

Children's
Tumor 
Foundation

Ending Neurofibromatosis Through Research



PROGRESS

2010 ANNUAL REPORT

“We are making progress. There is still basic research needed to unlock more of the underlying biology of NF, and discover drug targets and biomarkers. There is preclinical work to be done to see if currently approved drugs will work on NF, and to test promising new compounds. We are advancing work in all of these areas, and thanks to the body of knowledge developed over many years, we are now able to translate the basic research of NF into clinical trials.

Five years ago when I assumed the presidency of the Children’s Tumor Foundation, clinical trials for NF were a dream. Two years ago we announced our plans to begin funding them, and on this night last year we announced our first two. In 2011 we will fund four more clinical trials. And we will not stop until we have treatments for all of the complications of NF. This is a significant task, but I am confident that as I pass the baton to our next president, George Orfanakos, the Children’s Tumor Foundation will meet the challenges and progress even more rapidly in our quest to end neurofibromatosis through research.”

- John Risner, President Emeritus

OUR MISSION

The Children’s Tumor Foundation is dedicated to improving the health and well-being of individuals and families affected by neurofibromatosis (NF), the term for three distinct disorders: NF1, NF2 and schwannomatosis.

Our mission is to advance peer-reviewed research to develop treatments and cures for NF; support persons with NF and their families by making thorough and accurate information readily available; assist in developing clinical centers and best practices to improve access to quality healthcare for those who live with NF; and expand public awareness of NF to improve diagnoses, increase understanding of the challenges that NF presents, and encourage support for NF research.

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A LETTER FROM THE PRESIDENT

In 2010, the Children's Tumor Foundation dedicated more funds to research than any year in our history. This research is fueling the progress that will lead us to treatments for NF.

Since our inception in 1978, we have been committed to supporting the very best NF research wherever it may be. As you review this annual report I think you will be impressed by the results our programs produce. In 2010, we recorded more than 10,000 patients seen nationwide in our NF Clinics, supported nineteen ongoing NF-specific clinical trials and advanced 50 drugs or combination therapies through the preclinical pipeline. All of these successes, achievements on their own, are part of an integrated approach to research whereby the advancements of one program inform and enhance the abilities of other programs.

We are mindful of how we direct our resources, ensuring that each dollar is invested most wisely in the pursuit of our mission. The recognition we've received from Charity Navigator – the country's largest charity evaluator – with their highest rating two years running (an honor only 19% of nonprofit organizations can claim) is a strong validation of our commitment to transparency and fiscal accountability.

Through our Research Advisory Board, our research programs seed-fund early stage ideas that go on to receive attention, and in many cases follow-on funding from biotech and pharmaceutical companies. Further, our NF Preclinical Consortium and Clinical Trial & Research Awards test drugs provided to our programs from biotech and pharma companies to prove safety and/or efficacy.

In this way we engage companies, show them the potential for treatments in NF, and rapidly provide them with data to consider the opportunities of advancing the research and development of drugs. Last year alone we partnered with Novartis, Genentech, Pfizer, Avila, AstraZeneca, and Merck, among other companies. This year those partnerships will continue and expand as we search to find treatments for all of the manifestations of NF.

The spirit of collaboration was certainly strong at the Foundation in many respects in 2010. We were invited to participate at numerous prestigious conferences including BIO and FasterCures, where we presented our innovative approach to advancing treatments for NF. The Foundation also partnered with the Texas Neurofibromatosis Foundation in 2010, who offered to direct their resources to our research programs. We build these bridges in industry, business and within the NF community because doing so will allow us to find treatments and a cure, faster.

This would not have been possible without the generosity of our supporters. Whether making a major contribution towards NF research or fundraising through any number of special events or one of our national programs (NF Endurance, Racing4Research, NF Walk, Tea for NF), every dollar is making a difference. As we move forward into 2011 and beyond, we plan to build upon our previous success. We will expand our NFPC into a second phase, unveil our database and biobank and make whatever advances necessary to increase the efficiency and effectiveness of our work. We look forward to sharing with you that progress once again, and assure you that with each day we are moving one step closer to ending neurofibromatosis through research.

Sincerely yours,



George T. Orfanakos
President



George Orfanakos, President



STRATEGIC PLAN

In 2006, the Children's Tumor Foundation mapped out a five year strategic plan to advance NF research. The goal of the Strategic Plan was to establish priorities that would accelerate the identification of effective NF treatments, and improve quality of life for those with NF by the end of 2010.

The Strategic Plan identified five primary areas that would require focus and funding in order to significantly advance the development of treatments for NF: a preclinical drug testing pipeline, the establishment of an NF Clinic Network, the identification new NF biomarkers, the establishment of an NF Tissue Bank, and pilot scale NF Clinical Trials.

Since the time of the Strategic Plan the Children's Tumor Foundation has been the catalyst that has moved NF research toward the most significant accomplishments since the discovery of the genes that cause NF.

In 2006 the NF community had:

- Two to three NF specific clinical trials.
- Limited preclinical drug testing.
- No centralized information on NF clinics.
- No national NF tissue bank or patient registry.
- No or very limited industry interest in NF.

In 2011 the NF community has:

- Nineteen ongoing NF-specific clinical trials.
- An active preclinical 'pipeline' in which CTF has entered fifty drugs or combinations.
- The NF Clinic Network and increased consensus on NF clinical care.
- A national NF BioBank and Registry.
- Multiple industry collaborations and greatly enhanced visibility via philanthropic platforms CTF participates in e.g., BIO, FasterCures.

Through the implementation of the Foundation's initiatives, progress is being made on all fronts and for all types of NF; from discovery studies — understanding the molecular signaling deficits that cause the manifestations of NF — to the growth of preclinical drug screening initiatives and the emergence of a growing number of clinical trials.



INTEGRATED RESEARCH PROGRAMS

In 2006, preclinical drug testing was identified to be a major gap in NF research. In 2010 preclinical testing was the Foundation's largest area of focus through our NF Preclinical Consortium (NFPC) and Drug Discovery Initiative (DDI) Awards. CTF's NF Preclinical Consortium took on a major challenge: to test drugs in parallel in models of different NF1 and NF2 tumors. Guided by an Advisory Board heavy in industry expertise, the NFPC Centers have conducted a sophisticated level of drug testing that can be translated into clinical trials. NFPC has built up a growing pipeline of candidate drugs and established collaborations with companies including Novartis, Genentech and Avila Therapeutics. Building on these

accomplishments, in November 2010 the Foundation announced the intent to support expansion (to seven sites) and extension of NFPC with an additional \$3.75M commitment through 2013.

The DDI Awards program informs and provides candidate drugs for the NFPC pipeline. Through 2010 the Foundation has funded 35 DDIs, at an investment of \$900,000. The DDI program has initiated extensive industry collaborations (20 to-date), follow-on funding from government and industry, and many publications of studies (18 to date).



The NFPC scientists have learned techniques and metrics common in industry, and have pulled together a truly collaborative effort like none I have ever seen. This could only have been achieved with the financial and administrative support of the Children's Tumor Foundation.

- Jay Gibbs, Ph.D., AstraZeneca Chair, NFPC External Advisory Board,
CTF Medical Advisory Committee Member



IMPROVING CARE

NF Clinic Network

In 2007, the Foundation established the NF Clinic Network, the first nationwide network dedicated to improving clinical care and establishing best practices for treating those living with NF. Since then the Foundation has devoted more than \$800,000 to building what has become a 44-member Network that treated nearly 10,000 patients in 2010.

NFCN provides a unique resource for patients and families to both receive care informed by the latest advances in NF research, and learn more about NF, research being done on the disorder, and potential clinical trials they patient may qualify for.

Overall, NFCN has allowed CTF to gain a broad understanding of how NF clinical care is delivered in the US and to share this knowledge with NF patients and families seeking specialized care. The Foundation has received very positive feedback from both clinics and families about NFCN. As NFCN expands its activities, its impact will increase even more dramatically.

10,000

Only begun in 2007, in 2010 the NF Clinic Network saw 10,000 patients, both improving care and expanding the scientific communities knowledge of how NF affects individuals.



RESEARCH HIGHLIGHT

The establishment of the NF BioBank and Registry marks a significant advancement in the tools available to conduct NF research and improve clinical care. The BioBank and Registry will work in coordination with the NF Clinic Network to:

- Create a national database capturing individuals currently being seen through NF clinics across the country.
- Establish a bank of tissue collections - both ad hoc and hypothesis-driven - and ensures that these resources are made widely available and distributed to the NF research community for research projects.
- Engage individuals with NF directly in research and clinical trials by sharing with them information on current NF clinical trials and research opportunities.
- Expand and advance NF research by making available and promoting to the research and clinical community the resources of the NF Registry and BioBank.
- Establish outcomes-based guidelines for clinical care by collecting and reviewing clinical information derived through the registry.



FOSTERING SCIENTIFIC COLLABORATION

The Foundation has a long history of promoting collaboration among scientists and clinicians. 2010 saw that collaborative spirit take on an expanded role as the Foundation partnered with Texas NF to fund research through our Young Investigator Award. The partnership speaks to the quality of research of our program and to the results the programs are known to deliver.

The partnership was announced at the Foundation's 2010 NF Conference, held in Baltimore. This was the 21st year we've hosted this annual event and the largest Conference to date, drawing more than 300 attendees.

The NF Conference provides researchers and clinicians a chance to share findings and results that push NF research and care forward. The 2010 meeting included a combination of keynote speakers, overviews by NF laboratory leaders, panel discussions, and submitted abstracts. Sessions were themed, and session chairs were encouraged

to close with a summary of 'What we know, what still needs to be done, and what big unanswered questions remain?'



For the second year in a row the Foundation published the Proceedings from the Neurofibromatosis Conference in the *American Journal of Medical Genetics*, an important development in furthering the scope and understanding of NF research.

In addition to encouraging collaboration among scientists and clinicians, the Foundation actively works to build relationships with biotech and pharmaceutical companies to attract further interest in funding treatments and a cure for NF.

7

Number of partnerships the Foundation began and/or expanded in 2010:

- Novartis
- Genentech
- Avila Therapeutics
- Pfizer
- Merck
- Johnson & Johnson



PROVIDING SUPPORT

NF Forum

In 2010, the Foundation hosted our 2nd Annual NF Forum: National Patient and Family Symposium in Las Vegas. The NF Forum was created in response to the desire of the NF community to better understand the disorder as well as learn about advances in NF research. The key objective of the 2010 NF Forum was to facilitate a patient support weekend where individuals affected by NF and their families can learn about medical advances in NF, receive information on clinical trials they may be candidates for, get practical advice on issues facing them and learn about the important resources provided by the Foundation to help families cope with NF.

In addition to the informational and educational aspects of the Forum, the weekend also provides families affected by NF and a chance to share experiences and support one another through the challenges they face. The 2010 Forum saw many returnees from the inaugural Forum in Washington D.C. and helped build relationships that had been established at other Foundation events throughout the country.

The Foundation's commitment to patient support extends beyond the NF Forum with dozens of local symposia hosted across the country to inform and connect the NF community. Symposia are often held at NF Clinic Network member clinics where patients and families are given a chance to meet others affected by the disorder and engage with the care givers who can help ensure those living with NF receive optimal care.



MAKING CONNECTIONS



"It took me almost 6 years to make a connection that has changed the way I feel and the way I see this disorder. It was last year when I attended the NF Forum that I made contact with people just like me, families with sons or daughters who have NF, teenagers living with NF and adults sharing how it is to live with NF. I also learned about all the research that is being done to find a cure for NF, how the clinical trials are planned and executed, all about the different doctors that work around the country, dermatologists, plastic surgeons, neurologists, etc.



It was great to feel that we are not alone. There are many NF clinics around the country that work very hard for us. There are a lot of people that are part of fundraising for research even though in many cases NF is not part of their life directly.

The most amazing part of being in the NF Forum last year was all the wonderful people that I met. People that now are part of my life and that even if we are in the opposite side of the country, there is a special connection. These relations are for me the NF family that I looked for 6 years. I saw the children that have NF playing together. I met adults with NF that shared their experiences and how they live with NF. It just completely changed the way I felt about this disorder.

When I left Atlanta a year ago to attend the NF Forum, I was very scared. I can tell you now, that since I left Vegas last year, I feel empowered. I understand so much more how it is to live with NF. I feel more confident that we are making the right decisions to support our son." - Mariana

180

The number of attendees at the 2010 NF Forum, the first national event of its kind for the NF community.



MAKING CONNECTIONS

NF Endurance

NF Endurance provides individuals the chance to do what they never thought possible. The opportunity to defy the odds, and their own expectations to RuNFor a reason more important than themselves and achieve what they perceived to be impossible (or close to impossible!). With a dedicated group of Team Captains, NF Endurance builds a family experience around marathons, triathlons, cycling challenges, and other Endurance events throughout the country.



“I don’t even remember how I first heard about the NF Endurance Team, I ran my first marathon with them in 2009 and have not slowed down since. Being a part of the team has been incredible. I am stronger both physically and spiritually, and I am now a proud Team Captain of the Long Beach NF Endurance Team for the 3rd year running!” – *Olivia H.*

“Having now achieved my goal I am both elated and relieved, but more importantly I am grateful for the gift of running and the gift of my health. I also find myself thinking, “What’s next?” I certainly want to keep running until a cure is found, and after that will want to raise money to make NF treatments affordable. The answer? my running never ends!”

– *Bob Skold, Endurance Team Member, Foundation Staff Member*

NF Walk

Every step truly made a difference thanks to the more than 2,400 walkers who participated in NF Walks across the country in 2010. The NF Walk is a chance for individuals in a region to share the story of the challenges of NF, support one another, and rally to fight for a cure for the disorder. NF Walks give individuals and families the chance to involve their local community in finding treatments for NF, while educating them about what it means to live with the disorder.

In 2010, the NF Walk program continued its incredible growth and helped introduce 18 new regions and countless individuals to the challenges of living with NF. The program’s unique community nature allows for individuals to customize the event as best suits their area, and Foundation staff work closely with NF Walk volunteers to ensure a wonderful community experience.





TEAM

NF

Marathon Team

JULIE
11735
CORRAL E.

Darryl

NF

Endurance Team

DARRYL
11578
CORRAL E.



MAKING CONNECTIONS

Racing4Research



"It is difficult to express in words the overall experience we had but if I were to sum it up I would say "Inspiring". Our son Michael was able to meet his fellow NF Heroes and just enjoy being a kid with them! As a parent, this is something you cannot place a value on and I will remain forever grateful for allowing Michael that experience.

I can say without a doubt this weekend surpassed any expectation we had. My husband and I both realized it was because this was a race with true purpose and personal meaning. In racing you always want the win, in our minds CTF and TRG won the race before they even dropped the green flag!" - Karyn Z.

Racing4Research offers families an opportunity to view the challenges of NF in a different light by providing a positive experience that can be carried throughout the year. NF Heroes, children and adults who every day battle the challenges of NF, cheer on the Children's Tumor Foundation #4 car in the Rolex 24 Hours at Daytona every January. The event has become both an incredible racing experience and a wonderful support experience – with many families coming back year after year, and new families committing to join again the following year.

The 2010 campaign featured NASCAR star Kenny Wallace, who joined the Foundation in Racing4Research's largest fundraising effort to date. Additionally, a promotional version of the R4R car made pit-stops across the country, including at the NASDAQ Stock Exchange raising awareness about NF and the Children's Tumor Foundation's efforts to fuel the cure for the disorder.



STATEMENT OF FINANCIAL POSITION

Balance as of December 31,	2010	2009
ASSETS		
Cash and Cash Equivalents	2,632,346	2,011,726
Pledges and Other Receivables	16,915	197,798
Prepaid Expenses and other	209,198	130,977
Total Current Assets	\$ 2,858,459	\$ 2,340,501
Furniture and Equipment, net	22,460	14,624
Other Assets:		
Investments in Marketable Securities	3,588,531	3,005,050
Investments in Land	62,500	252,500
Inventory	25,315	-
Security Deposit	20,623	20,623
Other Asset	20,000	20,000
Total Other Assets	3,716,969	3,298,173
Total Assets	\$ 6,597,888	\$ 5,653,298

LIABILITIES AND NET ASSETS

Current Liabilities:

Accounts Payable	35,558	24,933
Accrued Expenses	36,690	37,992
Research Grants Payable	1,407,802	1,380,424
Total Current Liabilities	\$ 1,480,050	\$ 1,443,349

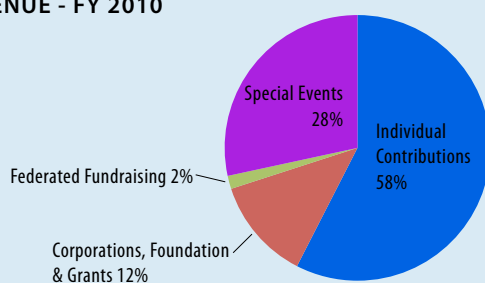
Long-Term Liabilities:

Grants Payable	190,250	109,000
Other Liabilities	20,000	20,000
Total Long-Term Liabilities	210,250	129,000
Total Liabilities	\$ 1,690,300	\$ 1,572,349

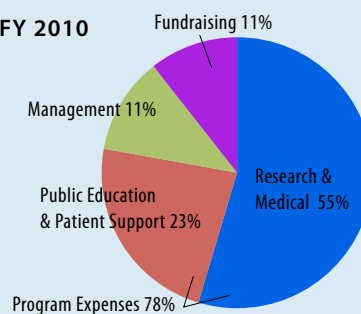
Net Assets:

Unrestricted, including 2010 and 2009 board designated net assets of \$3,402,654 and \$2,822,516, respectively	4,365,515	3,184,798
Temporarily Restricted	356,197	713,617
Permanently Restricted	185,876	182,534
Total Net Assets	\$ 4,907,588	\$ 4,080,949
Total Liabilities and Net Assets	\$ 6,597,888	\$ 5,653,298

REVENUE - FY 2010



EXPENSES - FY 2010



STATEMENT OF ACTIVITIES

12 months ending December 31,	2010	2009
Public Support, and Revenue:		
Contributions	4,287,180	3,853,008
Membership	5,185	4,825
Government grants	46,000	51,742
Corporations and foundations	899,538	894,175
Federated fundraising	121,444	113,195
Contributed goods and services	55,162	39,453
Other income	63,447	10,735
Interest and dividends	76,114	84,717
Gain (loss) on sale of assets	(2,188)	(2,972)
Realized and unrealized gain (loss) on investments	256,796	197,018
Total Public Support and Revenue before Special Events	\$ 5,808,678	\$ 5,245,896
Special Event Revenue:		
Special event revenue	2,330,815	1,542,811
Less direct benefit to donors	(236,725)	(209,874)
Net special event revenue	2,094,090	1,332,937
Total Public Support and Revenue	\$ 7,902,768	\$ 6,578,833
EXPENSES		
Program Expenses:		
Research and medical programs	3,864,568	3,884,830
Public education and patient support services	1,643,448	1,405,865
Total Program Expenses	\$ 5,508,016	\$ 5,290,695
Supporting Services:		
Fundraising	818,519	625,535
Management and general	749,594	505,275
Total Supporting Services	\$ 1,568,113	\$ 1,130,810
Total Expenses	\$ 7,076,129	\$ 6,421,505
Change in net assets	826,639	157,328
Net assets beginning, as restated	4,080,949	3,923,621
Net Assets, ending	\$ 4,907,588	\$ 4,080,949

This condensed financial information is derived from our audited financial statements included in our Annual Financial Reports. Copies are available by request, or in the About Us section of www.ctf.org.



bbb.org/charity





Alec Baldwin and 2010 NF Ambassador Rose Match Sura

FOUNDATION CONTRIBUTORS

The Children's Tumor Foundation expresses its deep appreciation to our supporters who in 2010 so generously contributed \$500 or more.

\$500,000 and above

Daniel & Jennifer Gilbert

\$200,000 and above

In Memory Of Issac & Sadie Fuchs

\$100,000 - 199,999

Agnes N. Williams
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NYU Cancer Institute
Pepsico Foundation Matching Gifts Program
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Pfizer Foundation Matching Gifts Program
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Skadden, Arps, Slate, Meagher & Flom LLP
Souderton-Telford Rotary Club
Suresh Nagapan & Sarah Jordan
SWS Bar BQ, Inc.
The 9th Floor Foundation, Inc.
The Ed Lee & Jean Campe Foundation, Inc.
The McGraw-Hill Companies
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Thomas Shankie
Tom Corney
Truist
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University of Michigan
Zygmunt & Audrey Wilf Foundation

\$2,500 - 4,999

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Andrea Vittorelli & Sukwan Han
Andrew and Amy Schafer

Arkansas Children's Hospital
Body Bronze, LLC
Brendon & Kirstin Lynch
British Columbia NF Foundation
Catherine Leys
ChemTreat, Inc.
Christopher & Mary Rulon
Cornell University - CMAA
Darawan Morrison
Darren & Marianne Mick
David & Holly Cook
David and Cindy Rulon
David and Gayle Ebel
David and Kristin Camiolo
Dennis Brininger
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IBM Employee Services Center
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Matthias and Jean Sheeleigh
Mattie T. Vega
Mello and Mary Jo Mitchell
Mendenhall Flying Lions Charities, Inc.
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Michael & Karyn Zazula
Michael & Melissa Phillips
Michael Lotter
Monson Savings
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Neurofibromatosis Association of Ireland
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America
Steve and Judy Kendra
Steven & Martha Grimmer
The Pierre Hotel, A Taj Hotel
Thomas & Melissa Grigg
Thomas Rust
Thomas Silvia & Shannon Chandley
Travelers Foundation - Community Action Award
Trustworthy Computing - Microsoft Giving Campaign
Tyres International Ind.
United Way of Metropolitan Atlanta, Inc.
Washington University in St. Louis
William and Cecelia Crouse
William and Lucy Bracer

\$1,000 - 2,499

5AM Venture Management, LLC
Aaron Goldberg
Aaron P. Smelser
Abigail Buss
Adam Mannes
Agnes Gund
Air Tech Cooling, Inc.
Alan & Caroline Furness
Alan & Sandra Schwartz
Alan & Shirley Sibley
Alan and Cheryl Cohen
Alan and Joanne Suna
Alexander and Karen Mauskop
Allan and Jane Rubenstein
Amber Owen
Amy Charters
Andreas and Adriane Halkias
Andrew & Laurie Brotman
Andrew B. Wrublin
Andrew K. Rayburn
Andrew Lance
Andy & Megan Tay
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Anthony Monterotti
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Antoinette Levison
APS Trucking Corp.
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Armen Manoogian
Arthur and Alice Domby
Arthur and Rebecca Shannon
AstraZeneca
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Barbara Miller
Barry and Rochelle Kaplan
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Brian Taylor
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Bruce and Madelyn Donoff
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