

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

CHILDREN'S TUMOR FOUNDATION

**ANNUAL**  
**REPORT**  
2021

BORN  
A  
FIGHT

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

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## What is NF?

NF is a term for a group of genetic disorders that cause tumors to grow on nerves throughout the body. Some type of neurofibromatosis or schwannomatosis occurs in approximately one in every 3,000 births. These disorders affect all populations equally, and may lead to blindness, deafness, bone abnormalities, disfigurement, learning challenges, disabling pain, or cancer.



## The Children's Tumor Foundation

is the world's leading nonprofit dedicated to funding and driving innovative research that will result in effective treatments for the millions of people worldwide who live with NF.

## 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,

As we move through 2022, Koselugo (selumetinib) is now an approved treatment for NF patients in 32 countries around the world! It's hard to believe that it was only two years ago that the U.S. Food and Drug Administration granted approval for Koselugo, the first-ever approved drug for any type NF. We are also proud to announce that we now have drug candidates in clinical trials for most manifestations of neurofibromatosis and schwannomatosis. All these treatment options are the reward of more than 40 years of Children's Tumor Foundation-funded research.

These transformative moments were made possible because of YOU. Donors to the Children's Tumor Foundation fund the best and most promising research. That research delivers results, tangibly improving the lives of more than 2.5 million people around the world living with NF.

Because of the fantastic discoveries of CTF-funded research, we can connect potential drug targets to viable medicines for NF. We are inviting pharmaceutical and biotech companies to negotiate access to additional drugs for clinical trials. These CTF partnerships are working! There are now ten companies working on NF. NFlection is ready to enter into a Phase 2b clinical trial with their topical MEK inhibitor; SpringWorks Therapeutics is showing encouraging data with a MEK inhibitor drug; and the INTUITT clinical trial has shared encouraging interim data of Brigatinib. Lastly, in collaboration with other funders, our investments in gene therapy are showing real promise.

Our global effort to offer updated diagnostic criteria for NF1 and Legius Syndrome was successfully published in 2021, and the revised criteria and nomenclature for NF2 and schwannomatosis followed in 2022. These changes will result in earlier diagnosis and better care for all our patients.

I am immensely proud of the work that the Children's Tumor Foundation is also doing to bring the NF community together in unique and creative ways. On May 17, World NF Awareness Day, thousands around the world gathered virtually to watch our awareness day livestream, raising thousands of dollars for NF research. Other CTF events continued in virtual formats, including the NF Conference, the NF Forum, and the Hackathon. Numerous special events, including our National Gala, became hybrid events, and were held both in-person and virtually. Our Shine a Light NF Walks and NF Endurance events adapted, too. We welcomed Cupid's Charity into our business operations near the end of the year, bringing so much fun and joy into fundraising for this important mission.

Our "Make NF Visible" and "Shine a Light on NF" awareness campaigns continue to flourish, attracting more people, volunteers, families, and industries to the NF cause. We continue to grow our body of patient resources and brochures and expand our NF Clinic Network so that new and previously diagnosed patients have the information and support they need.

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

Thank you to our NF researchers, clinicians, government regulators, industry partners, our dedicated Board, our fundraisers, donors, volunteers, and of course, our patients, their families, and caregivers. We are in this fight together, and only together will we prevail.

Warmly and gratefully,



Annette Bakker, PhD, President

# Leading the Way

At the Children’s Tumor Foundation, we’re working to better the lives of more than 2.5 million people who live with some type of neurofibromatosis or schwannomatosis. We envision a day when patients can live their lives free of the pain and difficulties that come with nerve tumors, 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 they will 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 patients with neurofibromatosis or schwannomatosis, 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 tumor types and all manifestations. Join us as we revolutionize how treatments are developed for those who need them most.

## TRADITIONAL RARE DISEASE MODEL

PATIENT

TREATMENT

**COST:**  
Hundreds of millions of dollars

### Why does it take so long and cost so much?

- Patient manifestations unclear
- Clinical trial recruitment can be slow
- Disconnect between discovery and treatment
- Silos mean that experts are isolated
- Time delays in reporting
- Data is not shared
- Much knowledge is lost

## CTF RESEARCH MODEL

PATIENT

TREATMENT

**GOAL:**  
Double the speed for half the cost!

### Why are we faster?

- NF Patient Registry accelerates clinical trial enrollment
- Team science connects discovery to treatment
- Open NF datahub for real-time data release
- Preclinical platform speeds up drug testing
- Key opinion leader network speeds up decision-making

# SELUMETINIB: The Path to Approval

CTF research discovery paved the way to the first FDA-approved drug for neurofibromatosis.

## 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 NFPI was clear: these teams completed 116 preclinical trials in 8 years, at a total cost of \$11 million. The preclinical studies led to multiple clinical trials, many of which are currently underway. 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 the size of 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 Initiative, wherein Nancy Ratner, PhD, and D. Wade Clapp, MD, demonstrated that MEK inhibitors (MEKi) have a massive result on plexiform neurofibroma 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

# Selu-bration

## Koselugo: First FDA-approved treatment for NF

The U.S. Food and Drug Administration (FDA) announced the approval of 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 was a major milestone for patients living with neurofibromatosis. Koselugo is the first-ever approved treatment for NF, and portends the potential for the development of treatment options for patients living with neurofibromatosis.

Announced in April of 2020, Koselugo's approval followed 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. 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, guaranteeing efficient use of donor/investor funding, and support from the federal government.

“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.”

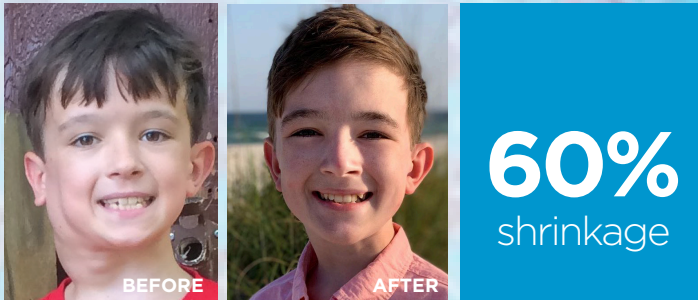
— Nicole Ullrich, MD, PhD, Boston Children's Hospital/Harvard Medical School

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. Our partners at NFlection are also working on a Phase 2b clinical trial with a topical MEK inhibitor for patients with cutaneous neurofibromatosis type 1.

Since the 2020 announcement, Koselugo has been approved for the treatment of NF patients in 32 countries. The AstraZeneca group of companies acquired Alexion, a global biopharmaceutical company focused on rare disorders. Alexion now distributes Koselugo throughout the world, adding to the growing list of partners working with



# 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 NF.

## **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 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 neurofibromatosis and schwannomatosis patient care.

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

### CTF PATIENT ENGAGEMENT PROGRAM

Patients and caregivers are recruited to our patient engagement training program, creating a team of Patient Advocates who are 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 all types of neurofibromatosis and schwannomatosis, 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. This Biobank is now managed by the Indiana University School of Medicine’s DHART SPORE program.

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

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

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

### **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, a team science initiative that began its work in 2016 and concluded in 2020. 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 formed 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 worked 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 2018. This consortium of multidisciplinary investigators from 12 world-class labs and medical centers performed rigorous drug testing that laid the groundwork for clinical trials to test a promising new compound for the treatment of NF2.

### Synodos for Schwannomatosis

An international consortium of clinicians and scientists from multiple disciplines make up the Synodos for Schwannomatosis team, another CTF consortium based on the successful Synodos model. In 2021 the project completed the work of 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-funded NF research leads the way to better diagnostic criteria and improved clinical care.

# Fueling Discovery

## CTF Discovery Fund

The Children's Tumor Foundation Discovery Fund for NF Research funds more than \$3 million in research grants each year, and accelerates drug discovery. 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 all types of neurofibromatosis and schwannomatosis, and brings young researchers into the field. This award program is one reason the understanding of NF has grown so rapidly. Many of CTF'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 and treatments; clinical-trial-enabling or ancillary studies; natural history studies; and investigations into clinical care in NF.



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



# Accelerating Innovation

## NF2 Accelerator Initiative

The Children's Tumor Foundation NF2 Accelerator Initiative is dedicated to finding effective treatments for NF2-related schwannomatosis, or NF2. This powerful initiative is bringing 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 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 at [nfdatalportal.org](https://nfdatalportal.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's three-pronged Phase One goals were fully funded and proved to have far-reaching impact. In 2022, the Initiative will continue the momentum and add a second phase to these endeavors, which will invest another \$1.5 million toward drug discovery, clinical trials, and gene therapy for NF2. This important work will further the live-saving progress for patients living with NF2.



## 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. Two independent groups were awarded funding under this initiative, and both were successful at demonstrating genetic correction of *NF1*-point mutations and selection of specific Schwann cell capsids. Both groups were awarded additional funding in 2021 to validate their results.

## 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 15–20% of children with NF1, and can cause significant health issues.

## Genotype-Phenotype

Research funded by CTF'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.

## 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, which 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.

## NF Diagnostic Criteria Workshops

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. In May of 2021, an update to the diagnostic criteria for neurofibromatosis type one (NF1) was published in *Genetics in Medicine*, the official journal of the American College of Medical Genetics and Genomics (ACMG). An update to the diagnostic criteria and nomenclature for NF2 and schwannomatosis was announced in the same publication in early 2022. These updates reflect the tremendous increase in knowledge about these disorders since the prior diagnostic criteria were established, and will allow for earlier and more accurate diagnoses for patients.

## NF Variant Curation Panel

The Children's Tumor Foundation has funded a ClinGen (Clinical Genome Resource) driven initiative to build a central resource that defines the clinical relevance for all NF gene variants (*NF1*, *NF2*, *SMARCB1*, *LZTR1*, *SPRED1*) for use in precision medicine and research. The expert panel is composed of 25 experts among molecular and clinical geneticists, genetic counselors, and other experts in NF from 9 countries and 18 different institutions.



# NF Conference

The annual NF Conference attracts more than 750 clinicians, researchers, industry representatives, and patient advocates, in person and virtually, who are interested in hearing about the most recent advancements in research and clinical care for neurofibromatosis and schwannomatosis. The event is a critical forum for consensus-building and advancing basic, translational, and clinical research in NF and related fields, while fostering collaborations within and beyond the NF community.

In 2021 the NF Conference convened for a second time as a virtual event; attendees were presented with the best and latest research and clinical care practices within a compressed, online format. In addition to the core agenda, attendees were able to view and listen to recorded poster presentations while a panel of judges selected the top three submissions from clinical and basic science entries. The meeting wrapped up with the presentation of the 2021 Friedrich von Recklinghausen Award, awarded to Marco Giovannini, MD, PhD, of UCLA.



## NF Hackathon

More than 300 participants took part in the Hack4Rare virtual event hosted by the Children's Tumor Foundation, bringing together healthcare startups, researchers, developers, and hackathon enthusiasts for five weeks of high-energy exploration, experimentation, and analysis. Their goal: to drive scientific and medical innovation and improve the lives of patients living with rare diseases. Among the participants was Team American, which was composed of members of the Operations Research team at American Airlines.

Six months after Hack4Rare concluded, more than 135 data technologists at American Airlines came together for a Charity Day dedicated to the Children's Tumor Foundation. The team analyzed donor data, identified information gaps, and helped CTF improve constituent outreach and engagement through enriched information strategies.



# CTF in Europe

Children’s Tumor Foundation Europe is a medical research NGO that 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 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) and the EMA (European Medicines Agency, the European equivalent of the FDA), while maintaining its commitment to funding and driving innovative research worldwide that will result in effective treatments for NF.

In 2021, the Children’s Tumor Foundation Europe focused on the consolidation of European clinic networks, the organization and planning of INFER (International NF Educational Resources) masterclasses for healthcare providers, the expansion of the NF Registry in Europe,

advocacy before EU institutions, and fostering trans-European as well as transatlantic collaborations.

The Children’s Tumor Foundation is also an associated partner of the Innovative Medicines Initiative (IMI). As such, CTF 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 Innovative Medicines Initiative to conceptualize and lead the design of integrated research platforms, enabling a more efficient and patient-centric drug development in Europe. CTF is the co-leader of the neurofibromatosis package of this exciting project, where NF is serving as a test case for rare diseases in general.



**INFER**

INTERNATIONAL  
NF  
EDUCATIONAL  
RESOURCES

A series of online educational lectures for medical professionals by leading NF experts

# Sustaining Hope

## NF Forum

The Children's Tumor Foundation's NF Forum took place virtually in 2021, in a series of livestreamed online webinars about the manifestations that occur in all types of neurofibromatosis or schwannomatosis. 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, and have the opportunity to meet NF researchers and medical professionals in attendance at the NF Conference.

In future years, the NF Forum will be called the NF Summit, and expand its reach to volunteers, clinicians, and the greater community.

## NF Clinic Network (NFCN)

The NF Clinic Network was established by the Children's Tumor Foundation to standardize and raise the level of NF clinical care nationally, and to integrate research into clinical care practices. By the end of 2021, the NF Clinic Network had grown to 67 clinics that serve approximately 15,000 patients each year. 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.

## 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.

## NF Camp

More than 100 teens and young adults attended the 25th Annual NF Camp, which was held virtually in 2021. 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. 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 again in 2021. 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 learning fundraising strategies from a panel of industry professionals. 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 individuals have joined the Foundation's NF Registry, making it the largest patient-entered 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 [nregistry.org](http://nregistry.org), but the data is being actively used—and appreciated—by researchers working on all forms of NF. The Registry is now on the OpenApp platform, which has made the site easier to use and allowed it to be translated into multiple languages, further increasing participation.

“

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

— David Viskochil, MD, PhD, University of Utah

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# Raising Awareness

CTF's marketing, communications, and advocacy efforts support patients and their families no matter where they are on their NF journey. Whether newly diagnosed, in the midst of a treatment regimen, or engaging with the broader community so as to improve broader awareness and understanding, patients and families can rely on CTF for the latest information about all types of neurofibromatosis and schwannomatosis. The Children's Tumor Foundation also provides outreach and engagement opportunities that expand NF knowledge to those around them.

All too often the patient 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 direction 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, and 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 "Make NF Visible" campaign draws attention across the globe to those living with NF.

**Make NF Visible**  
Children's Tumor Foundation

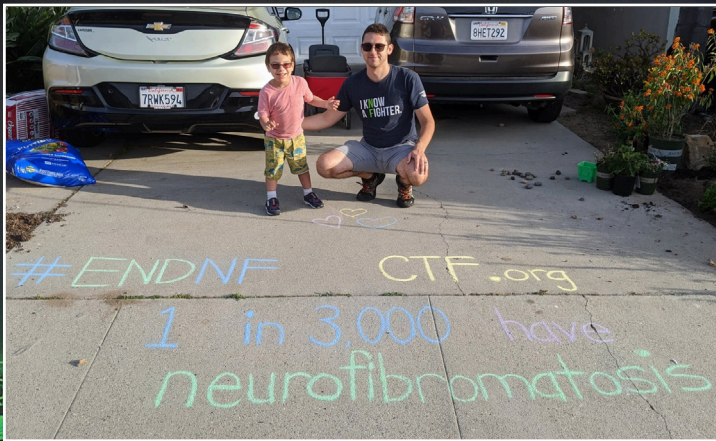


When people ask me about who I am, and I start telling my life story, that motivates them. So I fight NF by just living my life, and doing the best I can in every area, and spreading the word.

— Marcus, who lives with NF1



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



Thanks for donating **Ptasznik Cooper Norris Nancy Roberts**

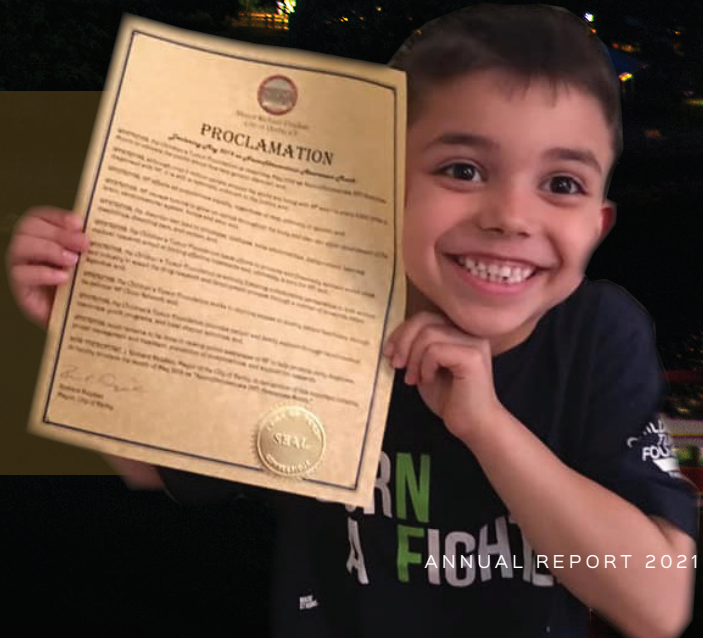
**MakeNF Visible**

**To Make a Donation Call 1-800-323-7938**

**SUBSCRIBE**

For the second year in a row, May 17 World NF Awareness Day was celebrated during a live virtual event, which featured numerous celebrity appearances and stories from NF Heroes, and raised funds for NF research.

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

## 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 the global pandemic, 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 in the fight to end NF.

## Shine a Light NF Walk

Shine a Light NF Walk is the signature fundraising event of the Children's Tumor Foundation, bringing NF 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. The 2021 Shine a Light NF Walks brought participants back together again in person to share a meaningful day with friends and family.





## Cupid's Charity

In late 2021, the Children's Tumor Foundation announced that it is absorbing Cupid's Charity into CTF's business operations. Cupid's Charity is best known for its annual Cupid's Undie Run event, proceeds of which go exclusively to NF research funded by the Children's Tumor Foundation. The union reflects mutual agreement by both organizations to fully bring the Cupid's program into CTF.

The first Cupid's Undie Run took place in 2010 in Washington, D.C. What started as a unique "let's put hilarity into charity" twist on traditional charity walks/runs turned into a national phenomenon attracting wide attention and increased funding for NF. In the decade since, Cupid's Charity has raised and donated millions of dollars to the Children's Tumor Foundation for NF research.



## NF Endurance

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






# 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 also actively engaged with the Defense Health Research Consortium. This Consortium is composed 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 2021, 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 CDMRP for Fiscal Year 2022. 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.



# National Ambassador

## Lilly Ann Brooks

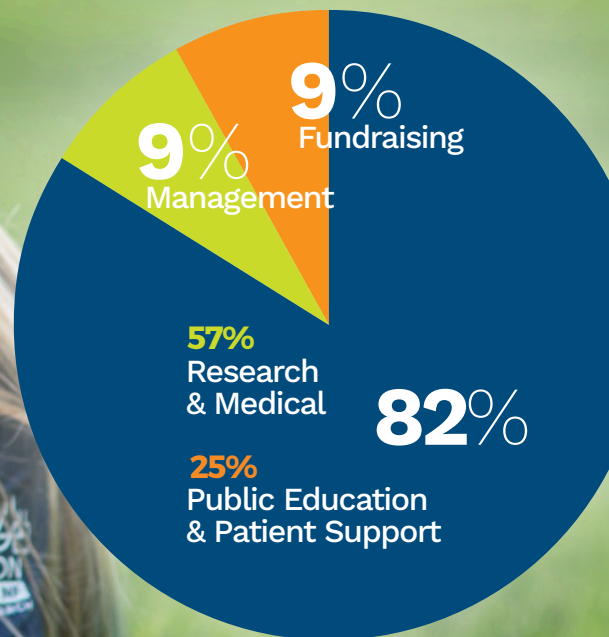
Lilly Ann was diagnosed with NF1 when she was 18 months old and has tumors on her spine, neck, chest, and upper right arm. She also suffers from severe scoliosis because of NF. But that has never stopped Lilly Ann.

Since June of 2016, Lilly Ann has been taking the MEK inhibitor selumetinib (Koselugo) as part of the clinical trial which brought this first drug for NF to market, and has seen a 20% reduction in the size of her tumors.

Lilly Ann now attends the University of Alabama where she is also a proud Alpha Delta Pi sorority member. Lilly Ann has made multiple media appearances due to her involvement with Cupid's Undie Run, Shine a Light NF Walks, Racing4Research, and NF Forums, beautifully sharing information about neurofibromatosis with the world alongside her supportive family.

# Financial Summary

## Expenses 2021



<b>Operating support and revenue</b>			
	<b>2021</b>	<b>2020</b>	<b>2019</b>
Contributions: individuals	\$8,071,808	\$5,943,186	\$10,406,627
Contributions: corporations and foundations	\$4,035,129	\$3,310,653	\$4,132,732
Bequests	\$185,000	\$580,538	\$878,802
Contributed goods	\$214,955	\$17,684	\$23,581
Other income	\$1,539,709	\$995,628	\$1,582,275
Government grants	\$1,077,026	\$691,400	
<b>CONTRIBUTIONS AND OTHER INCOME</b>	<b>\$15,123,627</b>	<b>\$11,539,089</b>	<b>\$17,024,017</b>
	<b>2021</b>	<b>2020</b>	<b>2019</b>
Special event revenue	\$1,818,650	\$1,084,549	\$780,795
Less: direct benefits to donors	(\$40,000)	0	(\$107,115)
Special event revenue, net	\$1,778,650	\$1,084,549	\$673,680
<b>TOTAL OPERATING &amp; SUPPORT REVENUE</b>	<b>\$16,902,277</b>	<b>\$12,623,638</b>	<b>\$17,697,697</b>

<b>Operating expenses</b>			
	<b>2021</b>	<b>2020</b>	<b>2019</b>
<b>Program Services</b>			
Research and medical	\$6,032,140	\$6,326,821	\$6,751,592
Public education and patient support	\$2,720,523	\$2,337,711	\$2,691,715
<b>TOTAL PROGRAM SERVICES</b>	<b>\$8,752,663</b>	<b>\$8,664,532</b>	<b>\$9,443,307</b>
<b>Supporting Services</b>			
Management and general	\$945,320	\$904,881	\$946,277
Fundraising	\$930,453	\$815,402	\$877,648
<b>TOTAL SUPPORT SERVICES</b>	<b>\$1,875,773</b>	<b>\$1,720,283</b>	<b>\$1,823,925</b>
<b>TOTAL OPERATING EXPENSES</b>	<b>\$10,628,436</b>	<b>\$10,384,815</b>	<b>\$11,267,232</b>

<b>Change in Net Assets from Operations</b>	<b>\$6,273,841</b>	<b>\$2,238,823</b>	<b>\$6,430,465</b>
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<b>Other changes</b>	<b>2021</b>	<b>2020</b>	<b>2019</b>
<b>NON-OPERATING REVENUE</b>	<b>\$561,848</b>	<b>\$532,959</b>	<b>\$745,552</b>

<b>Change in Net Assets</b>			<b>\$7,176,017</b>
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	<b>2021</b>	<b>2020</b>	<b>2019</b>
<b>Net Assets, beginning of year</b>	<b>\$20,460,111</b>	<b>\$17,688,329</b>	<b>\$10,512,312</b>
<b>Net Assets, end of year</b>	<b>\$27,295,800</b>	<b>\$20,460,111</b>	<b>\$17,688,329</b>

# With Thanks

The Children's Tumor Foundation is grateful for the continued support of the many individuals, corporations, foundations, and communities who have joined us in the fight against NF. Thank you for your help in advancing the Foundation's mission.

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“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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# NF Legacy Society

As a supporter and friend of the Children's Tumor Foundation, you have been vital in building us up from a grassroots group with just a few members into the leading organization we are 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 visit [freewill.com/CTF](https://freewill.com/CTF), contact the Foundation at [info@ctf.org](mailto:info@ctf.org), or call us directly at 1-800-323-7938.**

# TOP TEN ADVANCEMENTS IN NF RESEARCH 2021



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 at every step of the way.

Read about the important things that happened in NF research in 2021, which are even now laying the groundwork for greater scientific advancements in the near future.

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

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