ANNUAL REPORT 2014

Forging the Path

CHILDREN'S TUMOR FOUNDATION

ENDING NF THROUGH RESEARCH

contents

WHAT IS NF?

Neurofibromatosis (NF) is a term for three distinct genetic disorders: NF1, NF2, and schwannomatosis. NF can cause tumors to grow on nerves throughout the body and can lead to blindness, deafness, bone abnormalities, learning disabilities, disabling pain, and cancer.

MISSION STATEMENT

The Children's Tumor Foundation (CTF) is a nonprofit 501(c)(3) medical foundation dedicated to improving the health and well-being of individuals and families affected by the neurofibromatoses (NF).

The mission of the Children's Tumor Foundation is to:

- Encourage and support research and the development of treatments and cures for neurofibromatosis types 1 and 2, schwannomatosis, and related disorders

- Support persons with NF, their families and caregivers by providing thorough, accurate, current, and readily accessible information

- Assist in the development of clinical centers, best practices, and other patient support mechanisms (not including direct medical care) to create better access to quality healthcare for affected individuals

- Expand public awareness of NF to promote earlier and more accurate diagnoses by the medical community, increase the non-affected population's understanding of the challenges facing people with NF, and encourage financial and other forms of support from public and private sources

"We invite everyone - from patients to researchers to doctors to pharma to volunteers - to participate in clearing the pathway to a cure."

—ANNETTE BAKKER, PRESIDENT AND CHIEF SCIENTIFIC OFFICER

dear friends,

One day, in the not-so-distant future, we will look back and say, "2014 was a defining year for neurofibromatosis. 2014 was HUGE." Indeed, 2014 was an incredible year for the Children's Tumor Foundation and for those who live with neurofibromatosis (NF).

Since its formation, the Children's Tumor Foundation has been crucial to the development of solid scientific data about NF. In fact, to date, over 70 percent of all NF data in the world is the result of work funded or co-funded by the Children's Tumor Foundation. We invested in young researchers, which was definitely fruitful; many of those researchers, still active with the Foundation, are now top NF investigators making groundbreaking discoveries. Through its careful investments over the years, the Foundation has made an extraordinary impact in the field of NF research.

We are now playing an even greater role in the drug research and development process. We identified barriers to a more rapid drug discovery process, then designed systems and processes to eradicate those blockades. In 2014, we continued to implement a strategic business plan that invites everyone—from patients to researchers to medical personnel to pharmaceutical companies to government to volunteers—to participate in clearing the pathway toward treatments and a cure. We know we can't sit idly by if we want answers.

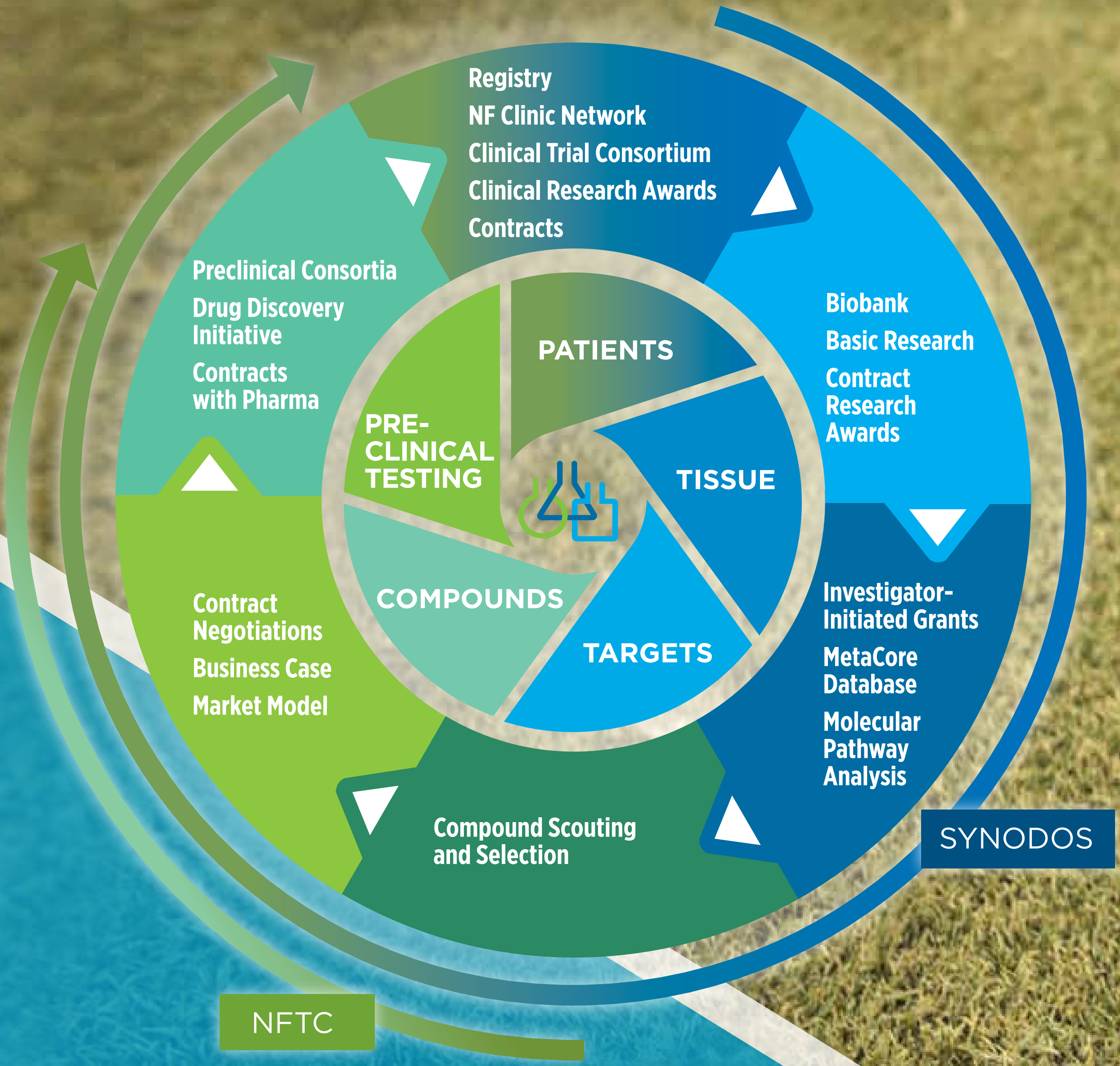
To our generous donors, thank you. The advancements you will read about in this report are possible because of the growing financial support the Foundation has received from you. You have entrusted us. And we promise the return on your investments will be incredible.

We know that whole-scale collaboration, data-sharing, and multidisciplinary consortia are the way forward. We know that a comprehensive, no-holds-barred approach is what it will take to end NF. Every dollar you have given has fueled this process; every cent you have invested is being used to tear down walls. Thanks to your incredible foresight and generosity, we are breaking through barriers and forging the pathway that will lead to a cure.

Let's END NF!

ANNETTE BAKKER, PhD
President and Chief Scientific Officer

REVOLUTIONIZING RESEARCH



Those who live with NF are central to all the work we do; the patient lies at the heart of our Foundation. The key to discovery literally exists inside the patient, who can provide researchers with tissue samples. These tissue samples allow us to identify the appropriate molecular targets for intervention. Once we know what those targets are, we can discover and develop appropriate compounds that will allow for therapeutic interventions. These therapeutic interventions move into preclinical testing and then, when they finally prove to be safe and effective, find their way back to patients.

Our comprehensive strategic business plan, announced in 2014 and outlined in the graphic above, is designed to speed the drug discovery process at all stages of the research and development process, so that we might more quickly bring meaningful results to those who need it most. The innovations we have put in place are intended to eliminate many widely acknowledged hindrances to timely drug discovery.

> “There is a lot of confidence and peace for us and our family knowing that the experts really are right here.”
>
> **—RENIE MOSS, PARENT AND WIFE OF FAMILY LIVING WITH NF**

FOSTERING COLLABORATION

The Children's Tumor Foundation firmly believes that solutions to NF will be found when researchers work together, not only with one another but also with experts in biotechnology and the pharmaceutical industry.

NF CONFERENCE

Founded in 1985, the NF Conference is the world's largest gathering of scientists and clinicians dedicated to advancing research and care for those living with NF1, NF2, and schwannomatosis. The annual Conference fosters cross-disciplinary interaction and collaboration with the hope of speeding the process between discovery and clinical benefit. In 2014, CTF invited even more stakeholders to the event, hosting a satellite session called "Innovative Business Opportunities in NF," which highlighted a growing interest from industry in NF and a strong incentive for companies to invest in this sector.

NEUROFIBROMATOSIS PRECLINICAL CONSORTIUM (NFPC)

In 2008, the Children's Tumor Foundation launched the Neurofibromatosis Preclinical Consortium (NFPC), a five-year $4 million program designed to identify and evaluate promising drug candidates for clinical trials through the collaborative efforts of the best academic scientists working on preclinical systems of various NF-associated tumors. At its conclusion in 2013, the NFPC included sites investigating animal models of plexiform neurofibromas, MPNSTs, NF1-associated leukemia, meningiomas, and vestibular schwannomas.

NEUROFIBROMATOSIS THERAPEUTIC CONSORTIUM (NFTC)

An evolution of the NFPC, the NFTC brings together four labs to find novel targets for clinical trials. The collaborative nature of the NFTC promotes efficiency and has advanced preclinical discovery beyond what could be achieved by labs working in isolation. To date, this consortium collaborated to perform and complete 37 preclinical trials across different models. These studies have identified 12 drug targets with promising efficacy. Thirteen clinical trials have occurred based on the rigorous preclinical data gathered by NFPC and NFTC members.

> “Synodos is one of the most audacious, beautiful experiments I have seen in a long time.”
>
> **—STEPHEN FRIEND, MD, PHD, PRESIDENT, CO-FOUNDER, AND DIRECTOR, SAGE BIONETWORKS**

SYNODOS

Dissatisfied with the traditional model of scientific research and encouraged by the success of the NFPC and the NFTC, the Children’s Tumor Foundation designed a prototype that emphasizes collaboration and cooperation among researchers rather than competition and data hoarding. In February 2014, the Foundation launched Synodos for NF2, a $3 million, multi-year initiative that has assembled a team of researchers from twelve world-class labs and medical centers. This comprehensive model brings together experts in basic, translational, and clinical research, all of whom have joined forces to share information and design strategies that will accelerate the drug discovery process for NF2. The Synodos model has already proven so successful in its first year that the Children’s Tumor Foundation has announced Synodos for NF1 for 2015, and an upcoming Synodos for Schwannomatosis.

> “We are moving palpably closer to treatments for all forms of NF, in large part as a result of bold and innovative new programs launched by the Children’s Tumor Foundation.”
>
> **—BRUCE KORF, MD, PHD, CHAIR, MEDICAL ADVISORY COMMITTEE**

THE YOUNG INVESTIGATOR AWARD (YIA)

The YIAs are open to pre- and postdoctoral scientists and physicians who are no more than seven years past receiving their degrees. The program encourages applications investigating novel ideas in basic research on all forms of NF and its complications. Not only does this program foster high-quality science and many discoveries, it also stimulates young scientists to pursue lifelong careers in NF research. Many of our senior researchers in NF were, in fact, recipients of our YIAs early in their careers.

DRUG DISCOVERY INITIATIVE AWARD (DDI)

The DDI award funds early stage research that, with relatively modest amounts of money, allows researchers to quickly screen high-risk/high-potential compounds in both *in vitro* and *in vivo* models. Researchers are encouraged to make their tools (candidate drugs, animal models, cell lines, etc.) publicly available for collaboration with other researchers.

CLINICAL RESEARCH AWARD (CRA)

The Clinical Research Award program supports early stage pilot clinical trials of candidate therapeutics or interventions for treatment of manifestations of NF1, NF2, and schwannomatosis. These small, open label (i.e., patients know they are receiving the drug) Phase 0 and Phase I trials are expected to generate data that will lead to further Phase II and Phase III trials of promising compounds. This grant mechanism also includes adjunct studies, such as the development of biomarkers, imaging protocols, and other clinical trial tools.

2014 CHILDREN'S TUMOR FOUNDATION AMBASSADOR

Bailey Gribben

At age 10, Bailey Gribben rather casually announced to his family that he couldn't hear out of one of his ears. Shortly thereafter, he was diagnosed with NF. While some people might understandably allow a diagnosis of a life-altering disorder to slow them down, Bailey responded with determined optimism: "I told my parents I did not want NF to stop me from following my dreams and I had to do everything possible to find a cure and stop NF from interrupting my life."

One year later, with three brain surgeries under his belt, Bailey and his family joined forces with the Children's Tumor Foundation through our Racing4Research program. He has been an unstoppable fundraiser and advocate for NF ever since, having raised over $80,000 for NF research. Bailey, now 17, has undergone a staggering 14 NF-related surgeries, but that has not stopped him from living life to its fullest. An honors student, he is the president of his school's National Honor Society, serves as a fundraising officer of the student council, and was elected to homecoming court during his senior year. His indomitable spirit shines through in everything that he does.

> "NF will never rob us of our spirit, of our passion to live and enjoy our lives...and it will never define who we are."
>
> **—BAILEY GRIBBEN**

NF FORUM

In 2009, the Children's Tumor Foundation hosted our first national patient and family meeting weekend, the NF Forum. Now held annually, the NF Forum allows those living with NF and their loved ones to attend a weekend of seminars, question-and-answer sessions with nationally renowned NF researchers, and social events designed to sustain a strong sense of hope within the NF community. In 2012, CTF began hosting the NF Forum adjacent to the NF Conference biennially, allowing for greater interaction between those living with NF, their families, and the dedicated professionals who are working tirelessly to end NF.

> "I came to learn about NF research and the strides made to find a cure. What I came away with was a sense of family – we are united to find a cure to end NF."
>
> **–KEN LINKOUS, PARENT OF A CHILD LIVING WITH NF**

NEUROFIBROMATOSIS CLINIC NETWORK (NFCN)

Established in 2007, the NFCN consists of 47 NF specialty clinics. Any multidisciplinary NF clinic in the U.S. may apply for membership. Clinics are invited to join based on factors including expertise in NF care, access to specialists, number of patients seen, commitment to educating colleagues and patients about the latest developments, and willingness to foster a relationship with local patient support groups.

NF CAMP

The NF Camp takes place over two weeks each summer at Camp Kostopulos in Emigration Canyon, Utah. Camp Kostopulos caters to individuals with special needs, providing numerous exciting and challenging recreational activities, including rope courses, rock climbing, horseback riding, swimming, fishing, canoeing, and frequent off-site day trips. NF Camp provides fellowship, friendship, and fun for youth living with NF. Many campers return year after year to reunite with old friends, make new ones, and create memories that will last a lifetime.

NF REGISTRY

In order to clear the pathway for those living with NF to become involved in clinical trials, the Foundation established the NF Registry in 2013. The Registry is a patient-centered, anonymized database that allows those living with NF to learn about clinical trials and initiatives connected to their particular manifestations of NF. The Registry, which also provides registrants with personalized, up-to-date information about their disorder, has grown to over 5,000 participants.

> “I’m grateful to the Children’s Tumor Foundation for bringing NF families together so that we can learn and help each other, and celebrate our NF Heroes!”
>
> **—SHANNON COULOMBE, MOTHER OF CALLIE, 3, WHO LIVES WITH NF**

From Main Street to Wall Street, the Children's Tumor Foundation is committed to cultivating the public's knowledge of NF.

In 2014, the Foundation maintained an active presence across social media (Twitter, Facebook, and Instagram), rang the opening bell at NASDAQ and the closing bell at the New York Stock Exchange, spoke at conferences, placed ads in shopping carts in over 4,000 grocery stores across the U.S. (thanks to the generosity of News America Marketing), and continued to publish the most up-to-date information from the NF world on our website, ctf.org, and in our quarterly newsletters.

Newspapers across the country published countless articles, and TV and radio stations broadcast segments featuring our NF Heroes, dedicated volunteers, and endurance athletes. Leading scientific and pharmaceutical publications *BioWorld, The Pink Sheet,* and *Genetic Engineering & Biotechnology News* highlighted the Foundation's innovative approach to scientific research and our willingness to form out-of-the-box partnerships with industry leaders and other nonprofit organizations. FasterCures and the Health Research Alliance also honored the Foundation's trailblazing work in their online publications.

The word is out and the message is clear: we are asking the world to join the mission to END NF.

The Stone Bridge in Johnstown, PA lights up blue and green in recognition of NF Awareness Month.

RAISING FUNDS

Whether sweating through an IRONMAN event, speeding through laps at the racetrack, joining a team of similarly-clad walkers for a community-building stroll in a park, or organizing a unique event close to home, our thousands of volunteers are essential. Cumulatively, this passionate and dedicated community has raised tens of millions of dollars to end NF.

Not only do these team members raise much-needed money to fund NF research, but they also expand the general public's awareness of neurofibromatosis with their energetic presence. Wherever events are held, our team members spread the word about this disorder, expanding the general population's understanding of the challenges facing people living with NF.

RACING4RESEARCH

Our Racing4Research program uses professional auto racing to increase awareness of neurofibromatosis and raise funds through corporate sponsorship, personal donations, and individual fundraising by our NF Heroes: people living with NF. Not only do many of our NF Heroes attend the Rolex 24 at Daytona, they also get to join our drivers in the pit, sit in the beautifully designed art cars, and truly feel like a part of the racing crew. Racing4Research has provided numerous NF Heroes with memories of a lifetime.

When it comes to ending NF, we're all on the same team.

NF ENDURANCE

Always ready for the ultimate challenge, our NF Endurance Team runs, bikes, and swims in events across the country and abroad. The Endurance Team is comprised of a broad spectrum of athletes, from those who are running in a 5K for the first time to experienced IRONMAN competitors.

NF WALK

Across the country, NF Walk brings together families, friends, and neighbors for fun-filled and inspirational events. From balloon animals to face painting to action heroes, our walks are bursting with energy from start to finish. Each event is as unique as the location where it is held.

COMMUNITY RELATIONS

Tea parties, sporting events, comedy nights, poker tournaments, and other one-of-a-kind fundraising events are supported by our Community Relations team. These events, held throughout the year, connect our nationwide team of volunteers with their immediate communities while raising funds for NF research.

Our team of dedicated and passionate volunteers advocate relentlessly for continual federal funding of NF research. While these federal grants do not directly benefit the Foundation, the recipients of the grants are doing research that is of great value to everyone in the NF community. And many of them received early funding of their work through the Foundation's YIA or DDI programs.

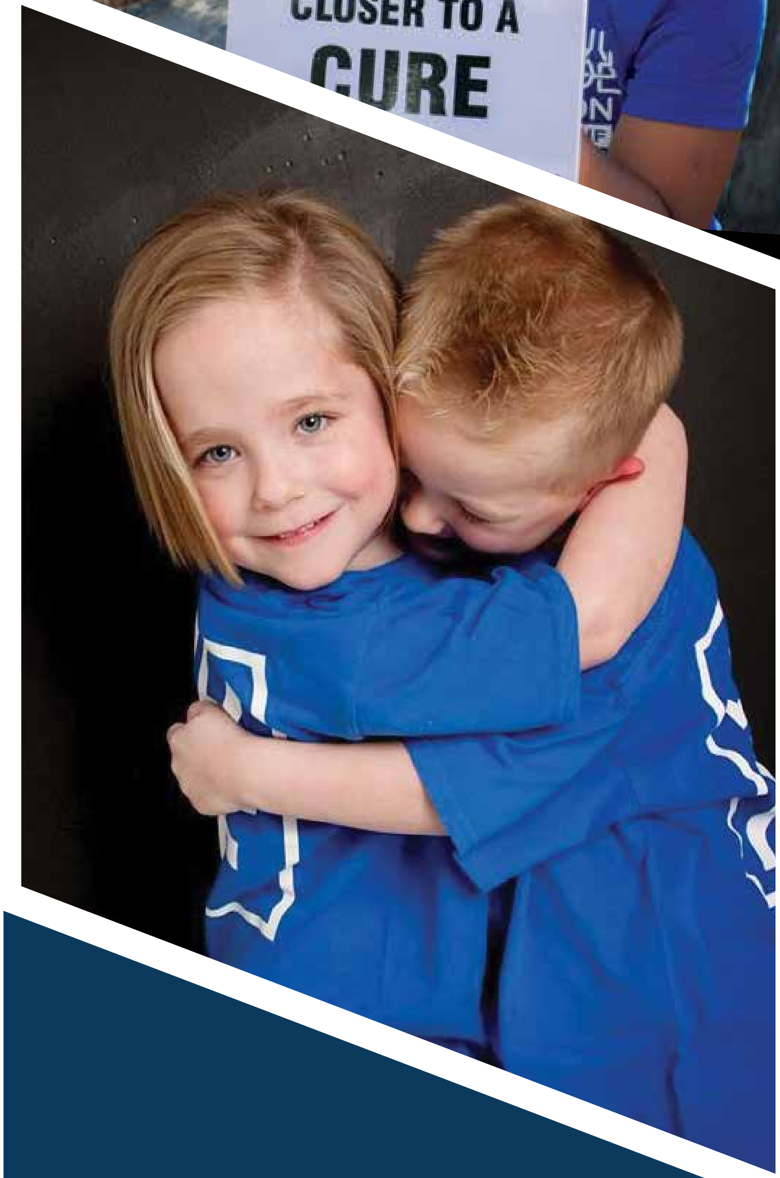
We first began actively lobbying for increased federal funding of NF research in the early 1990s. Through our efforts, Congress appropriated $8 million in 1996 to fund an individual program of the Congressionally Directed Medical Research Program (CDMRP) called the Neurofibromatosis Research Program (CDMRP-NFRP). Since that time, our advocates have secured over $270 million in federal funding for the CDMRP-NFRP. Over the last two years—a time of unprecedented furloughs and mandatory budget cuts—we secured $30 million.

Our advocacy efforts include social media, letter and email campaigns by our constituents, invitations to Foundation events, and personal visits with key congressional staff. In preparation for FY15, we devised an even more intense and personal approach. On June 5th, dozens of advocates—adults with NF and parents whose children live with NF—participated in a targeted one-day campaign, taking Capitol Hill by storm. Guided by our advocacy firm, Patton Boggs, and led by CTF employees, our teams conducted 34 meetings with members of the House of Representatives and the U.S. Senate, sharing their personal stories and highlighting the important work done by CTF—and the need for continued government funding of NF research.

> "We battle NF as a family, and join the Children's Tumor Foundation and all those who have neurofibromatosis in looking forward to the day that this disorder no longer exists."
>
> **—DESIREE TULL, LIVING WITH NF**
> **MOTHER OF BRAXTON, WHO IS ALSO LIVING WITH NF**

"I learned more than I could have ever imagined at the NF Forum, not to mention met a group of the wonderful, amazing, and courageous families affected by NF. My network is huge now."

—SAMANTHA CANANE, MOTHER



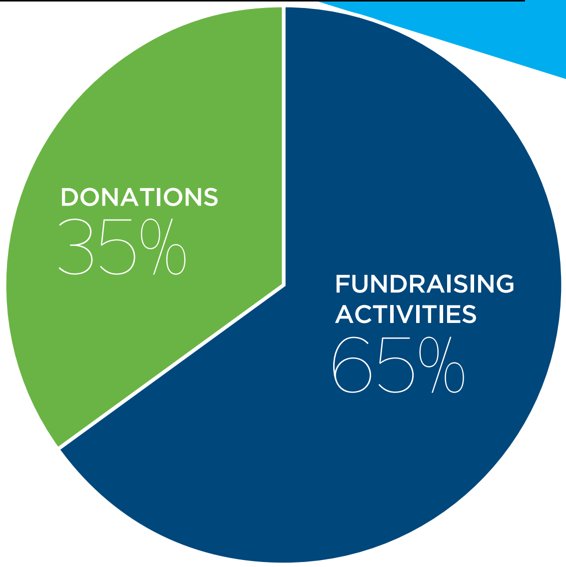
"What matters most? It's seeing the smiles on the faces of those families that I am doing this for. Giving them that hope and support that they are not alone in this fight."

—SILVIO A. MANZIANO, NF ENDURANCE ATHLETE

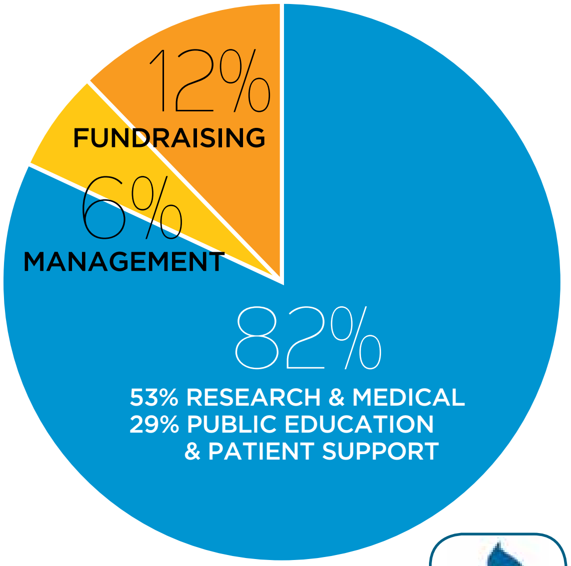
FINANCIAL SUMMARY

The Children's Tumor Foundation mission is clear - to fund the best research and programs that will lead to effective treatments for NF.

REVENUE 2014



EXPENSES 2014



OPERATING SUPPORT AND REVENUE

	2014	2013
Contributions – individuals	$8,394,155	$4,859,656
Contributions – corporations and foundations	$2,034,159	$1,187,633
Bequests	$108,398	$571,447
Contributed goods	$412,821	$205,922
Other income	$42,610	$229,554
CONTRIBUTIONS AND OTHER INCOME	**$10,992,143**	**$7,054,212**
Special event revenue	$5,121,565	$5,812,397
Less: direct benefits to donors	(385,917)	(325,326)
Special event revenue, net	**$4,735,648**	**$5,487,071**
TOTAL OPERATING & SUPPORT REVENUE	**$15,727,791**	**$12,541,283**

OPERATING EXPENSES

Program Services	**2014**	**2013**
Research and medical	$8,168,115	$6,357,258
Public education and patient support	$3,954,550	$3,489,791
TOTAL PROGRAM SERVICES	$12,122,665	$9,847,049
Supporting Services		
Management and general	$852,967	$739,138
Fundraising	$1,553,773	$1,436,451
TOTAL SUPPORT SERVICES	**$2,406,740**	**$2,175,589**
TOTAL OPERATING EXPENSES	**$14,529,405**	**$12,022,638**

CHANGE IN NET ASSETS FROM OPERATIONS	**$1,198,386**	**$518,645**

OTHER CHANGES

	2014	2013
NON-OPERATING REVENUE	$327,816	$646,463

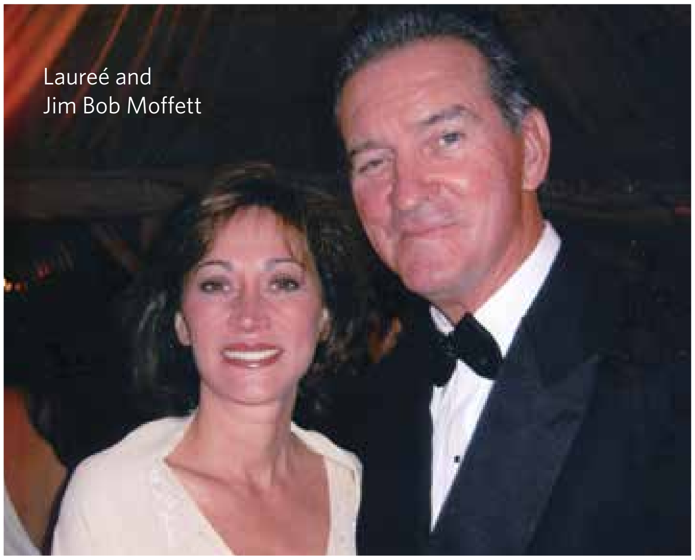
CHANGE IN NET ASSETS	**$1,526,203**	**$1,165,108**

	2014	2013
NET ASSETS, BEGINNING OF YEAR	**$8,822,320**	**$7,657,212**
NET ASSETS, END OF YEAR	**$10,348,522**	**$8,822,320**

With its repeat four-star rating from Charity Navigator, the Children's Tumor Foundation outperforms most other charities by adhering to good governance, best practices, and fiscal responsibility in the execution of its mission.

Synodos for NF1 Moffett Matching Fund

The Children's Tumor Foundation and the entire NF family thank Jim Bob and Laurée Moffett for their extraordinarily generous $2.5 million matching gift to fund Synodos for NF1. They believe that it is only through active giving and dedicated participation that together we can end NF. In that spirit, the Foundation also thanks all those who were inspired by this gift and have contributed to this fund, with their gifts matched dollar-for-dollar by the Moffett family.


Laureé and
Jim Bob Moffett

Robert Abatemarco
ABC Court Reporting, Inc.
Stuart Acker
Evelyn Acosta
Timothy Adams
Nancy Adams
Werner Adel
After Hours Printing Inc.
David Aho
Henry Albanese
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J. George Anderson
Stacey Anderson
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Heath Anderson
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Christine Bushaw
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Creative Smiles Dentistry
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Daniel Crouse
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Dean Gregory
Beth Grendahl
Linda Griffin
James Grisham
Robert Grossman, MD
Robert Grove
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Mary Jo Guidi
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Billy Gutierrez
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Susan Hall
Patrick Hall
Thomas Halton
Jack Hamilton
James Hancock
Sean Hannity
Kanoe Hardin
John Hardin
Yvette Hardy
Gregory Harvey
Robert Hash
Lynn Haslinger
Edward Heavey
Katie Henry
G.W. Henssler & Associates
Alma Hentz
John Heropoulos
Maurice Herz
Sierra Hewitt
James Higgins
Darrell Hill
Rashelle Hindman

> “Synodos is logical, it’s simple, and I believe in it. ” **—JIM BOB MOFFETT**

Alison Hobden
Christopher Hogan
Richard Horvitz
Edward Huether
Huntington Indoor Tennis
Maureen Hussey
Glenn Hutner
Lisa Israel
Frank Jachetta
Steven Jannace
Matt Jelavic
Zlata Jelavic
Mary Ann Jennings
Deborah Jensen
Holly Jimenez
William Johnson
Rosemary Johnson
Stephen Jones
Todd Jones
Patrick Jordan
Jerry Jusek
Kaffe 2 Inc.
Lisa Kagan
Geoffrey Kaiser
Douglas Kalbacher
James Kalenderian
Kansas City Southern Matching Gifts Fund
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Judith Kaplan
Liza Kappukattil
Geri Katsoulakis
Andrew Katz
Melanie Keister
Mary Keitel
George Kelly
Pamela Kelly
Michael Kelly
Mangharam Khushalani
Timothy Kiefel
Michael Kiger
Kiwanis Club of Southampton
Manfred Klatt
Mel Kleinman
Joyce Klett
Stanley Klimberg
Elizabeth Knight
Steven Kobren
Bo Kopynec
Keith Kowalsky
Craig Kral
Michael Kramer
William Krapf
Marilyn Krause
Ann Krietemeyer
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Laura Krietemeyer
Margery Krohn
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Carolyn Kulog
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Allan Lauber
Louis Laurino
Jane LeBlanc
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Teresa Leotta
Vincenza Leotta
CJ Lett
Jane Chiang Lin
Mike Lind
Frances Linsangan
Margot Lippe
Louis Locaso
James Lodato
Jeffrey Lohrbach
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Christopher Lopez
Mark Loree
Susan Lozano
Zhihao Lu
Peter A. Lucchese, DDS
Emily Luck
Ronald Luft
Larry Lunder
Charles Lutz
Lynch School of Ballet
Maria Lyons-Pellechia
Lake Lytal
M&J Plaza Realty Corp.
Ronald Machoian
Wayne Maibaum
Madeleine Maier
Michael Maloney
Christine Manolis
Cynthia Maple
Rosemarie Marciano
Frank Marinello
Marsal Family Foundation
John Martinkat
Donna Martone
Matthew Matera
Donald Matera
William Matteson
Christina Mazzella
Justin McArthu
Scott McAuley
Bryan McCready
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Carol Morris
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Sherri Morris
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with thanks

Furthering the mission of the Children's Tumor Foundation depends on the continued support of individuals, corporations, foundations, and communities that have joined the NF fight. To all those who have helped to advance the Foundation's mission in the past, and especially to those who did so in 2014, we express our deepest gratitude.

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Jim Bob & Laurée Moffett

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$250,000 TO $499,999

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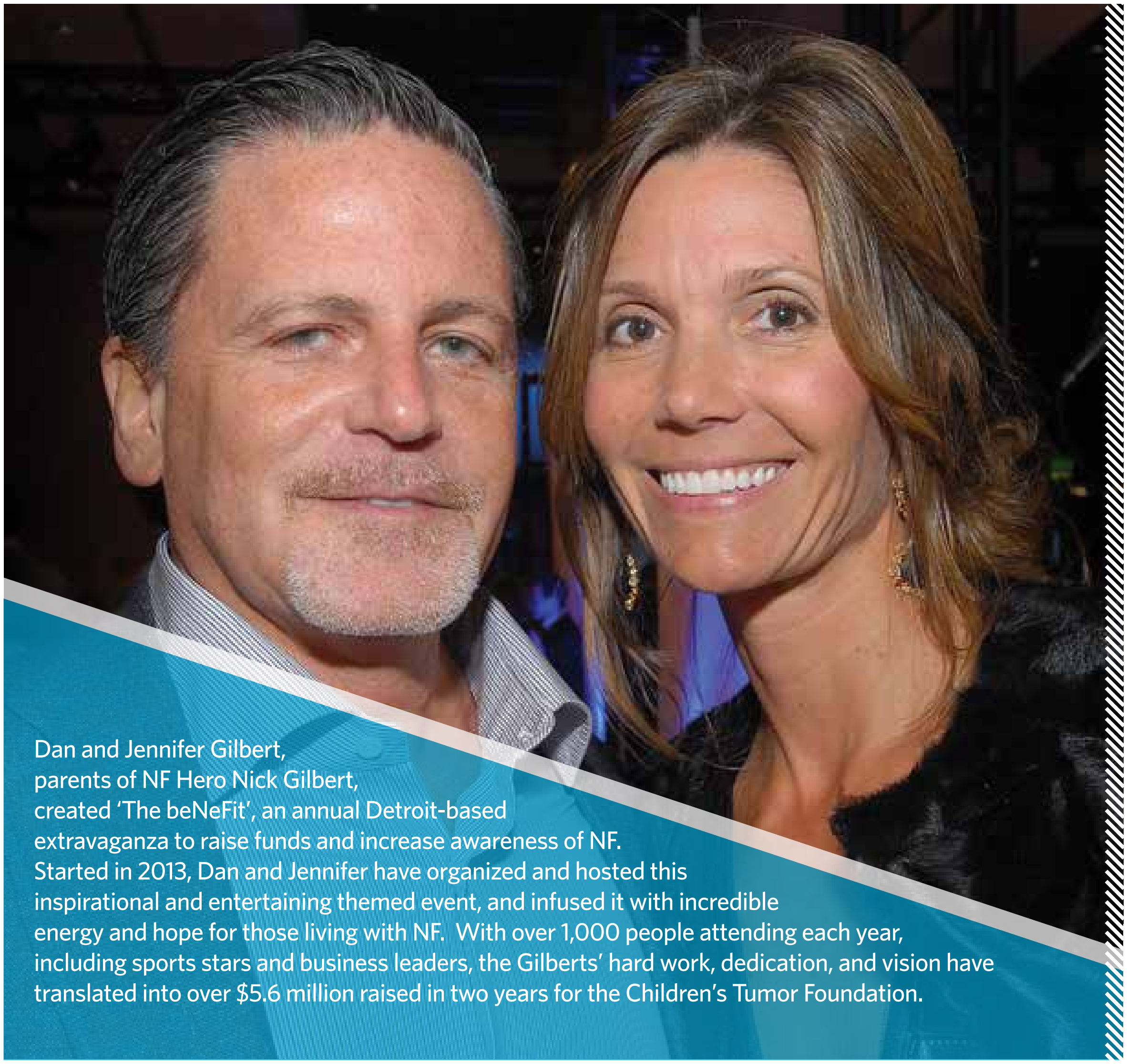

Dan and Jennifer Gilbert, parents of NF Hero Nick Gilbert, created 'The beNeFit', an annual Detroit-based extravaganza to raise funds and increase awareness of NF. Started in 2013, Dan and Jennifer have organized and hosted this inspirational and entertaining themed event, and infused it with incredible energy and hope for those living with NF. With over 1,000 people attending each year, including sports stars and business leaders, the Gilberts' hard work, dedication, and vision have translated into over $5.6 million raised in two years for the Children's Tumor Foundation.

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