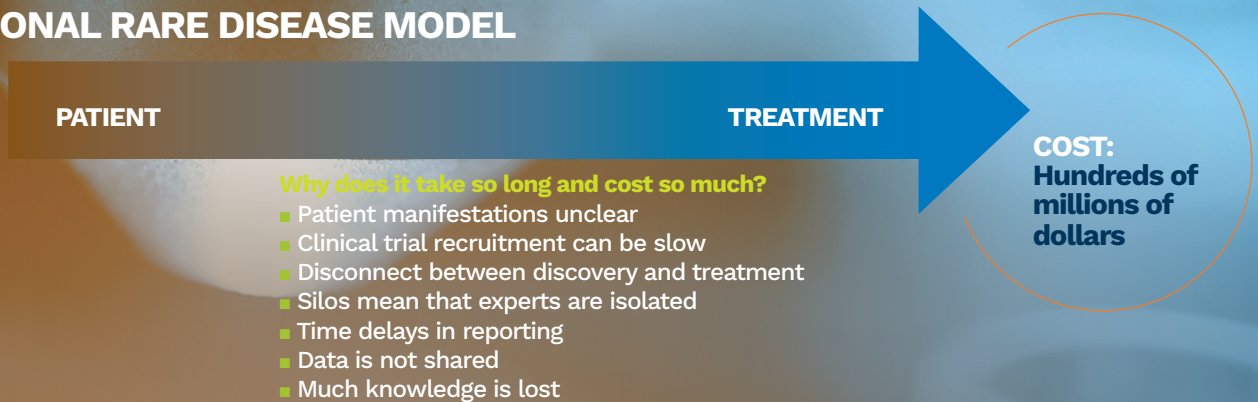
At the Children’s Tumor Foundation, we’re working to better the lives of over 2.5 million people who live with NF. And we’re doing so by focusing on the tagline in our name, Ending NF Through Research. We envision a day when NF patients can live their lives free of the pain and difficulties that come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

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

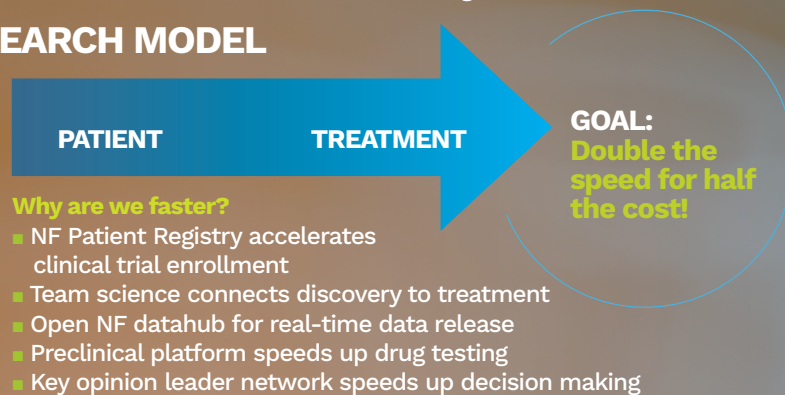
And the best part? CTF’s research model not only benefits NF patients, but also the millions of patients living with cancer, or one of the 7,000 rare diseases in existence.

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

## TRADITIONAL RARE DISEASE MODEL



## CTF RESEARCH MODEL





# SELUMETINIB: The Path to Approval

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

## NF Preclinical Initiative

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

Traditionally, it takes more than 15 years and costs hundreds of millions of dollars to translate a new discovery into one clinical treatment. The impact of the NF Preclinical Initiative is clear: these teams completed 116 preclinical trials in 8 years, at a total cost of \$11 million. The preclinical studies led to 16 clinical trials that are currently under way—one of those clinical trials included the MEK inhibitor selumetinib registration trial.

## The Path to Approval

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

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

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

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

— Brigitte Widemann, MD, National Cancer Institute, NIH



2019 Progress Leads to a 2020

# Selu-bration

Koselugo announced as first FDA-approved treatment for NF.

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

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

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

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

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

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

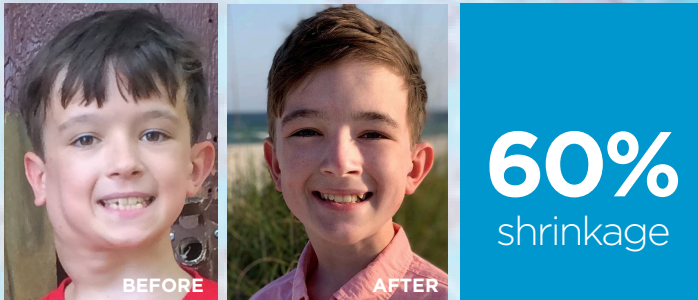
guaranteeing efficient use of donor/investor funding, and support from the federal government.

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

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



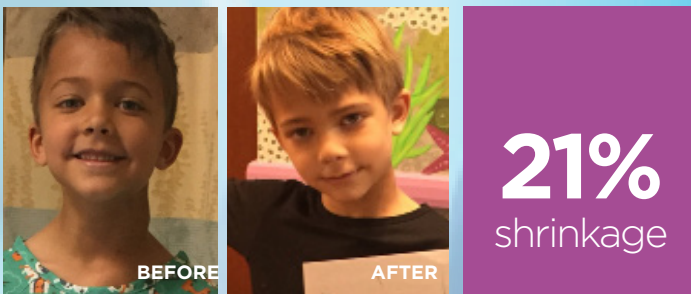
## Koselugo: Stories of the Road to Approval



“People don’t ask me what is wrong with my neck anymore. The drug does make me fatigued, which is tough since most kids my age are active in sports or physical activities that are challenging for me. But I’ve found activities that I enjoy, and friends that enjoy being a part of my life. I enjoy reading, gaming, boy scouts, coding, and more. I’m getting ready to start high school and I’m thankful for all the donors that funded the doctors and researchers who made selumetinib possible. Now that it is FDA approved, I am thankful that others may experience what I have experienced.”

— NF Hero Philip Moss

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



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

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



# Attracting Pharma

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

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

### CTF'S SYNODOS TEAM SCIENCE INITIATIVES

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

## **Where do we find experts?**

### CTF'S KEY OPINION LEADER NETWORK

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

## **Are there enough care and treatment centers?**

### THE CTF NF CLINIC NETWORK IS CONNECTING DOCTORS AND IMPROVING CARE

A growing network of CTF-affiliated clinics is cultivating relationships between patients and doctors, and working to standardize and improve NF patient care.

## **Are there patients engaged in the drug discovery process?**

### CTF PATIENT ENGAGEMENT PROGRAM

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



**Where can we find the patients to participate in clinical trials?**

**THE NF REGISTRY CONNECTS PATIENTS TO CLINICAL TRIALS**

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

**Where can we find new drug targets?**

**THE NF DATA PORTAL STORES OPEN DATA**

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

**Is there enough tissue available for testing?**

**THE NF BIOBANK PROVIDES TISSUE FOR RESEARCH**

In order to solve the problem of a scarcity of relevant tissue to test, CTF created a centralized library of openly available samples for biomarker discovery and development, to support all aspects of drug research.

**How can we standardize the endpoints of clinical trials?**

**THE REINS CONSORTIUM**  
(Response Evaluation in Neurofibromatosis and Schwannomatosis)

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

**Have these drugs been tested in animal models?**

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

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



# Driving Collaboration

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

## Synodos

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

## Synodos for NF1

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





## Synodos for NF2

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

## Synodos for Schwannomatosis

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

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

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





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

# Fueling Innovation

## CTF Discovery Fund

The Children's Tumor Foundation Discovery Fund for NF Research is an \$8 million investment over 3-5 years that will fund a minimum of 45 new research studies, and accelerate drug discovery for neurofibromatosis. This initiative is set up to attract and invest in the best and brightest minds, who will advance our goal of bringing new treatments to patients faster and more efficiently.

## The Young Investigator Award (YIA)

The YIA is the Foundation's oldest research award program and serves to advance understanding of the biology of NF1, NF2, and schwannomatosis, as well as bringing young researchers into the NF field. This award program is one reason the understanding of NF has grown so rapidly. Many of the Foundation's past YIA awardees have gone on to pursue lifelong careers in the field of NF research.

## Drug Discovery Initiative Registered Reports (DDI-RR)

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





### Contract Awards

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

### Clinical Research Award (CRA)

The Foundation's Clinical Research Award program supports early-stage NF research involving human subjects. These awards encourage studies of candidate therapeutics or other interventions for the treatment of NF1, NF2, or schwannomatosis; clinical-trial-enabling or ancillary studies; natural history studies; and investigations into clinical care in NF.



On behalf of my co-investigators, we would again like to thank you and all those who donated to CTF, for believing in our projects and funding our CRAs. We are proud that our CTF awards have now produced over \$5 million in federal research grants.



— Drs. Rob Avery, Michael Fisher, and Gena Heidary



# NF2 Accelerator Initiative

The Children's Tumor Foundation NF2 Accelerator Initiative is dedicated to finding effective treatments for NF2, substantial investment of \$2.3 million over three years. The NF2 Accelerator Initiative will bring new NF2 treatments to the clinic (and patients) by expanding the clinical drug pipeline for NF2, improving drug selection through the development of innovative testing models, and the development of gene therapy options that address the underlying genetic causes of NF2.

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

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

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

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





# Ongoing CTF Research

## The BRIDGE Initiative

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

## OPG Multicenter Study

The Children's Tumor Foundation and the Gilbert Family Neurofibromatosis Institute have collaborated on a five-year study of optic pathway glioma (OPG) in children with NF1. The study involves 25 NF clinics, and aims to provide clinicians with clear criteria that will help them decide when a patient should be treated, and when treatment (such as chemotherapy) should be avoided. OPG develops in 15 to 20% of children with NF1, and can cause significant health issues.

## Genotype-Phenotype

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

## NF1 Gene Therapy Initiative

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

## NF Diagnostic Criteria Workshops

The diagnostic criteria for NF1 and NF2 were established at the National Institutes of Health (NIH) consensus meeting in 1987, and the diagnostic criteria for schwannomatosis in 2005. Since that time, there has been a tremendous increase in knowledge about these genetic disorders. In 2017, a group of NF investigators reached out to CTF to sponsor a revision of the diagnostic criteria, sparking a multi-year process that has involved more than 90 leading NF experts from around the globe.

## Biobank: Body and Tissue Donation Program

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

## Volumetric Analysis

The Children's Tumor Foundation supported an important study for the completion of prospective clinical trial comparative validation between the National Cancer Institute (NCI) and Massachusetts General Hospital (MGH), to provide an unambiguous tool to monitor tumor progression.



# 2020 NF Conference

So many of CTF's events took a detour during 2020 due to the forces of COVID-19, and the annual NF Conference was no exception. Initially planned for three-and-a-half days in mid-June in Philadelphia, the NF Conference was transformed into a virtual event. The original agenda was shortened, but the attendees were still presented with the best and latest NF research and clinical care practices within a compressed two-day format.

The year 2020 was notable for being the 30th anniversary of the discovery of the *NF1* gene, as well as the first-ever FDA approval of a treatment for NF1, Koselugo (selumetinib). These benchmark events were recognized and celebrated during the course of the meeting.

The 2020 Virtual NF Conference was moderated via Zoom by co-chairs, Conxi Lazaro, PhD, of Institut Catala d'Oncologia in Barcelona, Spain, Matthias Karajannis, MD, MS, of Memorial Sloan Kettering Cancer Institute, and Nicole Ullrich, MD, PhD, of Boston Children's Hospital.

“2020 is a landmark year for NF1 because of the approval by the FDA of the first drug for NF1.”

— Francis S. Collins, MD, PhD, Director, National Institutes of Health

An inspirational opening address was delivered by NIH Director Francis S. Collins, MD, PhD, one of the two lead researchers whose work led to the discovery of the *NF1* gene. Dr. Collins reflected on the path to this landmark which simultaneously took place in his lab at the University of Michigan, and at the University of Utah, led by the late Dr. Raymond White. A session focusing on the gene discovery followed later that day, and was presented by Dave Viskochil, MD, PhD and Peggy Wallace, PhD, who at that time were CTF Young Investigator Awardees, and whose work in those labs contributed to the landmark discovery.

Dr. Collins also briefly touched on the remarkable story of selumetinib's road to the clinic, as well as recognizing the groundbreaking research currently being conducted, while looking to the future for many more discoveries, treatments, and maybe someday a cure.

## NF Hackathon

The Children's Tumor Foundation hosted its second annual Hack for NF, reformatted into a six-week virtual hackathon for NF research, in the fall of 2020. This event presents an innovative way for CTF to find solutions using the data analytics and research methodologies being used by researchers every day.

The 2020 virtual event garnered over 400 experts in different disciplines, including healthcare startups, developers,

solutions architects, and hackathon enthusiasts, working for six weeks to drive scientific and medical innovation and improve the lives of patients living with neurofibromatosis and other rare diseases. A final group of 150 participants submitted solutions ranging from new ways to analyze data and identify new drug targets, engaging patients via mobile devices, to data visualization apps and analytical tools for the NF Data Portal. Each winning project received a cash prize to continue developing their projects.





# CTF Europe

The Children's Tumor Foundation has formed a European-based medical research NGO, called Children's Tumor Foundation Europe, which serves as a partner organization to CTF in the United States.

Throughout its history, CTF has funded the best and most promising research globally, regardless of location, and as a result many European laboratories and clinicians have benefited from CTF support. Children's Tumor Foundation Europe is further strengthening the bonds between experts and research opportunities worldwide, in line with CTF's emphasis on open collaboration and open data.

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

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

In December of 2019, the Children's Tumor Foundation and 35 other organizations joined together in a project called EU Patient-centric clinical Trial pLatforms (EU-PEARL), a unique public-private strategic partnership funded by the

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

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

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

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



# Sustaining Hope

## NF Forum

The Children's Tumor Foundation's NF Forum took place virtually in 2020, in a series of five online webinars about specific types of NF and manifestations. This national patient education symposium allows those living with NF and their families to connect, support, and learn from each other. Families and patients learn together while attending seminars on relevant topics pertaining to neurofibromatosis and have the opportunity to meet NF researchers and medical professionals in attendance at the NF Conference.

## Patient Engagement

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

## Neurofibromatosis Clinic Network (NFCN)

The Neurofibromatosis Clinic Network was established by the Children's Tumor Foundation to standardize and raise the level of neurofibromatosis clinical care nationally, and to integrate research into clinical care practices. By the end of 2020, the NF Clinic Network had grown to 65 clinics that serve approximately 15,000 patients. Clinics may apply to join the NFCN and are evaluated based on many factors, including expertise in NF care, access to specialists, number of patients seen, and commitment to educating healthcare providers and patients about the diagnosis of and treatments for NF.



## NF Camp

More than 100 teens and young adults attended the 24th Annual NF Camp in July, which was held virtually in 2020 due to COVID-19. NF Camp usually takes place at the beautiful Camp Kostopulos in Emigration Canyon, Utah with ropes courses, horseback riding, and more. This year, virtual games, kitchen takeovers, arts and crafts, and laughter filled the week along with appearances by special guests such as Colorado Rockies baseball player Ian Desmond. Campers were able to come together to talk freely about their NF journeys, share their experiences, and make lasting friendships.

## Volunteer Leadership Council

Members of the Volunteer Leadership Council (VLC), our most active and dedicated volunteers, gathered for their annual Leadership Training Conference in a virtual format for the first time in 2020. This gathering provided an opportunity for volunteers and staff to interact and network together. They gained new insights about the latest scientific research, CTF program enhancements, and marketing initiatives, and spent time sharing and learning. Volunteer Recognition Awards (VRAs) were presented to volunteers to celebrate the contributions of Volunteer Leaders in several categories from our newest up-and-comers to our most tried and true champions.

## NF Registry

More than 10,000 have joined the Foundation's NF Registry, making it the largest patient-centered database of people with NF, and the only one designed to be available to all interested investigators. The Registry has proven to be a valid and useful tool for both patients and researchers, according to an analysis published in the journal *PLOS ONE*. Not only are thousands of patients from all over the world contributing their data online at [nfregistry.org](http://nfregistry.org), but the data is being actively used—and appreciated—by researchers working on all forms of NF. The Registry recently moved to the OpenApp platform, which will allow easier use, availability in multiple languages, and additional enhancements to further increase participation.

“

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

— David Viskochil, MD, PhD, University of Utah

”





# Raising Awareness

The Foundation's marketing, communications, and advocacy efforts ensure that no matter where one is on their NF journey – whether they are newly diagnosed, or in the midst of a treatment regimen, trying to explain NF to their kid's school, or engaging with the broader community so as to improve broader awareness and understanding – that patients and their families are supported with the latest and most accurate information about NF. The Children's Tumor Foundation also provides outreach and engagement opportunities that expand NF knowledge to those around them.

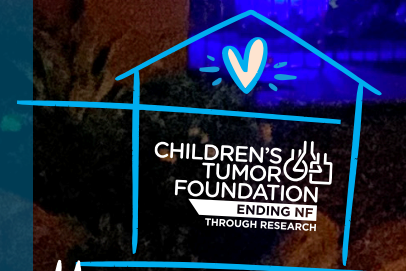
All too often the NF journey starts with an online search that leads to inaccurate or outdated information, and so the Children's Tumor Foundation prides itself on being a safe haven for all who need information and support. We provide the most up-to-date NF knowledge on our website and in our patient brochures, newsletters, webinars, and videos. We also drive a dynamic and engaging presence on social media,

connecting patients and families worldwide, ensuring that those who don't have NF support in their own community can find it through the global CTF family.

In a world that runs 24/7, the Foundation breaks through with impressive media outreach and public relations efforts that spread the message that NF is important and that NF patients deserve support for bettered lives. Our multichannel approach in print, digital, TV, and radio results in many hundreds of media pickups each year, and brings the NF story to hundreds of millions of people worldwide.

While NF is a serious condition that patients deal with each and every day, the Foundation creates inspirational and engaging tools that they can use to share their NF story in their own personal way – from 'I Know a Fighter' to 'Shine a Light on NF' to 'Make NF Visible' – we make sure that everyone knows our driving passion: to END NF.

The Foundation's annual NF Awareness Month campaign drew attention across the globe to neurofibromatosis and those living with this disorder. The 2020 theme was Home is Where the Heart Is, and we also introduced Make NF Visible through a beautiful photo and video series of incredible NF Heroes.



*Home is where the Heart is*

**BORN  
A FIGHTER.**



When people ask me about who I am, and I start telling my life story, that motivates them. So, I fight NF by just living my life, and doing the best I can in every area, and spreading the word.



— Marcus, who lives with NF1



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

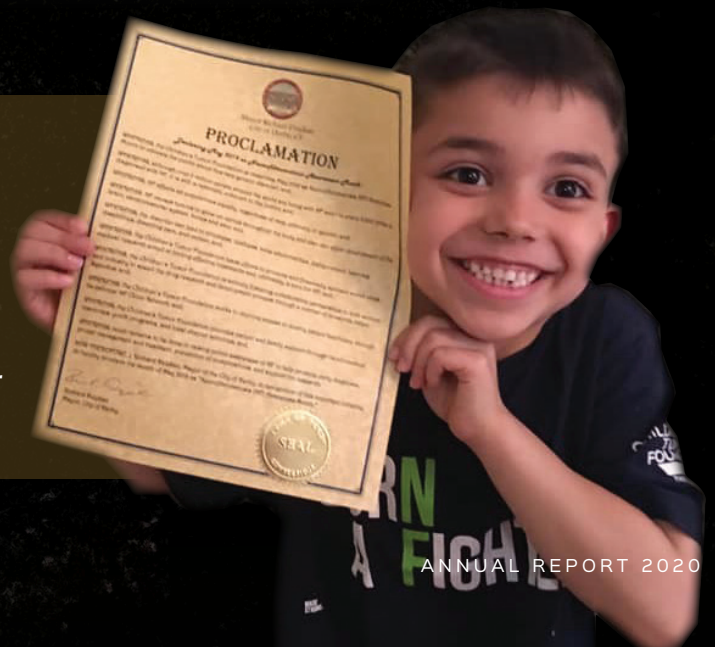


The first-ever CTF livestream event took place on May 17, 2020 and brought the NF community into the spotlight in celebration of our NF Awareness Month theme, "Home Is Where the Heart Is." More than 10,000 viewers raised over \$300,000 to end NF! Hosted by TV's Jonathan Sadowski, top celebrities and NF Heroes came together to Make NF Visible.



Actor and producer Jonathan Sadowski hosted numerous events throughout 2020, and was honored as the year's CTF Champion at the year-end Celebration Concert to End NF.

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

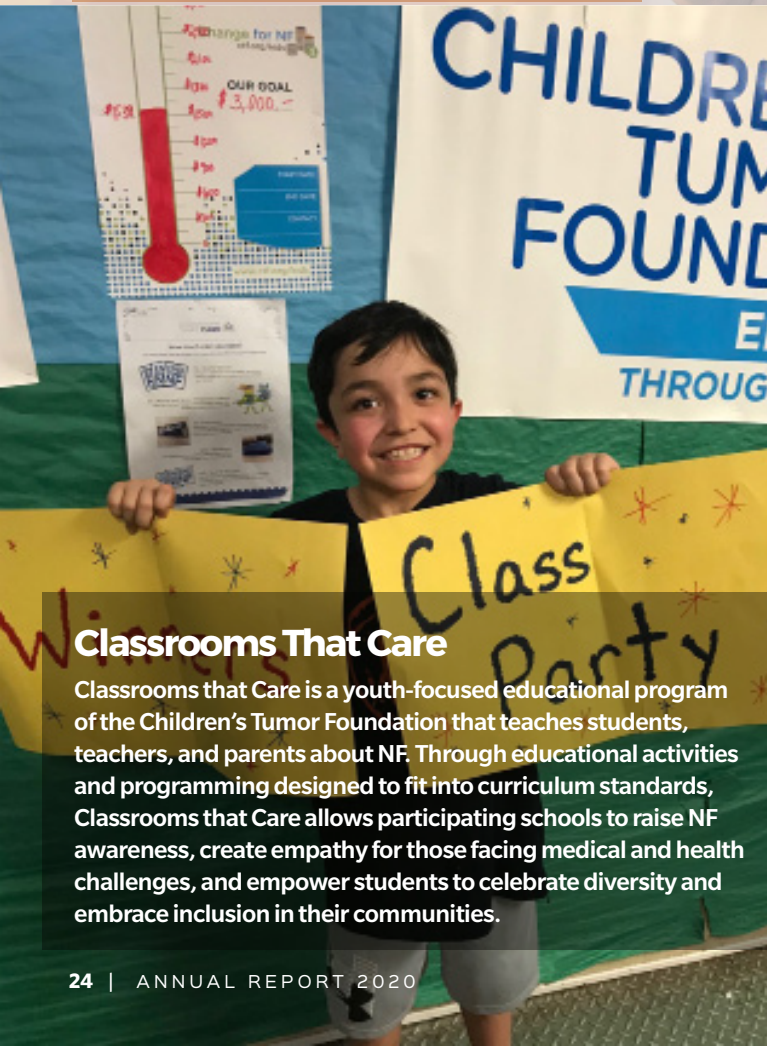




# Raising Funds

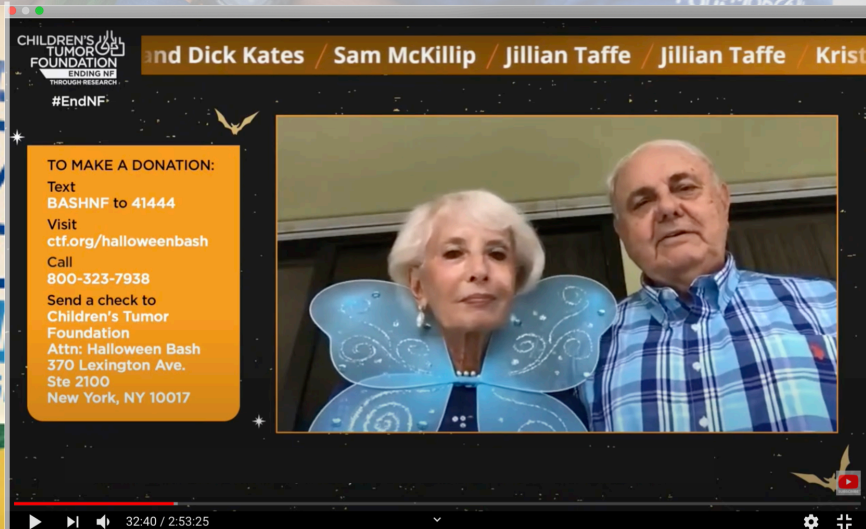
## Shine A Light NF Walk

Shine a Light NF Walk is the signature fundraising event of the Children's Tumor Foundation, bringing neurofibromatosis out of the shadows and inspiring the community to come together to raise critical funds for NF research. At these fun and inspirational events held across the country, communities rally around local families affected by NF. Frequent appearances of costumed characters, balloon animals, and face painting bring bubbling energy from start to finish. Throughout 2020, Shine a Light Walks took place in a virtual format, but will quickly return to live events as per state and CDC guidelines.



## Classrooms That Care

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



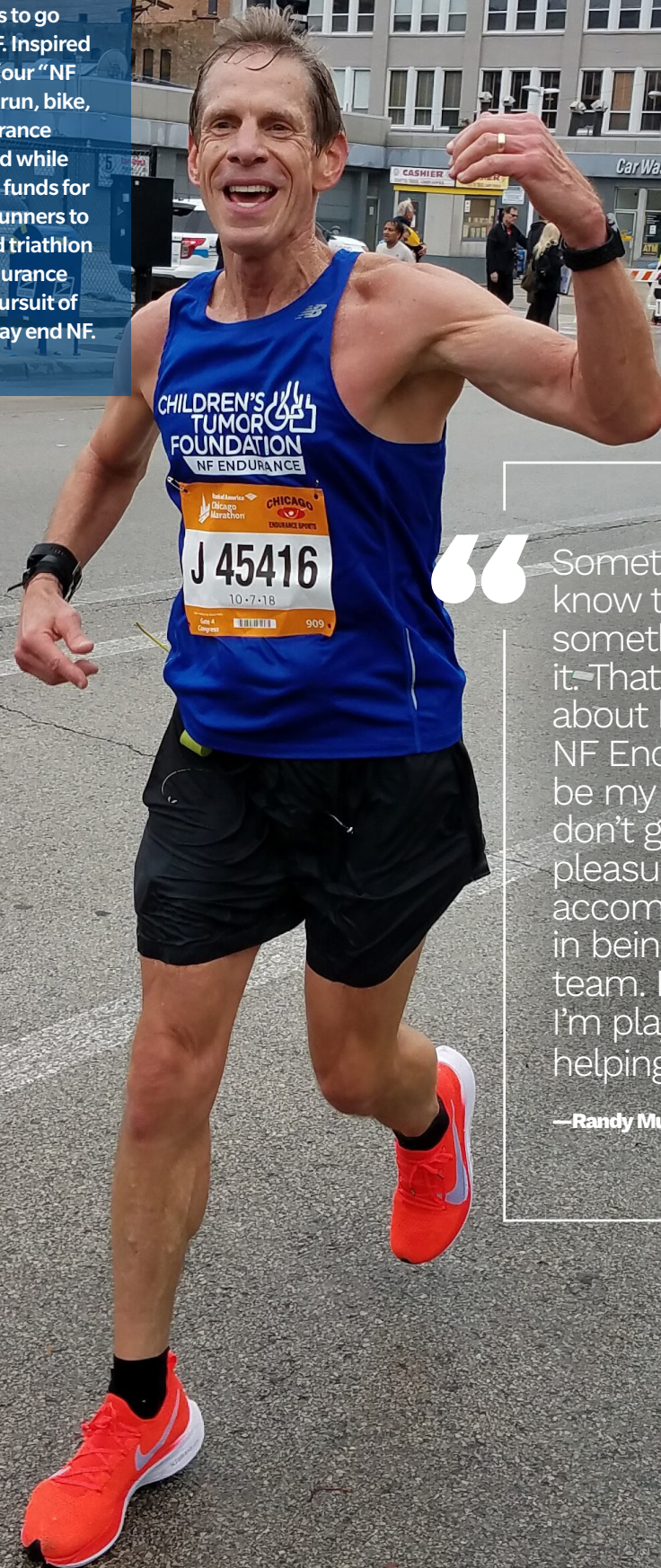
## Special Events

The CTF Special Events team works with volunteer committees across the country to organize festive fundraising galas, golfing tournaments, cocktail parties, and Dancing With Our Stars events. Meanwhile, "Fight NF Your Way" volunteers organize one-of-a-kind fundraising events, including comedy nights, fashion shows, and sweet tea stands that help fund NF research. Throughout 2020 the CTF special events team rose to the occasion with numerous successful online events that streamed via YouTube and Zoom. Additionally, a new program was created, Connect2Fight, which engaged livestream creators throughout the year in the fight to end NF.



## NF Endurance

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



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

—Randy Mullis, NF Endurance athlete



# Advocacy

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

Our voices are being heard! In 2020, because of continued strong advocacy work from the Children's Tumor Foundation and the NF community, bipartisan leadership in Washington, D.C. included \$20 million for NF research through the Department of Defense Congressionally Directed Medical Research Program (CDMRP) for Fiscal Year 2021, a \$5 million increase in funding from previous years. This funding supports strategic research resulting in new discoveries and better outcomes for NF patients and families, and will allow us to further develop scientific data, break through barriers, and forge a pathway to end NF.

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



# NF Ambassador: Brianna Worden

Brianna Worden was diagnosed with NF1 when she was two months old. She has a plexiform neurofibroma that encompasses her entire left side (excluding her leg). Brianna also has renal artery stenosis and hypertension, bone disfigurements, chronic pain and fatigue, learning disabilities, scoliosis, and has endured over 10 surgeries, including three spinal fusions, a wrist stabilization, and three tumor debulkings to her left arm where, each time, three pounds of tumor was removed. She was diagnosed the first time with a malignant neurosarcoma when she was a freshman in high school. The cancer returned two more times after that. When she had one of the cancerous tumors removed from her throat, her vocal cord was paralyzed for six months.

Now 24 years old, Brianna's role as an ambassador for neurofibromatosis awareness began many years ago, at the age of eight, when she first began advocating for neurofibromatosis with the Children's Tumor Foundation. She traveled with her mother to Washington DC, New York City, and Las Vegas to symposiums and forums to help others with neurofibromatosis and share her story.

In 2013, Brianna competed for and won the title of Miss Teen New York International with NF awareness and body positivity as her platform. She has always felt that those with NF are often put in a category of outcasts and she wanted to break that stereotype.

Before transferring to and graduating from Boston University, Brianna held NF Walks at her local community college. Brianna is an avid fundraiser, most recently at the Shine a Light NF Walk in Westchester, NY. Additionally, as a Patient Advocate, Brianna is using her voice and her story to contribute to all phases of the research process; already, Brianna has addressed the U.S. Food and Drug Administration (FDA) twice.

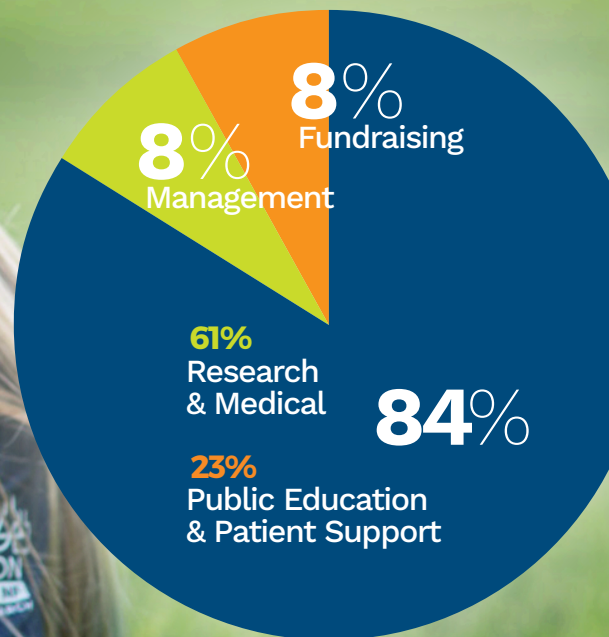
At the 2019 Children's Tumor Foundation National Gala in New York City, Brianna was honored as the 2020 NF Ambassador. This award is bestowed upon an individual with NF to recognize their courage living with the disorder and their personal efforts to further the Foundation goals of research, public awareness, and patient support.





# Financial Summary

## Expenses 2020





<b>Operating support and revenue</b>			
	<b>2020</b>	<b>2019</b>	<b>2018</b>
Contributions – individuals	\$5,943,186	\$10,406,627	\$6,932,165
Contributions – corporations and foundations	\$3,310,653	\$4,132,732	\$3,165,403
Bequests	\$580,538	\$878,802	\$581,164
Contributed goods	\$17,684	\$23,581	\$51,337
Other income	\$995,628	\$1,582,275	\$495,656
Government grants	\$691,400		
<b>CONTRIBUTIONS AND OTHER INCOME</b>	<b>\$11,539,089</b>	<b>\$17,024,017</b>	<b>\$11,225,725</b>
	<b>2020</b>	<b>2019</b>	<b>2018</b>
Special event revenue	\$1,084,549	\$780,795	\$1,371,526
Less: direct benefits to donors	\$0.00	(\$107,115)	(\$164,020)
Special event revenue, net	\$1,084,549	\$673,680	\$1,207,506
<b>TOTAL OPERATING &amp; SUPPORT REVENUE</b>	<b>\$12,623,638</b>	<b>\$17,697,697</b>	<b>\$12,433,231</b>

<b>Operating expenses</b>			
	<b>2020</b>	<b>2019</b>	<b>2018</b>
<b>Program Services</b>			
Research and medical	\$6,326,821	\$6,751,592	\$8,045,453
Public education and patient support	\$2,337,711	\$2,691,715	\$2,517,210
<b>TOTAL PROGRAM SERVICES</b>	<b>\$8,664,532</b>	<b>\$9,443,307</b>	<b>\$10,562,663</b>
<b>Supporting Services</b>			
Management and general	\$904,881	\$946,277	\$1,086,755
Fundraising	\$815,402.00	\$877,648	\$842,082
<b>TOTAL SUPPORT SERVICES</b>	<b>\$1,720,283</b>	<b>\$1,823,925</b>	<b>\$1,928,837</b>
<b>TOTAL OPERATING EXPENSES</b>	<b>\$10,384,815</b>	<b>\$11,267,232</b>	<b>\$12,491,500</b>

<b>Change in Net Assets from Operations</b>	<b>\$2,238,823</b>	<b>\$6,430,465.00</b>	<b>-\$58,269.00</b>
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<b>Other changes</b>	<b>2020</b>	<b>2019</b>	<b>2018</b>
<b>NON-OPERATING REVENUE</b>	<b>\$532,959</b>	<b>\$745,552.00</b>	<b>(\$128,565.00)</b>

<b>Change in Net Assets</b>	<b>\$2,771,782</b>	<b>\$7,176,017</b>	<b>(\$186,834)</b>
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	<b>2020</b>	<b>2019</b>	<b>2018</b>
<b>Net Assets, beginning of year</b>	<b>\$17,688,329</b>	<b>\$10,512,312</b>	<b>\$10,699,146</b>
<b>Net Assets, end of year</b>	<b>\$20,460,111</b>	<b>\$17,688,329</b>	<b>\$10,512,312</b>



# With Thanks

The Children's Tumor Foundation is grateful for the continued support of the many individuals, corporations, foundations, fundraisers, and communities who have joined us in the fight against NF. We are honored to be able to recognize our donors and fundraisers equally. Thank you for your help in advancing the Foundation's mission.

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



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

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



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

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



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# Top 10 Advancements In NF Research 2020

At the Children's Tumor Foundation, we're dedicated to bettering the lives of the over 2.5 million people living with neurofibromatosis (NF). We want to end NF as fast as we can by connecting the unconnected, leading the way with a strategy that applies innovative and inventive approaches to scientific advancement and improved patient care.

This pioneering approach attracts the brightest minds in research and industry to NF, revamps systems so as to accelerate the pathway from discovery to treatment, and includes the voice of the patient every step of the way.

Read about the incredibly important things that happened in NF research in 2020, which are even now laying the groundwork for even greater scientific advancements in the near future.

Stay informed with NF research updates throughout the year at [ctf.org/news](https://ctf.org/news).

[ctf.org](https://ctf.org)

## CLINICAL TRIALS

### GROWING THE NUMBER OF NF TREATMENT OPTIONS

1  
First NF drug ever approved by the FDA, specifically for NF1 inoperable plexiform neurofibromas.  
[ctf.org/firstever](https://ctf.org/firstever)

2  
First NF2 patients enrolled in the groundbreaking launch of the INTUITT-NF2 platform clinical trial.  
[ctf.org/nf2promise](https://ctf.org/nf2promise)

3  
First clinical trial dedicated to schwannomatosis, focusing exclusively on the issue of pain.  
[ctf.org/nomorepain](https://ctf.org/nomorepain)

4  
First clinical trial utilizing a topical gel for cutaneous neurofibromas in NF1.  
[ctf.org/skin](https://ctf.org/skin)

5  
Growing number of clinical trial options now available - over 68 now active!  
[ctf.org/moretrials](https://ctf.org/moretrials)

## PATIENT CARE

### EXPANDING PATIENT ACCESS TO BETTER NF CARE

6  
NF Clinic Network grows to 66 clinics, bringing better care and more options to NF patients.  
[ctf.org/betteraccess](https://ctf.org/betteraccess)

7  
CTF's Clinical Care Advisory Board goes global, expanding to Europe and Canada. NF knows no boundaries, and neither does the best NF care.  
[ctf.org/bettercare](https://ctf.org/bettercare)

## INNOVATION

### BUILDING THE NF FUTURE THROUGH NOVEL APPROACHES

8  
BRIDGE initiative attracts new partners - and promising drugs - from across the scientific world to the NF space.  
[ctf.org/bridgepartners](https://ctf.org/bridgepartners)

9  
NF Data Hackathon draws global audience and sparks fresh approaches to NF research.  
[ctf.org/hackwinners](https://ctf.org/hackwinners)

10  
Important progress in CTF's gene therapy research highlights potential for new treatment options.  
[ctf.org/genepress](https://ctf.org/genepress)





# NF Legacy Society

As a supporter and friend of the Children's Tumor Foundation, you have been vital in building this Foundation from a grassroots group with just a few members into the leading organization it is today, fully committed to finding treatments for neurofibromatosis. Make no mistake about it – the progress that has been made in the fight against NF is because of people like you, who are working to improve the lives of those with NF. It is a legacy of which you can be proud.

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

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

The Children's Tumor Foundation NF Legacy Society consists of individuals who have taken the extra initiative to ensure the future of NF research by including the Children's Tumor Foundation in their estate plans.

**To learn more about leaving a legacy and making a planned gift, please contact the Foundation at [info@ctf.org](mailto:info@ctf.org), or call us directly at 1-800-323-7938.**



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### Marketing and Communications

**Simon Vukelj**, Chief Marketing Officer  
**Rebecca Harris**, Senior Manager, Public Relations  
**Alissa Marks**, Director, Marketing  
**Susanne Preinfalk**, Director, Design  
**Vanessa Younger**, Director, Communications  
**Peiyu Zhang**, Data Analyst





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132 E. 43rd. Street, Suite 418 | New York, NY 10017 | 800-323-7938 | ctf.org

