

FORTY YEARS OF FIGHTING NF

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

# 2018 ANNUAL REPORT



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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.



CHILDREN'S  
TUMOR  
FOUNDATION

ANNIVERSARY  
1978-2018

## Founded in 1978,

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

## Our mission

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

## Our vision

End NF.



“

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

”

— Annette Bakker, PhD



Annette Bakker with 2018 NF  
Ambassadors Frankie and  
Olyvia Moriguchi

# Dear friend,

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

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

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

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

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

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

Gratefully,

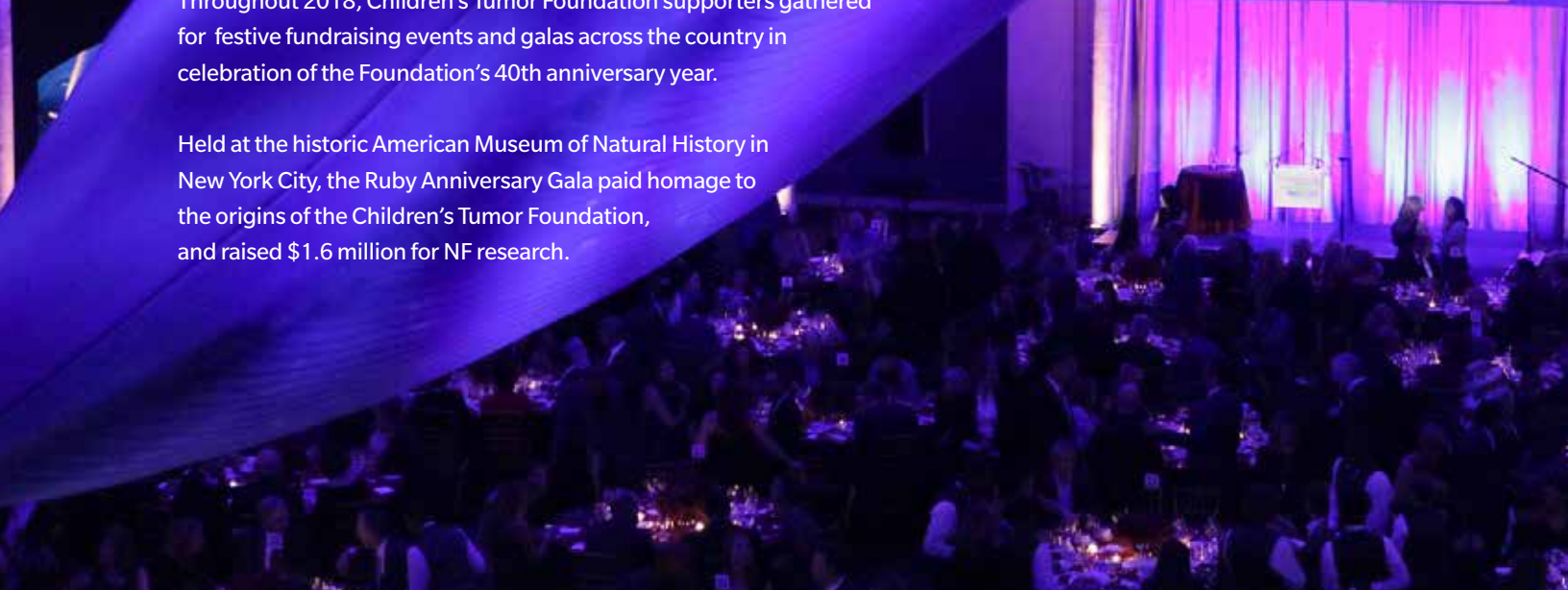
**Annette Bakker, PhD, President**

# Celebrating 40 Years of Ending NF

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

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

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



Those closest to the Foundation enjoyed a walk down memory lane during a springtime 40th Anniversary Cocktail Party.



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

— Francis S. Collins, MD, PhD,  
 Director of the National Institutes  
 of Health (NIH)



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



Allan Rubenstein, MD, one of the CTF Founders, with Rick Horvitz, our current Board of Directors Chair



Joan Engel, who served as NNFF President beginning in 1982, with her son, Ken Rudd, who currently serves on the CTF Board of Directors

# 1882

Neurofibromatosis was first described by German pathologist Friedrich Daniel von Recklinghausen. Today NFI is sometimes still referred to as “von Recklinghausen syndrome.”



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

## The Children’s Tumor Foundation 40 Years of Progress

# 1978

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

neuro·fibroma·tosis  
THE NATIONAL NEUROFIBROMATOSIS FOUNDATION, INC.



NNFF funded six scientists with the inaugural “Young Investigator Awards” to attract talented young scientists. This constant seeding of the NF field is one reason NF research has grown so rapidly over the past 40 years.



# 1992

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

# 1985

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



# 1982

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



# 1984

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



# 1990

On July 12, the discovery of the *NF1* gene in the labs of Francis S. Collins, MD, PhD and Raymond White, PhD made headlines. Two Young Investigator Awardees, Dave Viskochil, MD, PhD and Peggy Wallace, PhD played an instrumental role in that work.

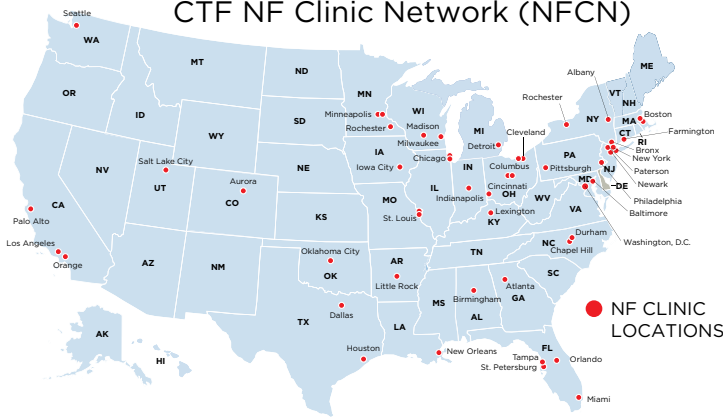


# 1993

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



## US Distribution of the CTF NF Clinic Network (NFCN)



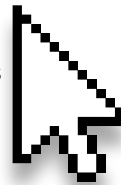
## 1997

In August, teens from around the world gathered in Utah for the first week-long NF Camp. Today, over 100 teens participate in NF camp in three week-long sessions.

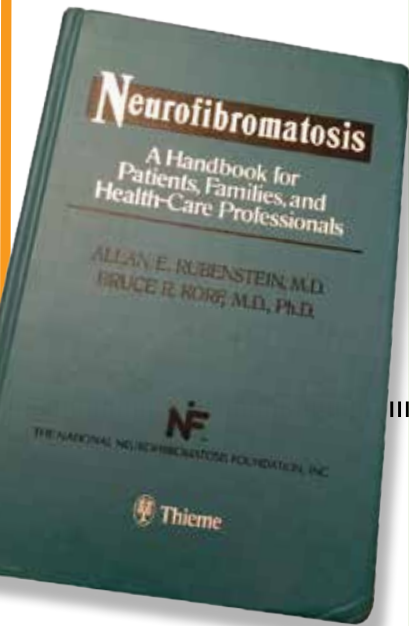
## 1994

The NF Clinic Network was established. Thirteen years later, it was revitalized to recognize NF clinics in the U.S. that provide an appropriate level of NF clinical care. Today, there are 54 participating clinics that see over 14,000 patients a year.

The NNFF created the first-ever website focused on NF. That site evolved into [www.ctf.org](http://www.ctf.org), which today receives over a million visits each year.



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



The Foundation sponsored a series of medical symposia in Asia, including a meeting in Beijing.



## 1995

The first edition of "Neurofibromatosis: A Handbook for Patients, Families, and Healthcare Professionals" written by Allan Rubenstein, MD and Bruce Korf, MD, PhD was published.

## 1990s-2000s

Volunteers across the country participated in CTF fundraising programs like NF Walk, NF Endurance, Racing4Research, Tea Party, and galas sponsored by local CTF chapters.

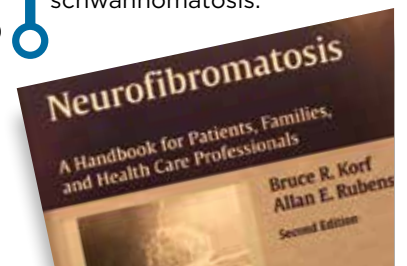


The NNFF changed its name to the Children's Tumor Foundation (CTF).

## 2005

Congress appropriated a record \$25 million for NF research via the Department of Defense's CDMRP-NRP. Since its inception, more than \$300 million has been designated for NF research.

The second edition of "Neurofibromatosis: A Handbook for Patients, Families, and Healthcare Professionals" was published and included information about schwannomatosis.



# 2006

The Drug Discovery Initiative Awards were launched to fund NF drug testing in the lab.



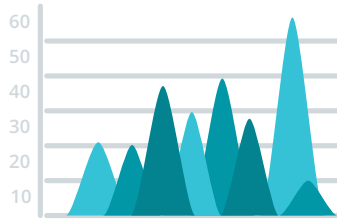
# 2007

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



# 2008

The Clinical Research Awards Program was initiated.



# 2009

The first NF Forum was held in April in Washington, DC.

# 2010

The first Cupid's Undie Run raised \$10,000. Now Cupid's Charity is an independent organization with a nine-year total of \$16.9 million raised.



# 2011

The first in-human clinical trial of the MEK inhibitor selumetinib was funded by CTF.

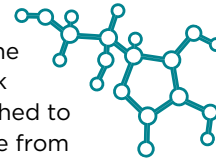


# 2013

The NF Therapeutic Consortium (NFTC) was launched to continue the work of the NFPC. The 116 preclinical studies performed have resulted in 16 clinical trials. In 2016, President Annette Bakker presented the NFTC with CTF's first Team Science Award.

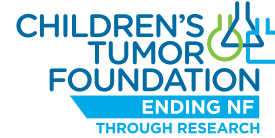
*LZTR1* was identified as a key gene in schwannomatosis by CTF Young Investigator Awardee Arkadiusz Piotrowski in the lab of Ludwine Messiaen, PhD.

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



# 2014

CTF released a new logo, and the hashtag #EndNF.



A new global team-science initiative called Synodos for NF2 was launched on February 3, when investigators met for the first time.



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

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



# 2012

The NF Registry was launched at the NF Forum.

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



**I KNOW A FIGHTER.**  
CTF.ORG

# 2015

In May, CTF launched the "I Know a Fighter" campaign, a rally cry for the NF community that captured the remarkable spirit of those living with NF.





# END WWW.CTF.ORG NF

CTF initiates an agreement with Sage Bionetworks to build the first data sharing portal for NF. Today, three other funders are committed to co-fund the platform.

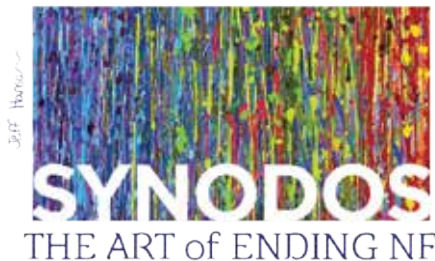


## 2016

Synodos for NF1 was launched on January 21, when investigators of the two Clinical Acceleration groups convened, followed by a February 28 meeting of the Low Grade Glioma group.



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



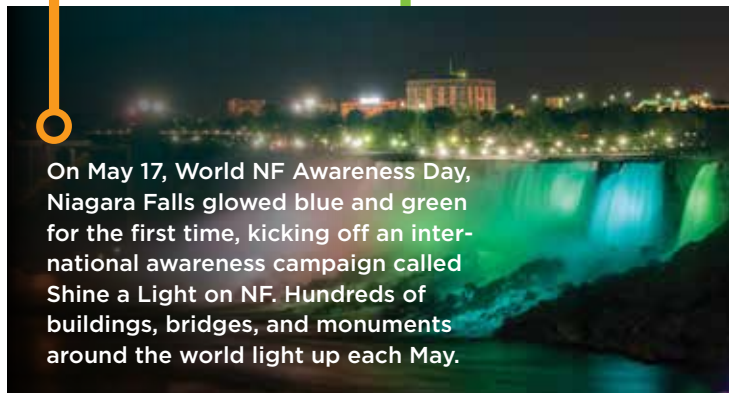
## 2017

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



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

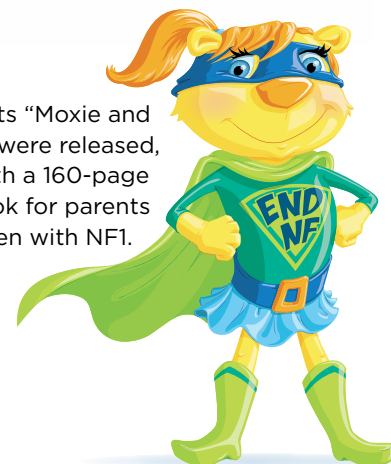
CTF formed a partnership with pharmaceutical company SpringWorks Therapeutics.



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



Mascots "Moxie and Sparx" were released, along with a 160-page guidebook for parents of children with NF1.



At the NF Conference, Brigitte Widemann, PhD, announced that a Phase I clinical trial for the MEK inhibitor selumetinib was showing a decrease in tumor volume. This trial was informed by the work of the NFPC.



BEFORE AFTER

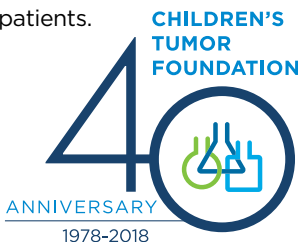
Results of the MEK clinical trial showed a tumor volume decrease in over 50% of plexiform neurofibroma patients.

## 2018

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

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

The Children's Tumor Foundation goes global and celebrates 40 years of driving research, expanding knowledge, and advancing care for the NF community.



# Leading the Way

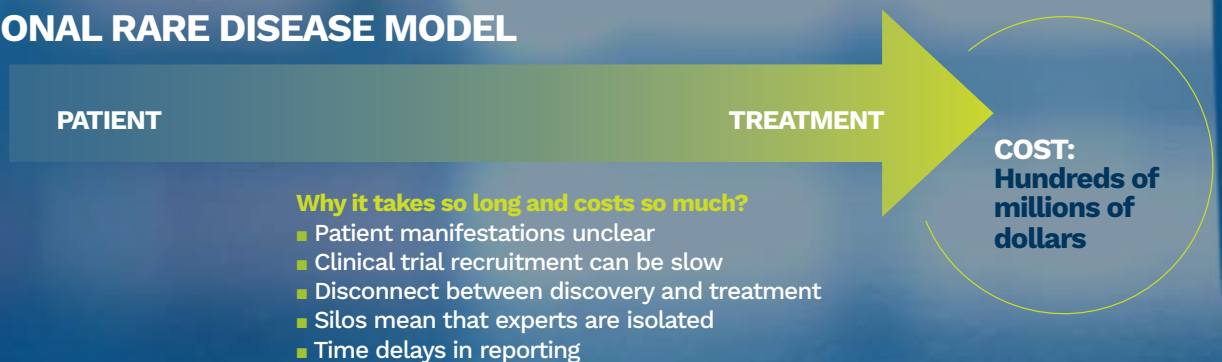
At the Children's Tumor Foundation, we're working to better the lives of over 2.5 million people who live with NF. And we're doing so by focusing on the tagline in our name –Ending NF Through Research. We envision a day when NF patients can live their lives free of the pain and difficulties that come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

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

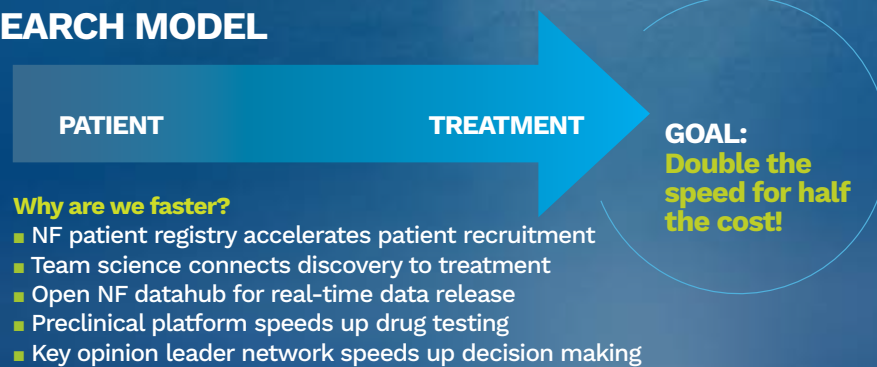
And the best part? CTF's research model not only benefits NF patients, but also the millions of patients living with cancer, or one of the 7,000 rare diseases in existence.

We're in a rush to find treatments for patients. Join us as we revolutionize how treatments are developed for those who need them most.

## TRADITIONAL RARE DISEASE MODEL



## CTF RESEARCH MODEL



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

— Nicole Ullrich, MD, PhD,  
Harvard Medical School

## MEK makes a difference

NF HERO: **Philip Moss**



BEFORE

AFTER

**57%**  
shrinkage

NF HERO: **Ryker Bennett**



BEFORE

AFTER

**42%**  
shrinkage

NF HERO: **Paige Doane**

**32%**  
shrinkage



BEFORE

AFTER

NF HERO: **Jane Constable**

**30%**  
shrinkage



BEFORE

AFTER

# 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 experts collaborate, participate, and immediately share all raw data in an NF Data Portal. By working together instead of in silos, we increase the efficiency of solving complex NF problems.

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

### CTF'S KEY OPINION LEADER NETWORK

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

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

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

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

## **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.

How can we  
standardize the endpoints of  
clinical trials?

### THE REINS CONSORTIUM

(Response Evaluation in NF and  
Schwannomatosis)

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

Where can we find new  
drug targets?

### THE NF DATA PORTAL STORES OPEN DATA

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

Have these drugs been tested in  
animal models?

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

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

Is there enough tissue  
available for testing?

### THE NF BIOBANK PROVIDES TISSUE FOR RESEARCH

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

# Driving Collaboration

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

## Synodos

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

## Synodos for NF1

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

## Synodos for NF2

Synodos for NF2 was launched in 2014 in order to provide clarity to patients about available drug options and identify new ones. This consortium of multidisciplinary investigators from 12 world-class labs and medical centers has performed rigorous drug testing that has laid the groundwork for clinical trials to test Brigatinib (a Takeda drug) for the treatment of NF2. This successful three-year, \$3 million program completed its work in April of 2018.



## NF Preclinical Initiative

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

Traditionally, it takes up to 16 years and costs hundreds of millions of dollars to translate a new discovery into one clinical treatment. The impact of the NF Preclinical Initiatives is clear: these teams completed 116 preclinical trials in 8 years at a total cost of \$11 million. The preclinical studies led to 16 clinical trials that are currently underway—one of those clinical trials is the MEK inhibitor selumetinib registration trial, in which patients are seeing significant shrinkage in the size of their tumors (read more below).

## Synodos for Schwannomatosis

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

## MEK Inhibitor Selumetinib Registration Trial

Over 70% of the patient participants in a clinical trial of the MEK inhibitor selumetinib have seen a reduction of 20-55% in their inoperable plexiform neurofibromas. Brigitte Widemann, MD, of the National Cancer Institute, reported at the Foundation's 2015 NF Conference that response data in this trial for children and young adults showed meaningful decreases in tumor volume. This highly successful clinical study was the result of CTF's NF Preclinical Initiatives, wherein Nancy Ratner, PhD and D. Wade Clapp, MD demonstrated that MEK inhibitors have a massive result on tumor volume in mice. The drug was first tested in a human subject as part of a Children's Tumor Foundation Clinical Research Award granted to Michael J. Fisher, MD in 2011.

## Orphan Drug Status

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

“ I think it's my responsibility—as a grandparent of a child affected by NF—to do everything I am capable of doing. And I know that CTF needs my support. It's vital. It's just so important. ”

—Carol Harrison Kalagher,  
Synodos for NF2 Benefactor

# Fueling Innovation

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

## TESTING CONCEPTS Clinical Research Award (CRA)

The Foundation's Clinical Research Award program supports early-stage NF research involving human subjects. These awards encourage studies of candidate therapeutics or other interventions for the treatment of NF1, NF2, or schwannomatosis; clinical-trial-enabling or ancillary studies; natural history studies; and investigations into clinical care in NF. In 2018 the Foundation awarded one Clinical Research Award for a study of L-Carnitine safety and effects on muscle.

## LEARNING MORE The Young Investigator Award (YIA)

The YIA is the Foundation's oldest research award program and serves to advance understanding of the biology of NF1, NF2, and schwannomatosis, and to bring young researchers into the NF field. This award program is one reason the understanding of NF has grown so rapidly during CTF's 40-year history. Many of the Foundation's past YIA awardees have gone on to pursue lifelong careers in the field of NF research. Two post-doctoral and three pre-doctoral students were awarded YIAs in 2018, two of which were co-funded by the NF Research Initiative (NFRI), which is made possible by an anonymous donation to the Boston Children's Hospital.

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

Through a collaboration with a top scientific journal, *PLOS ONE*, in a process known as "Registered Reports," CTF awardees are offered the Foundation's financial support as well as in-principle acceptance for publication by the journal. This model will allow for more rigorous, reproducible and transparent science, guaranteeing its awardees with an in-principle acceptance to publication, regardless of study outcome. This award evolved from the Foundation's classic Drug Discovery Initiative Award program. In 2018 CTF awarded three investigators with DDI-RR awards to fund projects in NF2 tumors and NF1 muscle weakness.

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

—Tena Rosser, MD,  
Children's Hospital of Los Angeles

## BIOBANK

### Body and Tissue Donation Program

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

### OPG Multicenter Study

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

### NF Animal Model Workshop

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

# Joint Global NF Conference

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

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

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

The NF Conference is recognized as the premier annual scholarly gathering of international NF researchers and physicians, and is considered a critical venue for the

presentation and integration of basic science discovery, translational data, and clinical trial outcomes, to both enhance the quality of ongoing research and improve clinical care.

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

This year's conference presented nine plenary sessions and seven parallel sessions, along with the bi-annual NF2/Schwannomatosis State of the Art meeting which ran in parallel on days three and four. Renowned keynote speakers from outside the NF community served to stimulate fresh discussions and promote the development of new collaborations.

The Joint Global NF Conference brought together the most diverse, international expertise in the world to meet and exchange ideas, and to do so in an environment that encourages and cultivates joint efforts.



# CTF Europe

**The Children's Tumor Foundation announced the formation of the new European-based medical research NGO, called Children's Tumor Foundation Europe, which will serve as a partner organization to CTF in the United States.**

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

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

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

The focus of Children's Tumor Foundation Europe will be to further build out relationships with European agencies and partners, including EFPIA (European Federation of Pharmaceutical Industries and Associations), while maintaining its commitment to funding and driving

innovative research worldwide that will result in effective treatments for NF.

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

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



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

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



# Sustaining Hope

## Patient Engagement

CTF's Patient Representative Training Program graduated its first class of "Patient Advocates" in May 2018. This Patient Engagement initiative is designed to prepare individuals with NF and their families to participate as advocates in NF research. Through online and in-person learning, the program's goal is to show patients how to add their perspective during all phases of the research process. Patient Advocates are trained to work with stakeholders such as researchers, research institutions, the pharmaceutical industry, the Food and Drug Administration, and patient advocacy organizations.

## NF Forum

The Children's Tumor Foundation's NF Forum took place in Atlanta from May 4-6, 2018. This national patient education and family gathering allows those living with NF, and their families, to connect, support, and learn from each other. Families and patients learn together while attending seminars on relevant topics pertaining to neurofibromatosis. The Foundation was awarded a prestigious PCORI grant (Patient-Centered Outcomes Research Institute) for the 2018 NF Forum.

## Neurofibromatosis Clinic Network (NFCN)

The Neurofibromatosis Clinic Network was established by the Children's Tumor Foundation to standardize and raise the level of neurofibromatosis clinical care nationally, and to integrate research into clinical care practices. In 2018, the NF Clinic Network grew to 52 clinics that serve approximately 14,000 patients. Clinics are invited to join the NFCN based on many factors, including expertise in NF care, access to specialists, number of patients seen, and commitment to educating colleagues and patients about the latest developments.



## The Volunteer Leadership Training Conference

In celebration of the Foundation's 40th Anniversary, 62 registered members of the Volunteer Leadership Council (VLC), our most active and dedicated volunteers, gathered for their annual Leadership Training Conference in Atlanta, Georgia. The conference allows VLC members the opportunity to have face-to-face interactions with staff and one another. They gain new insights about the latest scientific research, CTF program enhancements and marketing initiatives, as well as have time to share with and learn from each other. Volunteer Recognition Awards (VRAs) were presented to volunteers to celebrate the contributions of Volunteer Leaders in several categories from our newest up-and-comers to our most tried and true champions.

## NF Camp

Over 100 youth attended the 22nd Annual NF Camp in July, which was held in three week-long sessions. NF Camp takes place at the beautiful Camp Kostopulos in Emigration Canyon, Utah. Campers enjoyed horseback riding, rope courses, and day trips to local theme parks. At NF Camp, often for the first time, campers can talk freely about NF, share their experiences, and make lasting friendships.

## NF Registry

By the end of 2018, more than 9,000 individuals had joined the NF Registry, making it the largest patient-centered database of people with NF, and the only one designed to be available to interested investigators. The Registry has proven to be a valid and useful tool for both patients and researchers, according to an analysis published in the journal *PLOS ONE*. Not only are thousands of patients from all over the world contributing their data online at [nregistry.org](http://nregistry.org) but the data is being actively used—and appreciated—by researchers working on all forms of NF. Over 18 different studies and clinical trials have used the NF Registry to notify individuals who fit certain trial or study criteria.

“NF Camp is the highlight of my year! It is so much fun hanging out with people who have the same challenges as me and helps me feel like I am not alone in what I go through on a daily basis.”

—Kala Schvaneveldt, Utah

# Raising Awareness

The Foundation's marketing and communications efforts are committed to broadening knowledge of neurofibromatosis worldwide by providing the most up-to-date information about NF on our website and in the Foundation's publications. With a dynamic presence on social media, CTF is connecting NF families and spreading CTF's vision to those without an immediate NF connection.

The Foundation's media outreach efforts continue to grow, with countless articles in newspapers across the country. A growing number of TV and radio stations broadcast segments that feature stories of dedicated volunteers, NF walkers and endurance athletes, and NF Heroes and their families.

The **Shine a Light on NF** initiative cast a blue and green glow on buildings, bridges, and monuments around the country and around the globe, bringing the 2018 total to 205 landmarks spanning 11 countries.

*The Colchester-East Hants  
Public Library, Truro,  
Nova Scotia, Canada*

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

— Gwen Coverdale, CTF volunteer and NF mom



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



The Foundation’s annual NF Awareness Month campaign drew attention from across the globe to neurofibromatosis and those living with this disorder. The **IKNOW A FIGHTER** theme permeated numerous events held during the month of May, as members of the NF community took the lead in promoting NF awareness and the mission of the Foundation.



Proclamations were issued in 31 state houses and 40 city halls across the country recognizing NF awareness month. CTF engaged with their local leaders and helped ensure that more people in office know about NF and how it affects their constituents.



# Raising Funds

## Shine A Light NF Walk

Shine a Light NF Walk is the signature fundraising event of the Children's Tumor Foundation, bringing neurofibromatosis out of the shadows and inspiring the community to come together to raise critical funds for NF research. At these fun and inspirational events held across the country, communities rally around local families affected by NF. Frequent appearances of costumed characters, glow sticks, and face painting bring bubbling energy from start to finish.

## Classrooms That Care

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

## Fight NF Your Way

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

# 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.



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

—Diane Owens  
Endurance Athlete and  
NF Mom

# 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.

After receiving approval from both chambers of Congress, President Trump signed the FY 2019 Defense and Labor, Health, and Human Services Appropriations conference report into law on September 28, 2018. The conference report includes \$15 million in funding to support neurofibromatosis research and is vital to our fight to end NF. This funding will support strategic research through the Department of Defense’s Neurofibromatosis Research Program (NFRP), resulting in new discoveries and better outcomes for NF patients and their families. This would not be a reality without the tireless work and advocacy done by the Children’s Tumor Foundation, the NF Community, patients, and their families. This sustained federal funding will allow us to further develop scientific data, break through barriers, and forge a pathway to end NF.

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

# NF Ambassadors

Frankie and Olyvia Moriguchi were born in Eugene, Oregon. Both have NF1.

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

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

for working for the local bus station. Frankie is a great friend and a wonderful big brother.

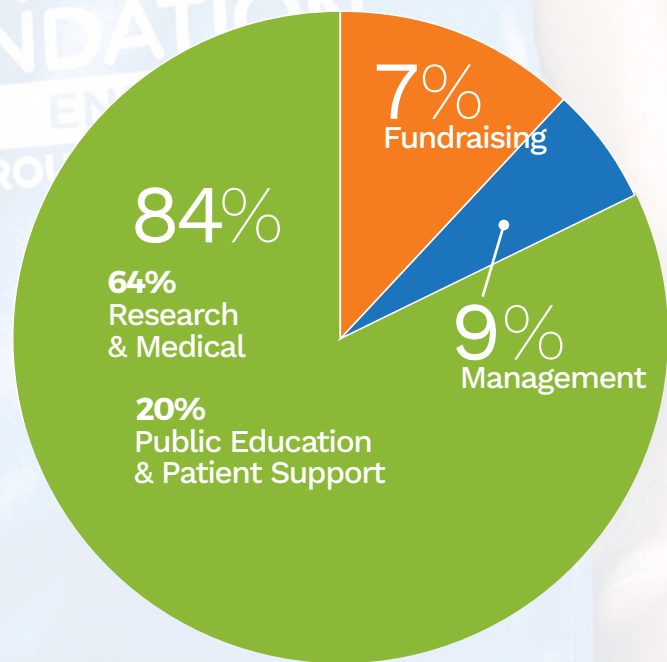
Frankie's sister, Olyvia, was an extremely curious child. Often, she would climb as high as she could without the fear of falling. Now age 19, she has had six surgeries. Her most recent was to repair her pectus, as her sternum was half an inch from touching her spine.

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

# Financial Summary



Expenses 2018



## Operating support and revenue

|  | 2018                | 2017                | 2016                |
|--|---------------------|---------------------|---------------------|
| Contributions – individuals                  | \$6,932,165         | \$5,382,209         | \$2,839,870         |
| Contributions – corporations and foundations | \$3,165,403         | \$3,285,858         | \$3,204,939         |
| Bequests                                     | \$581,164           | \$10,016            | \$102,522           |
| Contributed goods                            | \$51,337            | \$80,418            | \$763,721           |
| Other income                                 | \$495,656           | \$491,993           | \$851,491           |
| <b>CONTRIBUTIONS AND OTHER INCOME</b>        | <b>\$11,225,725</b> | <b>\$9,250,494</b>  | <b>\$7,762,543</b>  |
|  | <b>2018</b>         | <b>2017</b>         | <b>2016</b>         |
| Special event revenue                        | \$1,371,526         | \$2,600,665         | \$8,598,565         |
| Less: direct benefits to donors              | (\$164,020)         | -\$461,433          | (\$450,809)         |
| Special event revenue, net                   | \$1,207,506         | \$2,139,232         | \$8,147,756         |
| <b>TOTAL OPERATING &amp; SUPPORT REVENUE</b> | <b>\$12,433,231</b> | <b>\$11,389,726</b> | <b>\$15,910,299</b> |

## Operating expenses

|                                      | 2018                | 2017                | 2016                |
|--------------------------------------|---------------------|---------------------|---------------------|
| <b>Program Services</b>              |                     |                     |                     |
| Research and medical                 | \$8,045,453         | \$8,215,708         | \$7,618,638         |
| Public education and patient support | \$2,517,210         | \$2,116,742         | \$4,667,514         |
| <b>TOTAL PROGRAM SERVICES</b>        | <b>\$10,562,663</b> | <b>\$10,332,450</b> | <b>\$12,286,152</b> |
| <b>Support Services</b>              |                     |                     |                     |
| Management and general               | \$1,086,755         | \$968,659           | \$1,039,689         |
| Fundraising                          | \$842,082           | \$1,419,382         | \$1,862,625         |
| <b>TOTAL SUPPORT SERVICES</b>        | <b>\$1,928,837</b>  | <b>\$2,388,041</b>  | <b>\$2,902,314</b>  |
| <b>TOTAL OPERATING EXPENSES</b>      | <b>\$12,491,500</b> | <b>\$12,720,491</b> | <b>\$15,188,466</b> |

|   |         |            |           |
|---|---------|------------|-----------|
| <b>Change in Net Assets from Operations</b> | -58,269 | -1,330,765 | \$262,363 |
|---|---------|------------|-----------|

## Other changes

|                              | 2018                  | 2017             | 2016             |
|------------------------------|-----------------------|------------------|------------------|
| <b>NON-OPERATING REVENUE</b> | <b>(\$128,565.00)</b> | <b>\$565,099</b> | <b>\$304,524</b> |

|                             |                    |                    |                  |
|-----------------------------|--------------------|--------------------|------------------|
| <b>Change in Net Assets</b> | <b>(\$186,834)</b> | <b>(\$765,666)</b> | <b>\$721,833</b> |
|-----------------------------|--------------------|--------------------|------------------|

|                                      | 2018                | 2017                | 2016                |
|--------------------------------------|---------------------|---------------------|---------------------|
| <b>Net Assets, beginning of year</b> | <b>\$10,699,146</b> | <b>\$11,464,812</b> | <b>\$10,438,455</b> |
| <b>Net Assets, end of year</b>       | <b>\$10,512,312</b> | <b>\$10,699,146</b> | <b>\$11,464,812</b> |

# With Thanks

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

## Distinguished Donors

### **DISTINGUISHED BENEFACTORS**

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### **INSTITUTIONAL GIVING**

National Institutes of Health  
Neurofibromatosis Research Initiative  
Neurofibromatosis Therapeutic  
Acceleration Program  
The Patient-Centered Outcomes  
Research Institute

## Fundraisers

### **SPECIAL EVENTS RAISING MORE THAN \$50,000**

Caddies for Colin - Colin's Courageous  
Bay Hill Golf Tournament  
Dancing with Our Stars  
New England Gala  
NYC Poker Tournament

### **NF WALKS RAISING MORE THAN \$45,000**

Los Angeles NF Glow Walk  
and 5K Run  
NF Walk Boston  
NF Walk Cincinnati  
NF Walk Houston  
NF Walk Rochester  
NF Walk Seattle  
NF Walk South Florida

### **DIY EVENTS RAISING MORE THAN \$10,000**

Halloween Bash  
Staten Island Family Fun Day  
5th Annual #EndNF with Travis  
Classic Charity Golf Tournament

Tear the Cover off Cancer  
Baseball Tournament  
Two Counties, One Cause  
Basketball Tournament  
Kids Fashion For NF: Heroes  
for a Cause  
California International  
Marathon  
Little Heroes of North Georgia  
Summer Solstice 10K  
Orange Hills Golf Tournament  
Wine and Art Party

### **FUNDRAISING TEAMS RAISING MORE THAN \$10,000**

Angela Marie (Los Angeles  
NF Glow Walk and 5K Run, Buffkin)  
Aubri's Avengers (NF Walk  
Chicagoland, Raymond)  
Ava's Army (NF Endurance California  
International Marathon, Lowell)  
Camille's Tumor Fighting Superheroes  
(Halloween Bash, Thoms)  
Cataleya's Crusade (NF Walk  
Seattle, Castanon)

Chafing the Dream - Chicago4  
Connor (NF Endurance Bank of  
America Chicago Marathon, Brennan)  
Cluck NF (NF Endurance  
NYC Marathon, Moore)  
Colin Courageous (NF Endurance  
United Airlines NYC Half, Cashell)  
DeLilah's Dream Team (NF Walk  
Kansas City, Bigham)  
Dominick's Dinosaurs (NF Walk  
New York City, Merlucci)  
Dreaming for Danielle (NF Walk  
Houston, Clayton)  
Kendall's Crew (NF Walk Cincinnati,  
Samblanet)  
Kendall's Warriors (NF Endurance  
I Know A Fighter Boston, D'Arcy)  
Leyla (NF Walk Seattle, Ghassemi)  
Mighty Meeks (NF Walk  
Chicagoland, Meek)  
NF Tuminators (NF Endurance TCS  
New York City Marathon, Ferruggiari)  
NFE Team Garrett (NF Endurance  
America's Finest City Half  
Marathon & 5K, Baumann)  
Parker's Posse (NF Walk Houston,  
Bell)

run 4 robert (NF Endurance  
Team, Owenby)  
Sally's Pals (NF Walk Kernersville,  
Nagappan)  
Team Ella Bella (NF Walk Long  
Island, Evans)  
Team Isla (NF Walk Seattle, Riley)  
Team Joey (NF Walk Rochester,  
Chimento)  
Team Joseph (NF Walk Boston,  
Dangoia)  
Team LJ Smooth (NF Walk  
Richmond, Theobald)  
Team Maddox (NF Endurance  
Team, Steinert)  
Team Mariah (NF Walk Richmond,  
NF Walk DC, Williams)  
Team Nicholas (NF Walks Jacksonville  
& Arizona, NFE Tour de Scottsdale,  
Lindeback)  
Team Nico (NF Endurance Nashville  
Rock 'n' Roll Marathon, Tseffos)  
Team Renicks (NF Walk Alabama,  
Renicks)  
Team Taub (NF Walk South Florida, Taub)  
The Fighting Vikings (NF Walk Seattle,  
Nilsson)



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The 2018 NF Walk in Rochester, NY, led by Volunteer Walk Organizer Michelle Lampman, boasted 16 teams, 150 walkers and raised \$52,000. Now in its 8th year, the Walk continues to grow the NF community in Western New York. Working with the NF Clinic at University of Rochester Medical Center, the Walk has become an important event in connecting local NF patients and families, celebrating NF Heroes both young and old, and raising critical funds for NF research and awareness. Top fundraising Team Joey, led by the Chimento family, cumulatively raised more than \$41,000 since 2017. Participating in the Walk has been an incredible way to rally their family, friends, and community to support the fight to end NF, not only for five-year-old Joey Chimento, but for all those living with NF.

Kendall Newman  
 Harvey & Joan Newman  
 Newman's Own Foundation  
 Ryan & Kristy Nobles

Ohio Valley Region Porsche Club of America  
 Mike & Sara Orlando  
 Jeffrey & Diane Owens  
 Emily Parker

“One of the things that has struck me over the years is just how constant this Foundation has been for the NF community. From its nascent days as the National Neurofibromatosis Foundation, to today's Children's Tumor Foundation, this has been the place that people turn to for answers to the difficult questions. And that, ultimately, is what this foundation is all about - finding the answers to this demanding and challenging disease.”

— Richard Horvitz, CTF Board Chair, speaking at the 40th Anniversary Gala in New York City

# With Thanks

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Brian & Nora Berman  
Zachary Bernstein  
Bill Berry  
Jennifer Berube  
Jack Bick  
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Thomas & Laura Bona

## Fundraiser Highlight: Kendall's Crew



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

## Fundraiser Highlight: Anne Trussell

Anne Trussell has been involved with the Children's Tumor Foundation in many ways: as a member of the NF Endurance team where she completed 50 half-marathons and 7 full marathons in the last seven years. She has also shown her support of CTF as a member of the Arkansas Advisory Board since 2014, as a member of Volunteer Leadership Council and organizer of the "Wine and Art" fundraiser (which has raised more than \$75,000 to date), and most recently as a Star at 2018's Dancing with Our Stars event, where she won the coveted Mirror Ball Trophy due to her extraordinary fundraising and dedication to our mission.

“The Foundation was developed with the knowledge that at last there were doctors interested in neurofibromatosis and eager to work with us in promoting research into the cause, prevention, and cure of this devastating disease....We know that by sharing our ideas, hopes, and fears, those of us with the disease, and those close to us, will have a feeling of togetherness rather than isolation. The key is working together, and for that we need your support.”

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

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 Patricia Boughs  
 Julie Bouchard & Glenn Beyerman  
 Cheryl Boucher  
 Robert Bradford  
 Charlotte & David Bray  
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 Timothy & Sheila Drevyanko



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

Andrea Dukakis & John Hereford  
 Cynthia Duley  
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 James & Suzanne Earle  
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 Cristina Ferruggiari  
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 Walter Fitts  
 John & Beverly Fitzgibbons  
 Robert & Cynthia Fleming  
 Florescue Family Foundation



# With Thanks

## Fundraiser Highlight: The Fashion for NF Models



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

Florida Hospital Medical Center  
Daniel & Debra Fontaine  
Miles & Christine Forman  
Francis M. Fine Jewelry  
Joshua Freitas  
Mary Ann & Thomas Freye  
Julie & Jonathan Fritz  
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Grand Council of Cryptic Masons of the State of New York  
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Robert & Dana Greenwood  
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Harley & Rochelle Gross  
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Kiwanis Club of Midlothian - Chesterfield  
Michelle Kleger  
Wayne & Carol Knyal  
Michael Koegler  
Jamie Kohen  
George & Jutta Kohn  
Andrew Kokkino  
John & Jacqueline Konechne

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

— Allison Clarke, who founded Flashes of Hope along with her husband Kip. Their organization contributed more than \$600,000 to the Children's Tumor Foundation in 2018

Bruce & Michele Korf  
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 Michael & Linda Kowalik  
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 Laura A. Krietemeyer  
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**Fundraiser Highlight:** Leslie & Richard Kates



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

**Fundraiser Highlight:** Jeff & Diane Owens



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

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 Benjamin & Krista Maxwell  
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James Schmitz  
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Owen & Cecile Small  
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Alan & Vivian Smith  
Kimberly Snipes  
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Eric Sover  
John Spears  
Margaret Speciale  
Anthony Spinelli  
Mark & Lenore Spoonamore  
St. Dominic's Council  
Knights of Columbus  
Glenda Stachowiak  
Staten Island South Shore  
Grandmothers' Club  
#1028

## Fundraiser Highlight: run 4 robert



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

## Fundraiser Highlight: Mark & Hannah Ehrli

Esta Eiger Stecher  
Walter & Priscilla  
Steenbergen  
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Allison Stephens  
Claire Stephens  
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Leanne Story  
Stephen & Christine Stout  
John Striker & Eda  
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Miles and Dana  
Spencer  
Andrew & Bernice  
Suna  
Alan & Joanne Suna  
Debra & Ray  
Swafford  
Donald & Susan  
Swift  
Darby Swobe

## Fundraiser Highlight: Carol Harrison Kalagher



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



Left to right: MLB All Star and World Series Champion, Johnny Damon, Wireless Zone Executive Vice President, Dave Staszewski, Wireless Zone President, Brian Murtari, Hannah Ehrli, Joe Ehrli, Mark Ehrli

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

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Sheldon & Andi Taub  
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Jim and Mary Theobald  
Holden & Elsie Thompson  
Todd & Elisa Thompson

# With Thanks

## Fundraiser Highlight: Kristy Evans



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

Thrivent Financial  
Tom Tilaro  
Paul & Claudia Timko  
Stephen & Stephanie Timmons  
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Thomas & Lauren Tobin  
Collin Todd  
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University of Pennsylvania  
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Sean & Christine Yu  
Jarrod & Eun Yuster  
Zapa Energy, Inc.  
Zicherman Family Foundation  
Robert C. Zinnershine  
Brad & Lisa Zorfas  
Nancy Zuch

## Fundraiser Highlight: George Gaine



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



# 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.**



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

—Stuart Match Suna,  
CTF Board of Directors Member

# Ten Steps Forward in NF Research 2018

## 1 Synodos Continues to Deliver.

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

## 2

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

## 3

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

## 4

NF knows no boundaries, and as a result, **CTF went global**, launching its partner organization, Children's Tumor Foundation Europe. CTF has also been the NF lead with the European Innovative Medicines Initiative (IMI), and generated new relationships in China, so that all 2.5 million NF patients worldwide will benefit.

## 5

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

## 6

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

## 7

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

## 8

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

## 9

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

## 10

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

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*\*lists on this page as of July 2018*



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A FIGHTER.**

**CHILDREN'S  
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**ENDING NF  
THROUGH RESEARCH**