



# Letter from the President **Revolutionizing Research** 6 Fostering Collaboration **Promoting Innovation** 10 Sustaining Hope 12 Raising Awareness 14 Raising Funds 16 Advocacy 17 NF Ambassador 18 Financial Summary 20 Donors ON THE COVER This picture of Lucy, our outgoing five-year-old, was taken at the 2016 NF Walk in Washington, DC. It was a rainy day, so she wore one of our extra adult T-shirts to keep warm. Lucy was diagnosed with NF1 when she was six months old through a blood test after we noticed many café au lait spots. Lucy doesn't let her diagnosis stop her. Despite many doctor appointments, she knows how to enjoy life! After her diagnosis we felt completely helpless, so we scoured the internet looking for a way to unite with other NF families and to help fund research, which led us to the Children's Tumor Foundation. Since finding CTF, our family has attended three NF Forums and helped plan two local NF Walks. We are grateful for the connections we have made and are proud to be part of the CTF family! — Lisa, Lucy's mom ANNUAL REPORT 2016 | 1

# 66 Patients are at the heart of everything we do. 99

- Annette Bakker, PhD, President and Chief Scientific Officer



# Dear friends,

t the Children's Tumor Foundation—from the early days of the NF Preclinical Consortium, to our current Synodos Consortia focused on NF1, NF2, and schwannomatosis—collaboration has been our guiding principle. Clinicians, scientists, patients, family members, caregivers, volunteers, donors, fundraisers, industry members, and advocates work together to fulfill our vision: Ending NF.

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

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

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

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

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

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

Annette Bakker, PhD, President and Chief Scientific Officer

# Revolutionizing RESEARCH



## Strategic Plan

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



ith CTF's mission to "drive research, expand knowledge, and advance care for the NF community" firmly in mind, a number of important strategies for the future were defined.

#### The Children's Tumor Foundation Is Uniquely Suited To:

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

#### **Neurofibromatosis Research Needs Include:**

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

#### **Children's Tumor Foundation Funding Priorities:**

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

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

# Fostering COLLABORATION

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

#### **Synodos**

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

#### Synodos for NF2

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

#### **Synodos for NF1**

When establishing Synodos for NF1, which kicked off in the spring of 2016, CTF responded to what concerns NF1 patients most—better treatment options for NF1, as well as answers for low grade glioma patients, who have previously only been told to "watch and wait." Synodos for NF1 is made up of three separate consortia that bring together 24 investigators from eight leading institutions and two companies. Two teams form the Preclinical Acceleration component, and each will focus on the development of swine models that will closely resemble a human's response to a potential treatment, providing better development of clinical trials in humans. The third Synodos for NF1 team is working to develop treatments for low grade glioma, the most common childhood brain tumor affecting children with NF1.

#### **Synodos for Schwannomatosis**

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

**Process: The Neurofibromatosis Therapeutic** Consortium (NFTC) This successful research collaborative project brought together four labs to find novel targets for clinical trials. The three-year, \$4 million collaboration was co-funded with NTAP (Neurofibromatosis Therapeutic Acceleration Program) and was an extension of the Neurofibromatosis Preclinical Consortium (NFPC), a fiveyear, \$7 million program that concluded in 2013.

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



### **Progress: MEK Inhibitor Clinical Trial**

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

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

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

66 The first picture was taken in June of 2015, two months after Philip was discontinued from [the drug] Gleevec after eight months of tumor growth. We were sent home with no other option. When I asked his oncologist about other chemotherapies, she shook her head, took my hand and said, 'We are not going to treat your son like a pin cushion.' We walked out of her office with no hope, facing an uncertain future. The second picture is from September 2016, after a year on selumetinib (AZD6244). MIRACLE! You all are our miracle workers. 99

**Renie Moss,** mom to Philip, who lives with NF

## Promoting **INNOVATION**

Progress is being made in NF research that furthers the understanding of neurofibromatosis, leading the way to better diagnostic criteria, earlier diagnosis, and improved clinical care.

## TO UNDERSTAND

#### The Young Investigator Award (YIA)

The YIA is the Foundation's oldest research award program and serves to advance understanding of the biology of NF1, NF2, and schwannomatosis. The Children's Tumor Foundation is pleased to have funded four Young Investigator Awards (YIA) for 2016, including one pre-doctoral student and three postdoctoral fellows who are doing basic NF research. These young scientists will be funded through this award for two years. Many of the Foundation's past YIA awardees have gone on to pursue lifelong careers in the field of NF research, and have furthered the basic understanding of NF biology.

TO TEST THE CONCEPT

**Drug Discovery Initiative Award** 

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

66 My hope is that the work I am doing now will lay the foundation for new therapies for NF patients and grant us greater insights into NF. I consider it an honor to be dedicating my efforts to better the lives of others, and especially to a group of individuals who have demonstrated that they can overcome any obstacle that life presents to them 99

Stephanie J. Bouley, 2016 Young Investigator Award Recipient

## TO BRING TO PATIENTS

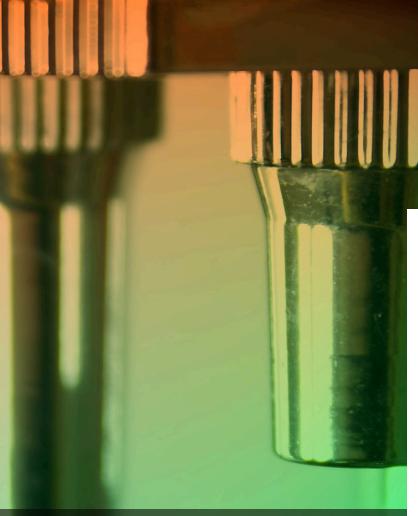
#### **Clinical Research Award (CRA)**

The Foundation's Clinical Research Award program supports early-stage NF research involving human subjects. These awards encourage studies of candidate therapeutics or other interventions for the treatment of NF1, NF2, or schwannomatosis; clinical-trial-enabling or ancillary studies; natural history studies; and investigations into clinical care in NF. In 2016, two CRAs were awarded: one for a phase two trial on bone mass in adults with NF1, and one to survey cognitive outcome tools in NF1.

## TO PROVIDE THE TISSUE TO STUDY

#### **Biobank: Body and Tissue Donation Program**

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



### **Progress: OPG Multicenter Study**

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

OPG develops in 15 to 20% of children with NF1. Although rarely life-threatening, these tumors can cause significant health issues, including vision loss, disfiguring bulging of the eye, and early puberty. A nagging question in the NF research community has been when or whether to treat OPG. Chemotherapy is the only treatment, so it is vital to know when this is necessary or when it can be safely avoided.

#### **NF Conference**

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



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

**Texas Governor Greg Abbott,** to the attendees of the NF Forum and NF Conference Joint Dinner

## Sustaining **HOPE**

66 By attending the different breakout sessions, I learned a great deal of information about the research that is being conducted that not only benefits children with NF, but adults as well. I loved meeting the other NF adults that are active with CTF and the different fundraisers. But the best part of the Forum is the hope it gave me for the future, and hope for the end of NF. 99

Tera Millecker-Willhelm, adult living with NF



The Children's Tumor Foundation NF Forum is a national patient education and family gathering, hosted in different cities across the United States. The NF Forum originated out of a desire to bring NF patients, families, caregivers, and friends together in an inviting atmosphere of education and fellowship. In 2016, nearly 300 people gathered in Austin, Texas to be inspired, to learn, and to unite as one large NF family.

### **NF Registry**

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



### **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 2016, the NF Clinic Network grew to 50 clinics that serve approximately 10,000 patients. Clinics are invited to join the NFCN based on many factors, including expertise in NF care, access to specialists, number of patients seen, and commitment to educating colleagues and patients about the latest



### The Volunteer Leadership Training Conference

The Volunteer Leadership Training Conference took place in June 2016 in Austin, Texas, just before the NF Forum. The gathering provides an opportunity for our active volunteers to learn how to grow their events, become more effective fundraisers, connect with each other, and learn more about the many programs the Foundation offers.

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



#### **NF Camp**

opportunity for teens and young adults ages 12 to 22 to meet others who are living with NF1, NF2, or schwannomatosis. Upon arrival at NF Camp, a new world opens. Often for the first time, campers can talk freely about NF, share their experiences, and make lasting friendships. NF Camp is a chance for young people to get away from it all, have fun, and enjoy Canyon, Utah on 25 beautiful acres in the canyons outside Salt Lake City.

66 I love NF Camp because, in this huge world that we live in, I don't feel so alone or different from the rest. 99

Hunter Jackson, Camper

# Raising **AWARENESS**

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

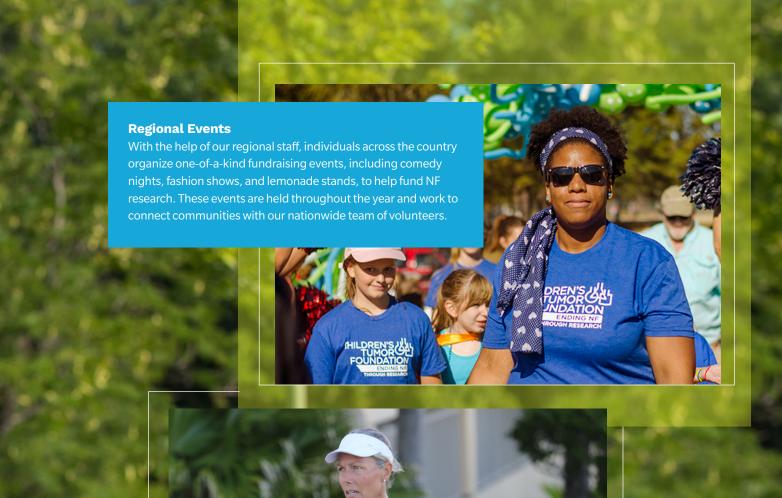
Peace Bridge in **Buffalo, New York** lights up blue and green for NF Awareness Month.

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

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







348

## **NF Endurance**



**Cancer Moonshot** 

Department of Defense.

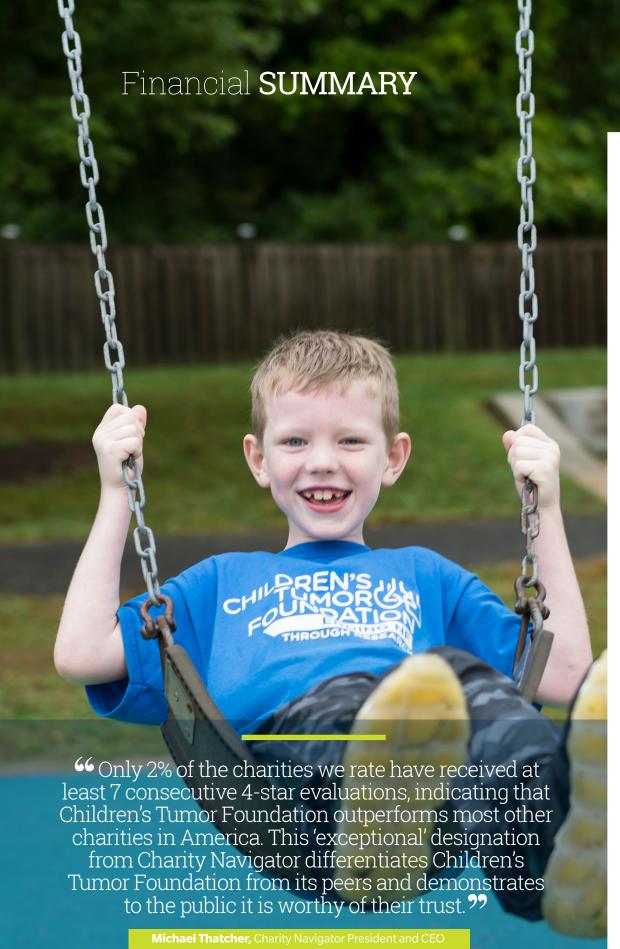
At the invitation of former Vice President Joseph Biden, Children's Tumor Foundation President and Chief Scientific Officer Annette Bakker, PhD, attended the Cancer Moonshot Summit in Washington, DC. This meeting of esteemed scientific leaders was dedicated to shortening the length of time it takes to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

Directed Medical Research Programs ("CDMRP") within the

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







REVENUE 2016

65% Fundraising Activities

EXPENSES 2016

F

80%

48% Research & Med 32% Public Education Patient Suppo





35% Donations

3 <sup>0</sup>	%	ing		
M	7	O	) me	n
ica	ıl			

	2016	2015	201
Contributions – individuals	\$2,839,870	\$4,476,610	\$8,394,15
Contributions – corporations and foundations	\$3,204,939	\$3,499,807	\$2,034,15
Bequests	\$102,522	\$508	\$108,39
Contributed goods	\$ 763,721	\$772,851	\$412,82
Other income	\$41,162	\$56,252	\$42,61
CONTRIBUTIONS AND OTHER INCOME	\$6,952,214	\$8,806,028	\$10,992,14
	2016	2015	201
Special event revenue	\$ 8,598,565	\$6,640,698	\$5,121,56
Less: direct benefits to donors	(450,809)	(405,301)	(385,91
Special event revenue, net	\$8,147,756	\$6,235,397	\$4,735,64
TOTAL OPERATING & SUPPORT REVENUE	\$15,099,970	\$15,041,425	\$15,727,79

Operating expenses	_		
Program Services	2016	2015	2014
Research and medical	\$7,267,779	\$7,935,871	\$8,168,115
Public education and patient support	\$4,667,514	\$4,417,617	\$3,954,550
TOTAL PROGRAM SERVICES	\$11,935,293	\$12,353,488	\$12,122,655
Support Services			
Management and general	\$1,039,689	\$978,477	\$852,967
Fundraising	\$1,862,625	\$1,692,756	\$1,553,773
TOTAL SUPPORT SERVICES	\$2,902,314	\$2,671,233	\$2,406,740
TOTAL OPERATING EXPENSES	\$14,837,607	\$15,024,721	\$14,529,405

Change in Net Assets from Operations	\$262,363	\$16,704	\$1,198,386
			1
Other changes	2016	2015	2014
other ondinges	2010	2013	2014
NON-OPERATING REVENUE	\$304,524	\$73,229	\$327,816
Change in Net Assets	\$566,887	\$89,933	\$1,526,203
		l l	
	2016	2015	2014
Net Assets, beginning of year	\$10,438,455	\$10,348,522	\$8,822,320
Net Assets, end of year	\$11,005,342	\$10,438,455	\$10,348,522

# 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.

#### **CHAMPIONS \$1,000,000+**

Cupid Charities, Inc. Gilbert Family Foundation Richard Horvitz and Erica Hartman-Horvitz Foundation

#### STEWARDS \$500,000+

Flashes of Hope/Kick It

#### PARTNERS \$100,000+

Richard Chyette William & Marlene Emerson Falic Family Foundation Inc. Nathan & Catherine Forbes Sally Gottesman Robert & Andrea Kramer William & Marcella Lerner Jeffrey & Francine Silesky

#### **PATRONS \$50,000+**

Estate of Eleanor Lee Barnes David & Michelle Carroll Chaparral Foundation Matthew & Karen Cullen Jay & Wendi Farner Bernard F. and Alva B. Gimbel Foundation James and Nancy Grosfeld

Foundation **Estate of Therese Howard**  Shawn M. Krause Todd Lunsford Richard & Rachel Mandell James & Laurée Moffett Stephen L. Piazza **RBC** Foundation USA Saks Fifth Avenue The Schechter and

Zimmerman Families of Schechter Wealth

Spiegel Family Foundation Stuart Match Suna The Colin Courageous Foundation, Inc. The Cupid Foundation, Inc. The Kettering Family Foundation

The Paul E. Singer Foundation Robert D. Walters, Jr.

#### **BENEFACTORS \$25,000+**

Marcia & Eugene Applebaum Family Foundation **Assurant Foundation** ATI Wireless Zone Foundation Irving Berlin Charitable Fund, Inc. Camuto Group Ellen & Stephen Carpenter Jeffrey & Marlene Cohen Jason Colodne Credit Suisse Securities Dorn Homes Inc. DTE Energy Foundation Mark & Julie Dunkeson Jeffrey & Wendy Eisenshtadt Enterprise Management Group, LLC G-III Apparel Group, Ltd. Geoff & Sherry Galloway Gary & Charlotte Gilbert Estate of Brandon Gotch Jodi & Lindsay Gross David Hake Linglong He & Charles Chen Brian & Jennifer Hermelin Linden & Michelle Nelson Honigman Miller Schwartz and Cohn LLP JP Morgan Chase Nancy Katzman & Randy Wertheimer Lockton Dunning Benefits Rvan & Heather Lovier Kevin & Elizabeth McMeen Peerless Clothing International Michael & Kelly Peterson Kevin Plank Quicken Loans Winthrop & Natalie

Rockville Center St. Patrick's Parade Inc. Don & Joni Rousseau Robert & Wendy Schaffer Dennis & Patricia Spencer Mark & Leora Tapper The Derfner Foundation **Roland Thoms** Turner Motorsport Corey Welch & Christina Coffman

#### SPONSORS \$10,000+

9th Floor Foundation Inc. Adrianna Papell Group Aerotek Allen & Company LLC All-Tech Inc. Duane Andrews Nick Apone William Baader David Barry Jeff & Julie Bass Belfor USA Group Inc. Belkin Burden Wenig & Goldman, LLP Hadas & Dennis Bernard Stephen & Mary Birch Foundation, Inc. Black Knight Financial Services Blue Team Restoration Robert Brainin & Nicola Kean Brainin Brown Foundation Tricia Brown-Fowler Timothy Bryan Colin & Sarah Bryar Thomas & Katherine Burrell Marisa Calderon Cantor Fitzgerald Relief Fund **Chrysler Foundation** Citizens Commercial Banking

Kip & Allison Clarke Clear Capital Seth & Talia Cohen Colasanti Construction Services, Inc. Robert & Meredith Colburn CoreLogic Solutions, LLC Crain Communications Inc. Darakjian Jewelers Benjamin Davey Nancy M. Davies Timothy Birkmeier & Malyka Degoa Ian & Chelsey Desmond

Donald & Eileen Baltzer Frederick & Diana Elghanayan **Equifax Foundation** Rick Estabrook & Deborah Healey Falcon Investment Advisors, LLC Fifth Third Bank - Eastern Michigan John & Marcy Fikany Firstronic, LLC Fisher Brothers Foundation Sidney & Madeline Forbes Franklin Theatre, LLC

Gable, A Visual Solutions Company Gallagher Family Foundation **GE** Foundation Shirley Gilbert Jay & Maria McCann Ghazal Adam Gittlin John G. Golfinos, MD Goodwin Procter LLP Scott & Robin Gottlieb Stephen & Myrna Greenberg Greenberg Traurig, LLP David & Meredith Griffin

David & Terri Friedman



Rockefeller

Ken Gross Nicholas & Kristin Guehlstorf William & Jenifer Hansson Cynthia Henebry & Andrew Schoeneman Heritage Optical Center Inc. Frank Hickingbotham Hudson's Bay Company Ilitch Holdings, Inc. Image One Corporation **Emily Johnson** Jones Day Andrew & Frances Kallman Jovce Keller & Michael Walch Kenwal Steel Corporation Milla & Jonathan Kest James & Sherri Ketai KMR LLP Kohl's Department Stores Leonard & Denise Komoroski LaBelle Electric Lamar Companies Alan & Linda Landis Jeffrey & Randi Levine Reuben Levy Ian Lopatin LowerMyBills.com Howard & Nancy Luckoff Tyronn Lue Macquarie Group Foundation Magnus Racing Richard and Jane Manoogian Foundation Peter & Jacquelyn McKenna Steven & Alyson McKenzie McMullen Family Foundation MeridianRx Paula Milgrom Stephen & Eve Milstein Jeffrey & Julie Morganroth Movado Group, Inc. National Basketball Association Kendall Newman Nomadic Expeditions, Inc. Lesley & Constantine Oslica John & Diane Owens Michael & Brooke Pachuta

Park Place Motorsports

Picket Realty Construction

**RAM Construction Services** 

Mitchell & Elizabeth Rodbell

Albert & Audrey Ratner

Jeff & Stephanie Perry

Consultants, LLC

Plante Moran

Matthew Rizik

ROSSETTI Co.

Jean Rothschild

**Bruce Schwartz** 

Priscilla Saunders

Raina Seitel Janet H. Shaver Aaron & Melissa Shepherd Win Sheridan Gary & Lisa Shiffman **SHoP Architects** Signet Jewelers Silvercup Studios Associates Somerset Collection Charitable Foundation Stempel Bennett Claman & Hochberg, P.C. Studio City Chamber of Commerce Foundation Suburban Motors Company, Inc. David & Rasheena Taub Robert & Julie Taubman The Collingwood Group, LLC The Gordon and Llura Gund Foundation The NF Team Foundation Rachel Tiven Robert & Felicia Tokarczyk Vess Family Foundation VF Sportswear, Inc. Juanita Victor Vidda Foundation Angelo & Colleen Vitale VMware Inc. Nate Walker Gertrude and William C. Wardlaw Fund Leslie Watts Wells Fargo Foundation Agnes N. Williams Zekelman Industries Zisson Foundation

#### FRIENDS \$1,000+

307 Dance Academy A G Foundation A Plus Pharmacy Inc. A. Eicoff & Company A. Pompo Electric, Inc. Jess Abell Michael Abrams Arshad Abdul Stuart & Debbie Acker Stephen Ackermann Acopia Home Loans ACT, Inc. Active Network Inc. Timothy Adams Brian Adelman **Aegion Corporation** Maria Dolores Aguirre David & Tara Aho Air Tech Cooling, Inc. Todd Albery

Allstate Foundation **ALP Signs Corporation** Alpha Delta Pi, Epsilon Delta Chapter Daniel & Robin Altman Amazon.com, Inc. American Asphalt - Repair & Resurfacing Co., Inc. American Express Foundation American International **Relocation Solutions ANC Sports** Andy & Judy Anderson Benjamin Anderson & Christine Casey Heath Anderson Martin Andersen-Gracia Andersen Foundation, Inc. Andrew & Katie Androff Nicole Antakli Lisa & Anthony Arena Arkansas Children's Hospital **Timothy Armstrong** Gregg Arnel Arrow Office Supply Arroya Vista Elementary Arthur's Prime Steakhouse Ascion, LLC Ashland Specialty Ingredients G.P. Rick Ashley Ashley Square Properties, HC Jason & Jennifer Auerbach Phil Austern Automatic Data Processing, Inc. Mercedes Avelar & Chris Rowland Amy Avitable Robert Baader Bacco Ristorante Matthew Bache Todd Bailey Christine & John Bakalar Michelle Bakken Hunter Bale **Bally Gaming** Adrienne Bank Florence Bank Bank of America Foundation, Inc. Bank of the Ozarks Ryan Bantz

David Alcaras

Jean Alfred

Service

Tyler & Crystal Alderdice

All Three Sedans & Taxi

Brock & Ginny Aller

Alliance Sign Up

R. Michael & Linda Alexander



## Dan & Jennifer Gilbert

On Saturday, November 19, 2016, Dan and Jennifer Gilbert hosted the beNeFit IV, "An Aquatic Affair to End NF" in downtown Detroit, where more than 1,700 guests helped raise \$5.1 million for NF research. Dan and Jennifer are parents to NF Hero Nick Gilbert, and they created "The beNeFit" in 2013 as an inspirational annual extravaganza to raise funds and increase awareness of NF. The Gilberts' hard work, dedication, and vision have translated into nearly \$17 million raised in four years for the Children's Tumor Foundation. Thank you, Dan and Jennifer for your unending support!

The Barasch Family Hubert & Diane Barksdale Chad & Nikki Barnhill Mary & Anthony Barra Roberta Barrett Tim & Sarah Barry David Barry & Anna Sewart Susan & Greg Bartelt **Barton Malow** Kenan Basha Angela Vallot & James Basker **Clifford Bates** John and Nellie Bastien Memorial Foundation Baugh Foundation, Inc. Bruce & Marlene Baumann Craig & Suzanne Baumann Michael & Susan Beal James & Karen Bearns Brent Beaulieu

William & Janet Beaulieu Beaumont Health **Beck Family Foundation** Carsten Becker Michael & Shaun Beckish Kris & Carrie Beeman Brian & Kelly Behrens Bell Bank Conor & Ariane Bell Dan & Dorothy Bell John Bell James & Carolyn Bellinson Ben E. Keith Co. Benchmark Steven & Kathy Benner Ed & Connie Bennett Steve & Bonnie Bentlev Eytan Benyamin & Michal Shulman Tom & Jenny Berman Beta Sigma Phi

# WITH THANKS-

Derek Bilcik & Lynn Rooney Bilcik Birch Run Capital Cheryl Bittel Allan & Ellie Bittker Joaney Black Thomas & Ginger Blackmon Jennifer Blaha David Bland & Susan Lesh Randall & Michelle Blau Suzanne Jaffee Bloom Catherine Blowe Blue & You Foundation Bluewater Movements, Inc. Harold & Penny B. Blumenstein Foundation Kamen Boev Thomas & Laura Bona Nelson & Carolyn Bonheim Jonathan & Shari Boos Kenneth & Julie Booth Regan Borg **Boyd Beauty** Keith & Erika Braccialini William & Lucy Bracer Kenneth Bradley Kelly Brady Jonathan & Katie Braue Harry Braunstein Michael Breslin **Bright Funds Foundation** Molly Brinkmeyer Bristol-Myers Squibb Foundation **Broder Family Foundation** Susan & Burton Brodsky Mindy Brooks Brooks & Jennifer Brown Esther R. Brown Joel & Andrea Brown Kristopher Brown Laurence Brown William Brown Cathy Browne Glen Brummer Mike Bruggeman Jessica Bryant Charlie Bucket Fund of Triangle Community Foundation Charlie Buckley **Bucks County Service Industry** Charities Bernie & Mary Beth Buescher John & Gina Buffa Buffalo Wild Wings Bullseye Guns and Ammo Richard & Gayle Burstein Ann Bussel and Morris & Anita Broad Bryce Buttmore Paul & Myriam Byrne Caesars Las Vegas

David & Judi Cain Jessica Caizza James Calderone David Caldwell Lacey Caldwell The Callaghan Family Jarrod & Samantha Canane Krista & Steve Capp Ron Capp Matthew Cardwell Carl Sterr Brandon Carmichael Carolina Hurricanes Stephen & Ellen Carpenter Carpenter Appliance Installs Inc. Mike Carr John Carter Sean Carter John Caruso Sean Casey Daniel & Carolyn Chasman Lyle & Jen Casriel Louis N. Cassett Foundation Lou Cassone Ant Cauchi Cavaliers Operating Company, LLC CB&I Inc. Center for Yoga Henry Chace Madeline Chadwick Hong Chae Champion Garage Management Corp Champlain Investment Partners, LLC **Charter Communications** Scott & Robin Chasse ChemTreat, Inc.

Mitchell Cherne Mark & Sharon Chertok Gregory Chew Children's National Medical Chipotle Mexican Grill CHM Warnick, LLC Cody Christensen William and M.L. Christovich Charitable Foundation, Inc. Christopher's Seafood and Prime Steak House Linda Clark Robert Clarke David Clay Christopher & Morgan Clayton Holly Click Jody Clyde Coastal Helicopters, Inc. **Christopher Coates** CoBank Cobo Center/SMG COG Trike-a-thon Ellen Cohen Jacob & Erin Cohen Daryl & Sheila Cohoon Coleman Chambers Rogers & Williams, LLP Dr. David Colleran Ionathan Collier Colliers International NY LLC William Collins Eric & Mia Colodne Colten Cowell Foundation Brigham G. Colton Come Together Foundation Cone Health Foundation

Kathy Cong David & Wendy Conn Continuum Services. LLC Michele Cook James Cooper Peter & Julie Cooper Cord Contracting Co., Inc. Core Physical Therapy and Sports Medicine PC Corner Bakery Cafe Dan & Nicole Cornwell Robert Schneider & Laura Coruzzi Michael Coughlan Jamie Craig CRC Insurance Services, Inc. Crew & Associates Tom Cronin Kecia Crosley Crowley Animal Clinic, Inc. Tina Cruz

CurtCo Robb Media Greg & Katherine Dahlberg Steve Daigle Daily News Michelle & David Damanskas Fred Damianos Tim & Debra Dansby David Foundation, Inc. Deidre Davis Patrick Davish DC Ranch Charlotte De La Fuente Gary Debode DE-CAL Inc. Mechanical Contractors Debbie & Edward Defelice Alex DelCielo Tom & Christie Dempsey John Dengel

Anthony & Jessica Curis

## **Dancing With Our Stars**

was a big hit in September in Little Rock, Arkansas. Local stars spent months rehearsing to perform at the event and competed to win the coveted mirror ball trophy. The 2016 winner was philanthropist and volunteer Susan Hickingbotham and the best performance trophy went to Win Rockefeller. The whole night was a win for the fight against NF, with \$227,000 raised for NF research. Thank you to former CTF Board Member Lesley Oslica and the volunteer event committee for their drive, energy, passion and hard work in putting this event together.



### DONOR SPOTLIGHT

**Emily Deschanel** Jay Deshpande Design Continuum Detroit Lions' Football Detroit Pistons - Palace Sports and Entertainment DetroitWick Heather & John Devereux Peter & Leslie Diamond Kevin Dickens Dickey's Barbecue Pit William Dillon John & Patricia DiNozzi Robert & Michelle Dintzner Robert & Anabelle DiPilla DJK Sales, Corp. Daniel Doctoroff Steve & Mindy Dodobara Pearl Doherty Jose & Jill Dominguez R. Bruce & Madelyn Donoff Michelle Donovan Timothy & Sheila Drevyanko David Dries Michael D. Dubay Tony Dunn **Durable Packaging** International Amanda Dye Dykema Gossett, PLLC Meg Dzurik James & Suzanne Earle Eastern Consolidated Easy Ice, LLC **Eaton Corporation** David & Gayle Ebel Brian & Laura Ebv **Eccola Foundation** Ed Lee & Jean Campe Foundation, Inc. Marie Hoffman Edwards Ralph & Ree Edwards Rae & James Eisdorfer Steven & Nicole Eisenberg Elite Fire Safety, Inc. Scott & Eva Elkins Richard & Carol Ellis William & Renee Elworthy Stephen & Joan Engel Steve & Susan Englehart Mark and Catherine Ensio Family Foundation Inc. **Ent Credit Union Enterprise Holdings** Foundation Scott Erath Craig & Renee Erlich Eric & Amy Ersher Terri Erwin

Heath Eskalyo

Eureka Union School District

Essex Bank

Euroworld MotorSports, LLC John & Marie Evans **Exotherm Corporation** John Krueger & Paula Faris Farrell Fritz, PC Neil Farrow William & Heather Faver Faxon Law Group, LLC Deborah & Douglas Feist Diane Fellows Lynda Fenton Ronald & Ronda Ferber Robb Ferguson Fern Freeman Jewelry Ed Ferrell Doug & Stephanie Finch Steven & Jane Fink FirstMerit Corporation Rose Fiscella & John Novello Paul & Sarah Fisch Mark Fisher Roger Fisher & Marilyn Meckham John & Beverly Fitzgibbons Darragh Fitzpatrick Denise Fitzpatrick Donald & Debra Fitzsimmons Hugh & Jenny Flack Jared Fleisher Robert & Cynthia Fleming Bruce Weider & Laurie Fletcher-Weider Florida Hospital Medical Center Ralph Focaracci David Foltvn Daniel & Debra Fontaine Eric & Kristin Forrest Forte Belanger John Fortney William Fox Fox Sports Net Ohio, LLC Jennifer & David Francis Robert Frank Maxine and Stuart Frankel Foundation Michael & Barbara Franklin Freda Freeman Scott Friberg Gregory Fromkin Frontstream - Voya Foundation Hiroshi & Misako Fujisaki Fulton Street Brewery, LLC Kevin & Susan Funke Matthew Gable & Debbie Krueger David Gallo

Tracy Galloway

Vero & Gloria Ganio

Ganzi Family Foundation

Thomas & Rosemary Gangel

Garage Employees Local Union No. 272 David & Christine Garant Felix & Lilliam Garcia Robert Garcia Gardendale First Baptist Church Mike Garfinkel GE United Way Campaign Geico Philanthropic Foundation Marilyn Gelder Mauro Geller Jason & Jamie George Mahmood & Schelaine Ghassemi Merrill Gildersleeve & Anore Novak Russell Gioiella Girlie Girl Bernard & Brenda Gitlin Daniel & Kristen Glazer Diane Glenn Global Indemnity Charitable Giving Committee Gary & Jeanne Glodek Paul Glomski Gloria F. Ross Foundation, Inc. Going Sign & Servicing Co., Inc. Goldman Sachs & Co. Goldman Sachs & Co. Matching Gift Program Stuart & Marcey Goldner Howard & Rosalyn Goldner Alicia Gomes Kenneth & Laura Goodkind Danielle Gordon Larry Gossard Geoffrey Gradler Wayne Graham Luke Graham Grand Council of Cryptic Masons of the State of New York Grandstand Sports & Memorabilia, Inc. Laura Grannemann & Mark Wallace Bruce Grantham Patrick & Eileen Grasso Lori & Samuel Grav Greektown Casino-Hotel

Robert & Dana Greenwood

Gregg Bussjaeger Memorial

Jason & Angela Gregorec

Matt & Cheryl Gribas

Foundation

Richard Grigsby

Beth Grindle

Michael Groh

Horacio Groisman

Harley & Rochelle Gross



# Cupid's Undie Run

February 2016 marked the seventh consecutive Cupid's Undie Run to benefit the Children's Tumor Foundation. Cupid's has grown in leaps and bounds since 2010, when participants raised \$10,000, to 2016, when they raised more than \$3.8 million. Everyone's favorite Valentine's Day-themed party has shown what an amazing group of generous do-gooders can do for a cause they believe in. Cupid's Undie Run is a fun and unique way to raise money specifically for NF research. The Children's Tumor Foundation is thankful for Cupid's adventurous spirit in the pursuit to find a cure for NF.

Groth Design Group Robert Grubb GSI. Inc. Guaranteed Returns John & Karen Guardiola Joseph Gurak Joel & Kelly Gurman H & L Electric, Inc. H.O. Penn Machinery Company, Inc. Seth Habberfield & Lisa Guess Hillel & Ruth Hachlili

Dan & Michelle Hacker Haddam Killingworth High School Haddam Killingworth Middle School Stephen Hamilton Adam Handwerker Don Hanigan Michael & Pamela Hanley Liam Hanley Hansae Co., Ltd Rush & Linda Harding Rush & Rachel Harding

# WITH THANKS-

Alan & Judith Harland William & Lenore Harris Harris and Eliza Kempner Fund Carol Harrison & Steve Kalagher Hartland Consolidated Schools Creekside Elementary Hartless Foundation Nick & Nicole Hartman Samuel Haupt Matthew & Nora Hay Thomas Hefferon Mason Hemphill Dave & Vivian Henderson Molly Henderson William & Louise Hendry Jeff & Jill Hennig Sarah Henry Heritage Biologics Inc. Heritage Vision Plans, Inc Tim Herland Maurice & Jacqueline Herz Dena Hibbs Herren & Susan Hickingbotham Barbara K. Hicks Bruce Hicks Tod Highfield Flaine Hill Hillcrest High School Jason S. & Meredith Hillman Cindy Hipp HMC Presents - Jingle Bells for Cancer Cells Joseph Ho Gary Lee & Denise Hodes L. Lee & Carole Hodges

Jeff Hoen Lisa Hofer Steve & Susan Hogan Jillian Fayelyn Holmberg Michael & Jocelyn Holt Kenny Hom Gregory Hoole Michael & Mary Horlick John Horton Zola and Marlene Horovitz Family Fund Leonard & Joan Horvitz Michael Weiner & Danielle Horvitz-Weiner Hotels for Hone Theodore Houck Kevin & Lisa Houle Adam House Penny Howland Stephen Hubbart Richard & Marianne Huelsmann Ann Hulley Jerry & Maureen Hunter Donald & Patricia Hurst Mark & LaDeana Huyler Bill Hyde HZ Ops Holding, Inc. I.C.A.N. Foods, Inc. Ilitch Holdings, Inc. I.U.O.E. Local 12 Charitable Golf Committee, Inc. ICAP Services North America LLC If It's Water Inc. Patrick Ifrah ImageCrew, LLC

Indian Trails Inc. Indiana University School of Medicine International Union UAW Local 3064 International Union of Operating Engineers Local 12 Bruce Israel & Lisa Pernick J.T. Magen & Company Inc. Michael & Mozelle Jackson Dana & David Jacob Scott & Rosalyn Jacobsen Richard & Amanda Jaffa Juan Jaimes Kevin laite Nasser & Samia Jallad John & Sally Jarboe Jarboe Sales Company William & Janney Jay Jesse & Tyler Jenner Mary Ann Jennings Hans & Barbara Jepson lose limenez Indie Walker Inc. Joe Muer Seafood John Varvatos Eric & Mary Beth Johnson Helen Johnson Mark Johnson Mark Johnson & Associates JOMCO, Inc. Sarah Jordan & Suresh Nagappan Kenneth R. Jordan Gavle Joseph Jupiter Bowl

Hans-Werner Kaas

Yevgeniy Kagan Robert Kahn Esther Kallman Katherine Kamprath Christopher Kanuck Barry & Rochelle Kaplan Peter & Elaine Kaplan Barbara Ann Karmanos Cancer Institute Danielle Karr Richard & Leslie Kates Aubrey & Roleen Katz Steven & Elizabeth Katzman Scott Kaufman George & Mariana Kaufman Ilan Kaufthal Jenny Kearschner Richard Keidan Allen & Vickie Kelley Kelly Gerber Jewelry Patricia Kelter Kendra Scott LLC William & Wanita Kennedy Beth Kerlin Emile Khader Nader Kharsa John Kiczek & Christine Seuffert Timothy Kiefel Bob Kilar Kinecta Federal Credit Union Daniel & Susan King Kiwanis Club of Midlothian -Chesterfield Ronald & Stacy Klein Mark Kleinknecht Joyce Klett

Ron & Tamara Knapp Harold Kobner George & Jutta Kohn Angela Kolarek John & Jacqueline Konechne Les Korbl Bruce & Michele Korf Gordon Krater Laura A. Krietemeyer Kristen Krzyzewski and David Yalowitz Family Foundation Nancy H. Krohn Robert & Jeri Krueger Margo & Anthony Kummer Ellen Kurtz & Stephen Smith Murray & Lee Kushner Marshall & Colleen Kutz Amy & Janusz Kuzdowicz La Bonanza Catering LLC Lakewood Village Shopping Diane Lalicki Leslie Lamacchia Lloyd & Lois Lambright Steve Landers Chrysler Dodge Langan Engineering Household Jason Lantieri Memorial Foundation Steve LaPorte Derek Latka & Blair Hess Jack & Mary Lawless Neal Lazar Lead Intelligence Inc. Chad Leathers John & Edyth Ledbetter Ronald & Debra Lederman Barry Lee Hui L Lee



Cocktails for a Cure

Incapital LLC



#### **DONOR SPOTLIGHT**

Douglas LeFevre Legacy Termite's Pest Control, Inc. Anthony & Lauren Leotti Fric Leshin Cooper Levenson, P.A. Robert Levin I. Buddy & Barbie Levine Phillip & Shelley Levine Wendy Levine Edward C. Levy, Jr. & Linda Dresner Levy Matthew & Stacy Levy Jeffrey Lewis Mary Lewisy Liberty Contracting Corp. Library Street Collective, LLC Life Fitness Timothy Lilly Liang Kung & Jane Chiang Lin Samantha & Steven Linden Andrew Lintner Paul & Yael Lipof Elliott & Allison Lissner Little Heroes of North Georgia LLC Littman Family Foundation, Inc. Karen Little Jim Livingston LMD Boudoir Justin & Jill Locklar Loco Cycle Marshall R. Loeb Henry Lombardi David Long Rabbi Harold S. Loss Karen Loussia Andrew & Dawn Lowell Louis Lowell Marc Lowenberg Terrence Lowenberg Carolyn Lowenstein Chris & Dani Luers Marcus Luft Snap Lumberton I Andrew & Nora Lusk John Lutz Brendon & Kirstin Lynch James M. Lyons Michael & Karie Lyon MacFarlane Dance LLC Sherwood Dance Academy Justin Maclaurin Joseph MacLeod Nathan & Mary Mahrer Kathleen Malsom Sandra Manfredi Manger & Associate

CPAs P.C.

Salvatore & Marylou

Mangiapane

Manitoba Neurofibromatosis Support Group Mauricio Manjarrez Eric & Betty Mannes Guy Manuel & Linda Goldstein Maple Direct, Inc. Mildred Marcoux Stephen Marino Marks Paneth LLP Aaron Marks Scott & Jennifer Marks Marsh & McLennan Agency LLC Marsh & McLennan Companies Marsh PCS Jeff & Ginger Marshall John Martin Linda H. Martin Daniel Mashoof Massey Services, Inc. Elaine & Thomas Matchett Angela Matthews & **Doug Santos** Suzanne & Chloe Matz Todd & Rachel Matzkin-Bridger Apphia Maxima John Mazur John & Florence McCarthy Nirja McCarthy Stephen & Kate McCurdy Chad Rodgers & Eric McDaniel John & Nancy McFeeley Bryan & Mindy McGinn McGlinchey Stafford, PLLC Bridget McKeon Fred & Elizabeth McLeod Brian McMahon Josh McManus Walter & Shannon McNall Del Mecum, Jr. Surbhi Mehta Paul & Lili Meilink Rodrigo & Luz Mejia Timothy & Deborah Melton Jane Mendez Merced Elks Lodge #1240 Philip Mercurio Meritor, Inc. Gina Metrakas Metro Diner Management, LLC Metro Sanitation LLC Metropolitan Real Estate Group, LLC Metropolitan Theatres

Corporation

MHE Foundation

John Miceli

Metro-West Appraisal Co., LLC

Eileen Newell

Michigan State University Athletics Millennium Sounds, Inc. Richard & Margaret Miller Miller, Canfield, Paddock and Stone, PLC Deborah Miller Mark Miller Nicole Miller Minnechaug Regional High School Don & Patsy Mintmire Mello & Mary Jo Mitchell Joann Miyamoto JJ & Liz Modell Modern Woodmen of America Jasmine Moezzi Frederick & Shelley Molineux Susan Molineux Mommy & Daddy Daycare Darlene Monzo Angela Moody Harold Moody Carole Moore James & Cathy Moore Katherine Moore MOR Healthcare Consulting Jamie Morck Grace Morgan Valencia Morris Mortgage Bankers Association Motor City Electric Co. Motor City Office Solutions Steve Mount Randall & Karen Mourot William Moyssiadis Mr. Greenjeans Produce Inc. Mulberry Mechanical Corp. Dan Mullen Steve Muller Kevin & Stacey Mullins Chip & Cindy Murphy Lisa Murphy & Cindy Bourgeault Joseph Musso John Nabholz Wayne & Susan Napierata Ajay Narula Stephen Nathan National Fire Fighter Corp. David Nazaroff David Nelson Renee Nelson Stanford Nelson Brian & Yim Neugeboren Neurofibromatosis Society of Nova Scotia Anita & Charles Newberg Michael & Judy Newell



## Richard A. Horvitz and Erica Hartman-Horvitz

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

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

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

# WITH THANKS-

Harvey & Joan Newman NewMarket Foundation News America Marketing Leo Nicolini Mark & Jeanne Nielsen James Niesewand Ryan & Kristy Nobles Zach & Jenna Noel Jeffrey & Constance Noiva Ronda & Victor Norris North Shore LIJ Health System Amanda Norton Anthony & Heather Nuckolls Nicole Nummela Irving & Barbara Nusbaum Cynthia O'Brien Dianna O'Doherty Amy Bishop & John O'Hara Karen & Dennis O'Keefe Thomas Obrecht Ohio Valley Region Porsche Club of America Old Republic National Title Insurance Co. June Oller-Moya & Jeffrey Moya John & Cathy Olszewski Om Spa OnCourse Learning One Mission Fundraising, Inc. Orange County American Italian Women Oregon Oral Surgeons Simon & Dana Oren Michael Orlando Chad & Anne Mary Orr Kevin & Susan O'Shea Our Lady of Grace Roman Catholic Church Wesley & Carolanne Owenby Lisa Oven Jason & Kristin Pace George & Sandra Pace Pactiv LLC Michael & Kathleen Paesano Pak's Karate Academy of Michael & Angela Palmiotto Par Plumbing Co., Inc. The Parade Company Paramount Marketing Group Helene Parcesepe Deborah Parente & Kenneth Butler Parker Audi Parker Cadillac Holly Parker Richard & Nancy Parker **Brittany Parling** Glenn Pasch & Mayra

Roger & Kathy Penske Pepsico Silicon Valley Community Foundation Kent & Marisa Percv Paul & Karen Perella Anthony & Laura Perfetti Perkins Coie Trust Company Laura and Isaac Perlmutter Cancer Center at NYU Langone Medical Center Douglas & Colleen Perry Therese & Daniele Pessia Gary & Sandy Peteler Rosilyn Petersen Charles & Carolyn Peterson **Todd Peterson** Mark Petroskev Don Pfeifer Paul & Tricia Pfeifer Pfizer Foundation Matching Gifts Program **PGA Tour Superstore** Robin & Erik Phelps Sandra & Thomas Pierce Richard Pietch Frank & Margaret Piil Zach & Michelle Piner Starr Piner Charles & Patricia Pittman Dave & Nicole Plummer Police and Fire Federal Credit Union Nancy Pollard Portofino Restaurant Inc. Rick Portwood Premier Event Technology, LLC Melissa Price & John Murphy Paul & Angel Price Zachary Price Kevin & Kathryn Prokop PUBB of Conshy, LLC Anthony Pulice

Punch Bowl Social John R. Purdue Charitable Giving Fund of SEI Giving Fund Hattie & Ted Purtell Howard Rachlin Kathryn Raethel Rags For Riches Foundation Patrick Rakers Randall-Paulson Architects, Inc. Eric & Abby Randolph RateMarketPlace Brian & Pat Ratner Andrew & Heather Rayburn Raymond Antos Trust Rayonier Operating Company, LLC Jason & Stacey Raznick **RBC Trust Company** (Delaware) Judith & Donald Rechler Foundation, Inc. Daniel & Lisa Reck Red Diamond, Inc. Trent Redden Steve Reddy Helena Redshaw Caroline & Jonathan Reel Dale L. Reese Foundation Timothy Reilley Thomas Reilley Daniel & Joan Reilly Renaissance Charitable Foundation Inc. Bradley Reynolds & Jaclyn Godic Melvin & Patricia Rice Jack Richards Lisa Richardson Rickie Richey Richmond University Medical Center Anne Riesbeck

Matt & Kate Riley John Risner & Sharon Parente Robert Rivenburgh Frank & Theresa Riviera Alan & Jerye Ann Robbins Robert B. Samuels, Inc. **Donald Roberts** Jared Roberts Norman & Bettina Roberts Foundation, Inc. Jeff Robertson Brian & Kimberley Robinson James & Barbara Robinson Roccos Wilshire Inc. Caio & Tatiana Rocha **Rock-Pond Solutions** Rocks Off Gary & Colette Rodbell Albert A. Robin Family Foundation Barry & Jody Rogow Florence Roffman Will & Tara Rogers Joseph Roisman Matt Roling Frank & Victoria Romano Allan & Maxine Rose Elizabeth Rose Jeff Rosen Nancy S. Rosen Eleanore Rosenberg Laurence & Lori Rosenberg Toni Ross Mark & Dianne Ross Michael & Melanie Rothenberg Ronald & Carol Rothrock Diana & Charles Rothstein Ronald & Ursula Rottloff Allan Rubenstein & Jane Halperin

Patrick Michael Rubin Scholarship Fund, Inc. Kenneth C. Rudd Mary Ruggeri Bibi Rupnarain Patrick Russell Edward Russnow Beth Ruwe S. Charatan Realty, Inc. Nicholas Sacco Todd & Karen Sachse Sacramento Adventist Academy Jeffrey & Kimberly Sakwa Michael Saleh Salesforce.com Foundation Susan Salneter Jessica & Brett Samblanet San Juan United Way Kathy Sandelin **Scott Sanders** Sanford Medical Center Fargo William & Christina Sargent Arshad Abdul Sattar Mark & Vicki Saviers Richard & Linda Schaps Bluma Schechter Michael Scherl Jeff & Anna Schifrin Martin & Andrea Schlossberg Ian Schmidek Joseph Schmitz John & Pattianne Schnabel Diane Schneiderman Michael & Susan Schroeder Charles Schwartz & Cathy Sosnick Schwartz Daniel & Roxanne Schwartz Marc Schwartz & Emily Camiener Sandra & Alan Schwartz Darla Scott



Bracer Pasch

DONOR SPOTLIGHT

Jon Scott Smith Seckman Reid, Inc. Abby Smith Veronika Scott Doug Seabolt John & Sabrina Smith Steven & Pamela Smith Robbie Searing Angela Sebald Smithfest Foundation, Inc. SMPS Family Fund Thomas Sebold & Snell Prosthetic & Orthotic Associates, Inc. Securitas Security Services Laboratory Harris & Sharon Snyder USA, Inc. Scott & Michelle Segal Lisa Spindler Photography Inc. Sei Bella Med Spa Richard & Gail Sobel Select Equity Group Melissa Sosa-Longo & Foundation Frank Longo Doobie & Jackie Sellers Mark & Shonda Sosebee Lawrence Serf Susan Sosnick Session M,Inc South River School Carolyn E. Setlow Southeastern Construction & Seton Catholic School Equipment Co., LLC Giselle Seychett Southern Glazer's Seymour & Barbara Leslie Adam & Rani Speck Teri Speckhardt Foundation Shannon Favia Original Mark & Lenore Spoonamore Michael & Amy Sprung Artwork Samantha Sharpe Square Media Steven Sheckell Steve Squinto Sheet Metal Workers Union Scott & Emily Stackman Local 19 Harris & Sharon Snyder Dong & Lisa Shen Starlite Room/Brixx Bar Claude & Sue Shepherd & Grill Kathryn Shepich Gordon & Nancy Starr Jonathan Staver & Rachel Martin Sherlock Andrea & Roger Sherr Shinola Detroit, LLC Steamfitters' Local Union 420 Elizabeth Shock Esta Eiger Stecher Kenneth Shure & Nicole & Todd Steinert Liv Rockefeller Tamara Stenshoel Philip & Judith Shwachman Carrie Stern Alan & Sandra Sibley David & Dianne Stern Sideline Sports Photography Lynn S. Stern Muriel F. Siebert Foundation Glenn Stevens Mark Simmons Judith & James Stillwell Craig & Cheryl Simon Jenn Sting Joann M. Simon Matthew & Ronda Stoffer Nick & Sarah Simpson Leanne Story Sims Chiropractic Center, LLC Max Stomber Erik Sims John & Betsy Stone J. Bradford Sims Martin & Mary Ann Stone Puneet Singhvi & Stonewood Construction Meenal Mehta Alesa & Martin Story Sissy's Log Cabin Stout Risius Ross, Inc. Dave & Melanie Sizemore John Striker & Eda Modesta Paul & Maxine Skaff Rachel & Derek Strum Graham Skidmore STUDIOS Architecture Skinner Plumbing & Robert & Arlene Subin Suffolk Transportation Heating Corp. Rolly Slatt Service, Inc. John Pavolotsky & Romy Slatt Ryan & Callie Sullivan Melinda Friedeberg Michael Sullivan Summer Solstice Foundation, Inc.

Alan & Joanne Suna

Sunbelt Rentals & S.R.E.

Vicki Match Suna

Randy & Sasha Sloan David & Robin Small

Melvin & Shirley Small

Owen & Cecilie Small

Brett Sundheim Stephanie Sutherland Cesar Kenji Suzuki Debra & Ray Swafford John Sweet Michael Swenson Donald & Susan Swift Anne Syme SYSCO Food Services of Central Florida Tom & Amy Szabo Estate of Louis R. Tabit Takeda Pharmaceuticals USA Inc. & Affiliates Joseph Talbot Tapper's Diamonds & Fine Jewelry Frank & Mary Ann Tataseo Marc & Ronna Taub Sheldon & Andi Taub John Taylor Susan Taylor Tecma Group LLC Tepel Brothers Printing Co. Peter & Claudia Terkildsen Texas Health Huguley Hospital Jason Thacker The Daily Move Challenge The Ford Family Foundation The Home Depot Foundation The Huntington National Bank The Mandelbaum Foundation The Marcus Foundation, Inc. The Nederlander Company/ Broadway in Detroit The Printer Inc. The Rink at Campus Martius Park, Magic Ice USA, Parc Restaurant The Signature B&B Companies Craig De Thomas George & Chrissy Thomas Thompson Foundation Kenton Thompson Todd & Elisa Thompson Thrivent Financial Claudia & Paul Timko Gabrielle Tiven Thomas & Lauren Tobin Glen & Judi Tomaszewski Julie Tomsula Matt Topper Townhouse Training for Warriors Long Island Mark Tricano Justin & Jodi Trivax Troutman Sanders, LLP

Jared Kushner & Ivanka Trump

Anne & Larry Trussell

Todd & Lisa Tucker



## Flashes of Hope

Since it was founded in Cleveland in 2001, Flashes of Hope has photographed close to 60,000 kids fighting cancer to help them look and feel attractive and invigorated again using a still image as a confidence booster, while they cope with the depths of the disease.

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

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

The Children's Tumor Foundation extends our utmost thanks to Flashes of Hope and its founders Kip and Allison Clarke for their continued support in funding NF research.

# WITH THANKS

Carey Tump **Turner Construction** Company Foundation Adam & Sarah Turner Alyssa & Marc Tushman Herbert & Grace Tyler John & Helen Tyrybon Liang D. Tzeng UAMS - Winthrop P. Rockefeller Cancer Institute Chris Uhl Ulster Carpet Mills (North America) INC. **Ultimate Parking** Management, LLC Underhill - Jericho Fire Dept United Parcel Service United States Information Systems, Inc. United Way of Central Maryland United Way of Long Island United Way of Metropolitan Atlanta, Inc. University of Kentucky University of Michigan University of Virginia Health Systems Wayne & Mary Ann Upshaw USA Fiji Outreach V. Costa Contracting Corp.

Ashley Vacanti Mark Vadon Mattie Iverson Vadon Michael Valdes Cliff & Deborah Vallier Marisa & Robin Vanbokhorst V-Cole Enterprises, Inc. Jeffrey & Christine Veatch Mattie T. Vega Venture Solutions Venue Solutions Group, LLC Fna Verdi Verizon Foundation Verizon Wireless Girija Verma Paul & Valerie Verona Saul Victor Villa San Clemente, LLC Vito's Pizzeria Wachtell, Lipton, Rosen & Katz Darren Wainer Jason & Katy Wakin Walbridge Dan Waleke & Cindy Kiss David Walker Steven & Lottie Walker Family Foundation Margaret Wallace & Wayne McCormack Harold & Laura Wallof

Walmart Foundation Niamh Walsh Richard & Carol Walsh Walt Disney World Resort Rich & Rhonda Wampler Catherine Ward Frin & Patrick Ward Jerry Wass Aaron Watkins Thomas & Priscilla Watkins Jennifer Watson Robert Watson Wawa Inc. Wayne State University Wayne Valley Football **Booster Club** Brenda Wayne Danny & Donna Weaver Webasto-Edscha Cabrio Evana & Roger Webster Weichert Realtors - Integrity Group Chad Weinbaum Matthew Weinberg Bryan & Margie Weingarten Bob & Karen Weisberg Aaron Weitzman Welca Messiah Lutheran Church Marc & Eileen Weller

Wells Fargo Advisors, LLC Wells Fargo Community Support Campaign -DoTopia Greg Wells Melissa Wells Lisa Wendel Memorial Foundation Paul & Patricia Werner Westerville Central Athletic Boosters **Bob White** Donna & Frederick White Drew White Michael White Joseph Whitehead Whiting-Turner Contracting Company Zygmunt & Audrey Wilf Foundation Louis & Roberta Williams Mary Williams Robert & Pamela Willis Dan Wilpon Richard Wilpon Robert & Suzanne Wilson Wind at Your Back Steven & Risa Wittels Gregg & Beth Wolpert Howard & Perle Wolpin Women Run Arkansas

Chad Woodard William Wortzman Wright and Co. Rick & Debbie Wright Wrightson, Johnson, Haddon & Williams, Inc. Andrew B. Wrublin Sandra & Thomas Wuliger Ronnie Wurtzburger Wycliff Kent Grousbeck & Corrine Basler Grousbeck Trust Susanna Van Wyk Mary Yarmuth Xi Ye Ken & Jessie Yue Jarrod & Eun Yuster Michael & Sarah Zambo Ellory Zamler Jeremy & Katherine Zehr Zeichner Ellman & Krause, LLP Thomas Zeifang Philip Zelman Zieben-Mare LLP Robert C. Zinnershine Brad & Lisa Zorfas



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

#### **Board of Directors**

Richard Horvitz, Chair Tracy Galloway, Vice Chair Randall Stanicky, Treasurer Gabriel Groisman, Secretary Bruce R. Korf, MD, PhD, Chair, Medical Advisory Committee

**Linda Halliday Martin,** Chair Emeritus

**Daniel Altman Robert Brainin William Brooks Daniel Gilbert** John Golfinos, MD **Matthew Hav Chad Leathers** Stuart Match Suna John McCarthy Steven L. McKenzie Laura Perfetti **Michael Peterson Kenneth Rudd** Rachel B. Tiven **Karl Thomson** Dave Viskochil, MD, PhD Peggy Wallace, PhD

#### **Honorary Directors**

Suzanne Earle Michie Stovall O'Day Alan Robbins, MD Carolyn E. Setlow Nate Walker

#### **Ed Stern**

Pro Bono Counsel **Allan Rubenstein, MD,** 

**Director of Medical Affairs Emeritus** 

### **Medical Advisory Committee**

Bruce R. Korf, MD, PhD, Chair Annette Bakker, PhD Jaishri Blakeley, MD Karen Cichowski, PhD Suzanne Earle Tracy Galloway Richard Horvitz Michael Morin, PhD Marco Nievo, PhD Roger Packer, MD Scott Plotkin, MD, PhD Ed Stern Stuart Match Suna Dave Viskochil, MD, PhD

Peggy Wallace, PhD

#### **Foundation Staff**

Annette Bakker, PhD, President and Chief Scientific Officer Reid Horovitz, Chief Operating and Financial Officer

#### **Research and Medical Programs**

Salvatore La Rosa, PhD, Vice President,

Research and Development

Vidya Browder, PhD, Basic Science Manager

Maria Carela, Grant Manager

Kate Kelts, Patient Support Coordinator Pamela Knight, Director, Clinical Program Patrice Pancza, Research Program Director

Heather Radtke, NF Clinic and Symposium Coordinator

**Traceann Rose**, Director, Patient Engagement **Sarah Rosenberg**, Senior Executive Assistant; Manager of Special Projects & Board Affairs

#### **Development**

Allison Cote, Regional Development Manager
Emily Crabtree, Director, Development Operations
Angela Dumadag, Regional Development Manager
Angela Earle, Director, Development Innovations & Kids Program
Adam Gracia, Regional Development Manager

Adam Gracia, Regional Development Manager Channell Hogan, Regional Development Manager Lolita Jerido, Regional Development Manager Kelly Mills, Regional Development Manager Julie Pantoliano, Regional Development Manager Kristine Poirier, Senior Director, Development Kim Robinson, Regional Development Manager

#### **Major Gifts & Major Events**

Melissa Sosa-Longo, Vice President, Major Gifts Rebecca De Ornelas, National Manager, Special Events Mary Vetting, Stewardship Manager

#### **Finance and Administration**

**Catherine Blessing,** Director, Human Resources **Monique Boucher,** Gift Processing Manager

Sarah Bourne, Director, Finance

**Albert Diaz,** Director, IT and Salesforce Administration

Margaret Flaccamio, Fulfillment Coordinator
Keena Hutchinson, Gift Processing Coordinator
Morgan Kellogg, Gift Processing Assistant
Latisha Maxwell, Gift Processing Coordinator

**Danielle Meyer**, Technical Support, National Programs

Carey Milligan, Accountant

Rosa Amelia Perez, Project Administrator

Connie Sorman, Senior Manager, Volunteer Engagement

#### **Marketing and Communications**

Simon Vukelj, Vice President, Marketing and Communications Rebecca Harris, Public Relations Manager Alissa Marks, Marketing Senior Manager Susanne Preinfalk, Design Director Vanessa Younger, Communications Senior Manager

As of May 2017

