

DOUBLE YOUR DONATION: The Moffett Family 2.5 Million Dollar Matching Gift Fund

Longtime supporters of the Children's Tumor Foundation, Jim Bob and Laurée Moffett, have exhibited their generosity once more in the fight against NF with a \$2.5 million matching gift donation to the Children's Tumor Foundation. The donation is to support the Foundation's newest consortium science effort, Synodos for NF1.

"This generous pledge from the Moffetts comes at a transformative moment in NF research, and will have significant impact in the development of new treatments for NF," said Annette Bakker, President and Chief Scientific Officer of the Children's Tumor Foundation. "On behalf of the entire NF community, we are deeply grateful for their ongoing commitment in the fight to end NF."

Jim Bob Moffett added, "This effort is logical, it is simple, and I believe in it."

Synodos is an innovative approach by the Children's Tumor Foundation to develop treatments for NF through a multidisciplinary consortium of scientists from various backgrounds and institutions, all committed to collaboration and data-sharing so as to lead to faster and better treatments. Synodos for NF2 is underway; this gift from Mr. & Mrs. Moffett will launch Synodos for NF1.

Please visit ctf.kintera.org/synodosnf1 to make a donation. All contributions made through this page will be matched dollar-for-dollar.



CTF Launches SYNODOS FOR NF1

Due to the huge success of the Synodos for NF2 consortium, the Foundation is launching two Synodos for NF1 Calls. Both will be aimed at creating multi-disciplinary consortia that address central issues in NF1.

The first Synodos for NF1 initiative ("Call A") will focus entirely on low-grade gliomas with emphasis on a deep understanding of the biology of these tumors and identification of new molecular mechanisms using a plethora of analysis techniques.

The second Synodos for NF1 initiative ("Call B") will focus on the development of innovative methodologies or animal models that can accelerate preclinical evaluation of innovative treatments and, therefore, accelerate the path to a cure.

Each Call will be funded at \$2 million over three years. Deadline for applications is 5:00 p.m. EST on Friday, January 16, 2015. Please visit ctf.org/Research/Synodos-for-NF1.html to apply.

Synodos for NF1 will be multidisciplinary in nature. Researchers and clinicians with different areas of expertise, such as basic biology, animal pharmacology, imaging, and clinical work, will be included in the consortium. The sharing of data and results will be supported by the Foundation, and the Sage Bionet-work platform will be expanded to Synodos for NF1.



Children's Tumor Foundation President, Annette Bakker, PhD, along with members of CTF's Board of Directors and several NF Heroes, rang the New York Stock Exchange closing bell on July 10, 2014. Coverage appeared on numerous TV outlets including CNBC, CNN, Fox Business, and Bloomberg.

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LETTER FROM THE PRESIDENT

Annette Bakker, PhD



Sometimes, taking a leap of faith is the only way forward.

Dr. Marge Foti, MD, PhD, is a great inspiration to me. As CEO of the American Association for Cancer Research, Dr. Foti's visionary work in the study of cancer manifested itself in Stand Up To Cancer's highly successful "Dream Team" model. This model unites talented researchers from multiple institutions, emphasizes collaboration and information sharing in order to expedite the drug discovery process, and ultimately provides faster clinical benefits to cancer patients. When first articulated some years ago, Dr. Foti's "Dream Team" idea was unprecedented. She thought outside-of-the-box and took a leap of faith, believing wholeheartedly that the "Dream Team" approach would yield results.

Dr. Foti's leap of faith is paying off; Stand Up To Cancer is delivering incredible results. Now backed by some of the most powerful players in the entertainment industry, the organization raised \$109 million dollars in early September to further fund their outstanding research. Dr. Foti has proven that sometimes you need to do things differently in order to make the world take notice.

I am also inspired by Dr. Steven Friend, MD, PhD, the founder and president of Sage Bionetworks, who has that same spirit. Some of you had the pleasure of hearing him speak at the NF Forum in Washington, D.C. He is a proponent of pushing people out of their comfort zones and asking them to reconsider their operational models and adapt their thinking to new ideas when needed.





Dr. Foti and Dr. Friend have been immensely supportive as the Children's Tumor Foundation took its own leap of faith, adopting a funding and research model based on Stand Up To Cancer's "Dream Teams." We knew a similar approach was right for neurofibromatosis research, so we launched Synodos for NF2 and a united front of extremely talented scientists and a panel of world class reviewers, some of whom are also part of Stand Up To Cancer, agreed that the initiative merited funding and participation. The results are just outstanding; Synodos for NF2 delivers! This amazing team of scientists, as well as the reviewers, will be guests at our upcoming gala in New York City on October 30th.

With the success of Synodos for NF2 already apparent, we recently took a second leap of faith. We knew the same model would work for NF1. We found an incredible businessman who understands that the return on investment in CTF-funded research is clinical trials that will lead to treatments for our patients. With the generous support of Jim Bob and Laurée Moffett, we now are launching Synodos for NF1.

Not so long ago, we would not have thought any of this was possible, but here we are! With teams of highly talented scientists working together, sharing resources and research, we are breaking down barriers and accelerating the speed of drug discovery. We do this with a fierce determination modeled on the impressive fortitude we see in the patients living with NF. For them, we wake up early in the morning and work late into the evening. For them, we will not stop until we find a way to end NF.

There is no better place to make a difference for those with NF than the Children's Tumor Foundation. Please join us in any capacity you can as we work to revolutionize the field of neurofibromatosis research.

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2014 DRUG DISCOVERY INITIATIVE AWARDS: Round 1 Recipients

The Drug Discovery Initiative (DDI) awards program is focused on seed funding preclinical drug testing studies on neurofibromatosis in cell or animal models, and is one of the most successful Children's Tumor Foundation programs to date. The Foundation is pleased to announce the most recent recipients of this important grant.

Miriam Smith, PhD
University of Manchester

Treatment of Neurofibromatosis Type 2 (NF2) by Exon Skipping

Neurofibromatosis type 2 (NF2) is a neurogenetic disorder that predisposes patients to develop tumors of the nervous system. It is known that NF2 disease is caused by mutation of the NF2 gene. Dr. Smith will use the DDI award to develop a cutting-edge method to 'rescue' mutations in coding regions of NF2, where 98-99% of small mutations are found.



Gregory Riggins, MD PhD
Johns Hopkins University

Testing Combinations of FDA-approved Agents with and without Radiation Therapy in an NF2 Schwannoma Murine Model

Dr. Riggins will use the DDI award to examine the safety and efficacy of radiation combined with compounds that effect NF2 tumor growth through multiple pathways, including kinase inhibitors and mTOR inhibitors. He will first test the toxicity and efficacy of each compound alone and then will test their effect together with and without radiation therapy.



David Largaespada, PhD
University of Wisconsin-Madison

Targeting Hyaluronic Acid for NF1-associated Tumors

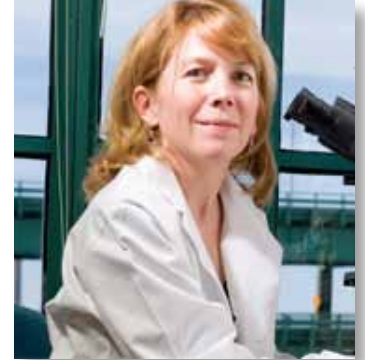
Malignant peripheral nerve sheath tumors (MPNST) remain the leading cause of death for NF1 patients and most therapies have failed to demonstrate effectiveness against plexiform neurofibromas and MPNSTs. Recently, Dr. Largaespada and colleagues showed that a combination of two drugs, RAD001 and PD-901, were effective at treating mice that develop Schwann cell tumors. To improve drug delivery to the tumors, Largaespada will combine these drugs with PEGPH20, which has been shown to safely and effectively improve drug delivery and efficacy of chemotherapy in patients.



Andrea McClatchey, PhD
Harvard Medical School

Preclinical Investigation of Centrosome Unclustering Drugs in NF2-mutant Schwannoma

Excess numbers of centrosomes, a part of the cell that is essential for normal cell division, occurs in many different tumor types and is a feature of tumors that differentiate them from normal cells. Merlin has a key role in controlling the number of centrosomes within cells. Dr. McClatchey will use the DDI award to test if NF2 tumors are more sensitive to drugs that target excess centrosomes.



For more information, please visit www.ctf.org/ddi.



More Children's Tumor Foundation Resources Available in Spanish

This fall, CTF is introducing two new features for the Spanish-speaking members of our community. People whose first language is Spanish will now be able to go to www.nfregistry.org and access the surveys in Spanish. In addition, our popular Newly Diagnosed with NF1 booklet is now available in Spanish. For copies, or a link to this publication on our website, please email info@ctf.org.

Children's Tumor Foundation Attends 16th European Neurofibromatosis Meeting

The 16th European Neurofibromatosis Meeting, a conference that is convened every two years, was held September 4-7 in Barcelona, Spain. Scientists and clinicians from across Europe and the United States made presentations related to new findings in neurofibromatosis research with an emphasis on the psychosocial dimensions and unique challenges of living with NF.

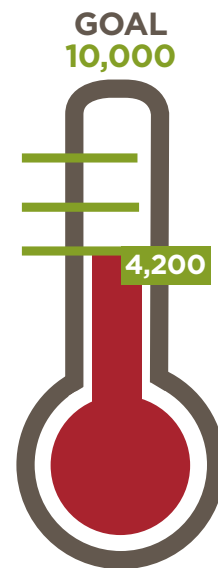
Dr. Annette Bakker, PhD, President and Chief Scientific Officer of the Children's Tumor Foundation, gave a presentation at this meeting on "News and Opportunities from CTF." Dr. Bruce Korf, MD, PhD, Chair of the Foundation's Medical Advisory Committee, and Dr. Jaishri Blakeley, MD, Director of the Johns Hopkins Comprehensive Neurofibromatosis Center, also presented. John Heropoulos, Vice President of Advocacy and Community Building at CTF, attended the Science and Research meetings and took part in the Program for Lay Groups. It is very important for the Foundation to be present at these meetings as it nurtures relationships between NF researchers and lay people from the United States, Europe, and around the world. The sharing of scientific and medical information, and the exchanging of thoughts and ideas on how NF families live and thrive in all cultures, is of vital importance to finding better treatments for neurofibromatosis and more creative ways to support those with NF.

NF CLINIC NETWORK UPDATE

Two new clinics have been added to our NF Clinic Network (NFCN). **All Children's Hospital/Johns Hopkins Medicine** in St. Petersburg, FL and the **University of Rochester Medical Center** in Rochester, NY were recently approved as NFCN members by CTF's Clinical Care Advisory Board. This brings the NFCN to 47 centers.

NF REGISTRY UPDATE

Thanks to the efforts of dedicated NF clinicians, our volunteers, and people in the NF community, the NF Registry has reached a total of about 4,200 members. Although we still need to recruit many more, this is a large enough number to do a preliminary data analysis. This analysis is expected to yield results by November 2014, and will be used to demonstrate the value of the NF Registry, and for other purposes, such as finding out if we need to reach out to specific patient populations that are under-represented. The analysis will be presented on CTF.org and submitted to scientific journals to show both the value of the NF Registry and how we can improve it. For more information, or to join, please visit www.nfregistry.org.



SAVE THE DATE



SAVE THE DATE

APRIL 17-19, 2015
NF FORUM | SCOTTSDALE, AZ



Children's Tumor Foundation in the News!

The Pink Sheet, a leading biotech publication, recently published two widely-read articles about the Foundation's business partnership model. Please visit ctf.org/blog to read more about the coverage, titled *Neurofibromatosis*

Could Drive Cancer Indications, Advocacy Group Says, and *A Shift in Thinking: FDA Moves Towards Easier Neurofibromatosis Endpoints*. Both articles illustrate CTF efforts in fostering a faster path to drug approval.

Pharma&MedTech
BusinessIntelligence

NEUROFIBROMATOSIS THERAPEUTIC CONSORTIUM PRECLINICAL UPDATE

The **Neurofibromatosis Therapeutic Consortium** (NFTC) has successfully completed its first year.

On Aug 14th, the NFTC's steering committee and advisors held a meeting at the Children's Tumor Foundation's office to evaluate the 2013-14 effort, and approve the proposed 2014-15 activities. Karen Cichowski, PhD, Scientific Director of the NFTC, reported the Consortium's findings and the increased throughput of compounds with a total of 22 trials tested in the first year, compared with 52 trials completed in the 2008-2013 period.

NFTC advisors who participated in the meeting included Gideon Bollag, PhD, CEO of Plexicon, Jake Vinson, MHA, Director of the Prostate Cancer Clinical Trials Consortium, Brigitta Widemann, MD, of the National Cancer Institute, Helen Chen, MD, of the Cancer Therapy Evaluation Program, and Karen Chen, PhD, Chief Scientific Officer of the Spinal Muscular Atrophy Foundation.

The group was pleased with the work completed by the NFTC members. The results of these studies not only increase the understanding of how treatments may benefit NF patients, but these preclinical studies are particularly meant to bring the very best drug candidates to clinical trials. Also, the Congressionally Directed Medical Research Program (CDMRP) funded clinical trials consortium group was very impressed with the NFTC's results as reported at the meeting in Washington D.C. last June. The members of CDMRP were confident that the NFTC adds substantial value in deciding which molecules to prioritize for clinical trials.

The Isaac and Sadie Fuchs Genotype-Phenotype Study

One of the great challenges facing individuals living with NF1, and their families, is the uncertainty of what the future may bring. For example, a patient diagnosed with NF1 may suffer from learning disabilities, bone abnormalities, optic nerve tumors, tumors elsewhere in or on the body, and a number of other potential complications. Or they can face none of these complications at all. That uncertainty, and the uncertainty of how to treat a complication that does arise, is fundamental to the challenge of battling NF. To address this concern and to answer a number of important scientific inquiries about the nature of NF1, the Foundation has set out to fund a study that examines NF1-related mutations and their likely outcomes.

Approximately 6,300 different gene mutations have been identified in NF1, yet very few NF1 genotype-phenotype correlations have been firmly established. The Isaac and Sadie Fuchs Genotype-Phenotype Correlation Study in NF1 – which will be funded by the Children's Tumor Foundation, and initiated at the University of Alabama at Birmingham's Medical Genomics Laboratory – will work to unravel the connection between the specific gene mutation of individuals living with NF1, and the way that mutation manifests itself.

This study will serve the NF1 population in three important ways: 1) it will allow better understanding of biological targets for treatments, and in turn develop better treatments for NF1; 2) it will inform clinicians of which patients are the best candidates for clinical trials; and 3) it will provide individuals and their families with a better idea of what health concerns they need to monitor most closely – and consider preventative care for.

For more information, please contact **Garrett Gleeson**, Children's Tumor Foundation Program Director, at **646-738-8545** or **ggleeson@ctf.org**.

RESEARCH NEWS

Synodos for NF2 Update

The Synodos for NF2 consortium, comprised of eight institutions and 12 Principal Investigators, first gathered on February 4th to arrange all of the necessary agreements, and officially began laboratory activities on May 1, 2014.

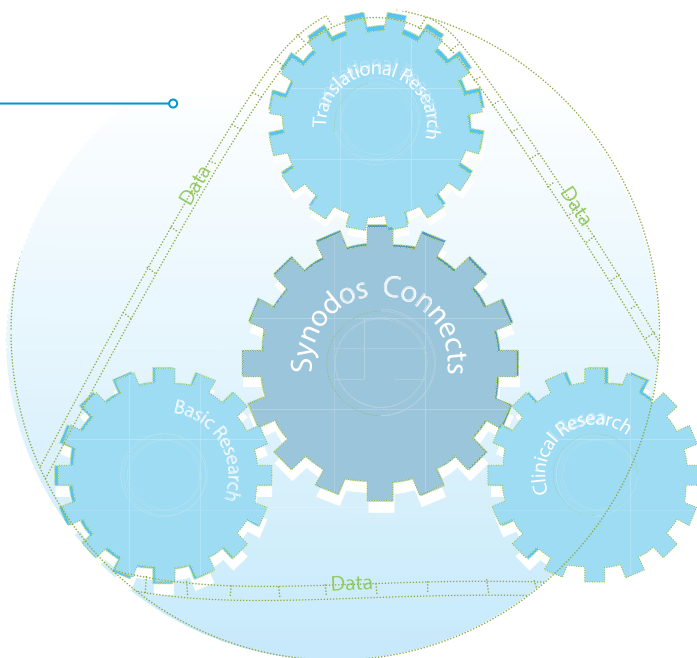
Since then, the group has been working at an impressive pace, generating the first set of data and moving towards achievement of the first milestone in the plan.

The group is responding with synergy and enthusiasm to the project's progression. Sage Bionetworks is very engaged in managing the project data and they have enriched the new datasets with existing literature data from other sources. They are committed to fully supporting the researchers and are building all the necessary, tailor-made tools that are needed to analyze the forthcoming data.

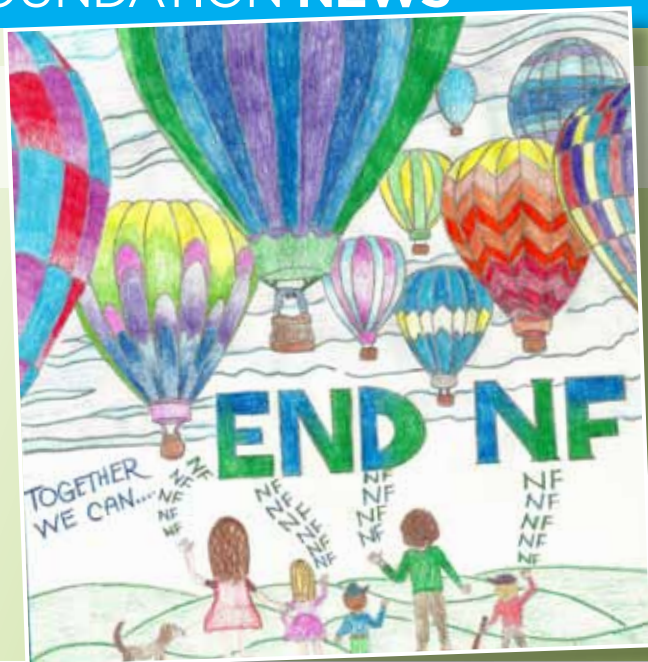
According to the project plan, the next milestone is due in February 2015 with the completion of the primary screening of the selected drug on all selected cell lines. In May 2015, the second main milestone will be reached with major results coming from analysis of data; Synodos for NF2 will have full transcriptome, Kinome, and exome analysis. The latter will allow a fully informed start of the in vivo studies.

The first six-month review of the project will take place on Oct 30th in New York City, the day of the Children's Tumor Foundation's annual New York gala. The steering committee will meet to learn about the progress of the project, the overall

analysis of the project plan, the confirmation of next year's milestones, and the associated budget needs. The Principal Investigators, as well as the Synodos for NF2 reviewers, will be present at the NYC gala to celebrate collaboration.



FOUNDATION NEWS



Kids Program T-Shirt Design Contest Winners

The Children's Tumor Foundation Kids Program, an initiative in which children complete age-appropriate races at NF Endurance and NF Walk events, hosted its first Kids T-Shirt Design Contest over the summer. More than 40 creative entries from kids across the country were submitted. The winning design was drawn by three sisters, Emma (age 13), Calin (age 9), and Braidy (age 6), who worked together in honor of their brother, Sean, who has NF1. Their design will be featured on T-shirts for CTF Kids Program events beginning this fall. To see all the entries, or to learn more about the Kids Program, please visit www.ctf.org/kids.



Three Cheers for Team Garrett!

For the second year in a row, Team Garrett banded together to run America's Finest City Half Marathon in San Diego to show their love and support for Garrett Baumann, who lives with NF2, and his family. This year the team more than doubled in size, with over 100 participants, and raised \$25,000.



RUNNING IN THE WINDY CITY

It has been a busy summer in Chicago! The Rock 'N' Roll Half Marathon took place in July and the Chicago Triathlon closed out August. Team News America Marketing led the way with over \$13,000 raised! Race season came to a close with the iconic Bank of America Chicago Marathon where nearly 50 athletes raised over \$65,000!



NF Endurance AROUND THE WORLD

Next year brings two international races! The Virgin Money Marathon in London will be held on April 19, 2015 and an exciting new addition, the BMW Berlin Marathon, is on September 27, 2015. Entries are still available! For more information please, contact **Lauren Walsh** at lwalsh@ctf.org.

HELP US MEET OUR GOAL

We need to raise \$300,000 by December 31, 2014 to meet our NF Walk goal of \$1 million to fund treatments and a cure for NF. Help us by joining or donating to an NF Walk TODAY! www.nfwalk.org

Recent Events

SEATTLE: Congratulations to Team Isla who raised more than \$18,000 for NF research! Team Isla consisted of 45 family and friends walking in support of Isla Riley at the Seattle NF Walk.

PORTLAND: The second annual Portland NF Walk was a fun event for families and the community alike. Participants enjoyed face painting, a Kids Hero Dash race, a hula hoop contest, break dancers, a photo booth, and a raffle.

UTAH: Everyone had an amazing time at the Utah NF Walk which featured a fire truck, a photo booth, Lowe's building kits, fantastic raffle prizes including a trip to Disney Land, and costumed Star Wars characters.

DENVER: Participants at the Denver NF Walk had a day of fun featuring a kids' carnival, balloon animals, yoga, a silent auction, live music, massage chairs, a Kids Hero Dash race, and more. The event raised over \$40,000 for NF research!

NF WALK SUMMIT: The weekend of July 25-27th, 27 NF Walk organizers, committee members, and team captains attended the first NF Walk training and education summit in Portland, OR. The weekend was a successful collaboration of volunteer training, education, and empowerment. All involved returned home motivated to grow NF Walk events to their full potential.



UPCOMING NF WALKS

November 8:
Las Vegas

November 15:
San Diego

Are you looking for a place to meet and connect with other NF families? Look no further than an NF Walk! Visit www.nfwalk.org to find an NF Walk event in your area. We are planning our spring schedule of events, so be sure to visit our website often and mark your calendars!





Racing4Research: Raising NF Awareness and Trophies!

It's been a summer of raising NF awareness and raising trophies for our Racing4Research teams across the country (and into Canada as well)!

Along with our partner teams, Park Place Motorsports and Compass360 Racing, the Children's Tumor Foundation "Art Car" program – featuring the eye-catching livery with artwork by renowned artist and NF Hero Jeffrey Owen Hanson – has captured nine podiums including wins by both C360R Hondas. In June, the No. 75 Honda of Ryan Eversley and Kyle Gimple took an exciting win at Watkins Glen while the No. 72 of Karl Thomson came home with top honors at Brainerd in August. Throughout the season, Children's Tumor Foundation NF Heroes have been on hand at tracks across the country – from Kansas to New York, Virginia to Ohio – sporting their blue CTF T-shirts and cheering the teams to victory.

"It's wonderful to have had such great success with our partner teams this season," noted Racing4Research Program Director Jill Beck. "At each event, we invite local families living with NF to cheer on our Art Cars. Seeing their smiles and knowing that they face the challenges of living with this disease daily makes us push even harder to raise donations to fund the research that will end NF."

As the season begins to wind down, with season finales in Salt Lake City, Utah and Atlanta, Georgia, the program will shift its focus to The Benefit New York – the Foundation's annual fundraising Gala that, this year, will feature the Racing4Research program. Jeff Hanson will be honored as our CTF Ambassador and Park Place Motorsports, Vess Energy, and Compass360 Racing will be recognized for their unwavering support of the Foundation and NF research. Three of the CTF "Art Cars" will be on display outside of The Plaza Hotel on Thursday, October 30th, and many live auction items will be donated by CTF's partners in the racing community including Pirelli, Honda Racing, McLaren, and BRM Chronographs. It should prove to be an exciting evening of fundraising as we continue to fuel the cure for NF!



MEET THE STAFF

Emily Crabtree



HOMETOWN:

Crystal Lake, IL

CURRENT TOWN:

Chicago, IL

EDUCATION:

BS in Applied Behavioral Sciences from National Louis University.

WORK WITH THE FOUNDATION: I'm the Program Director for the NF Endurance team and work remotely in the "Chicago Office."

FAVORITE EXPERIENCE WITH THE FOUNDATION:

My favorite part of this job is seeing the connections that our athletes make with the kids in our NF Hero program. Seeing runners cross the finish line at these races while raising money in honor of a child with NF is so incredibly moving. It makes me realize that what we do on a daily basis really makes a difference. People not only push themselves to the limit with their fitness goals, but also with their passion to fight NF. There is nothing better than seeing a video posted on Facebook by one of our NF Heroes encouraging an athlete to keep going with their training and to keep fundraising. Who could say no to that?!

FAVORITE HOBBY: My husband and I recently had an addition to our family – a goldendoodle puppy! Hazel, who is now six months old, has all of a sudden become the center of our lives. We love taking her on long walks, playing with other dogs in the neighborhood, and taking her to the dog beach. We've even joined a Chicago Doodle Facebook group and do regular outings with fellow goldendoodle owners in the city!

MEET THE BOARD

Kenneth Rudd



HOMETOWN: New York City

CURRENT TOWN:

I still live in New York City.

EDUCATION:

Amherst College and the University of Virginia School of Law

WORK WITH THE FOUNDATION:

In 2007, I had the privilege of being recognized as the CTF Ambassador at the annual Gala in New York. I was elected to the Board of Directors in 2014. I look forward to serving the Foundation, helping it grow, and furthering its very important goals.

FAVORITE EXPERIENCE WITH THE FOUNDATION: I have been around the Foundation to witness its growth from shortly after it was founded to becoming the amazing organization it is today. I was a child when I first consulted with Dr. Allan Rubenstein, one of the three founders of the then National Neurofibromatosis Foundation. My parents soon got significantly involved, and my mother, Joan Engel, was the Foundation's first president after one of the other co-founders, Lynn Courtemanche, stepped down. Indeed, for a time the Foundation's offices were in my family's den! It was been truly awesome watching the Foundation grow from those early days, to the hiring of its first full time professional staff, to seeing the significant milestones that have been reached with the Foundation's assistance, including the discovery of the NF1 and NF2 genes and other scientific achievements. I have also been privileged to see the growth in the Foundation's successful fundraising efforts, having attended most annual benefits since the very first Harvest Dinner. I hope to continue these experiences now in my new role.

FAVORITE HOBBY: I used to scuba dive, but unfortunately it's been several years since I've been diving. I hope to pick that up again.

NEW FACES AT THE CHILDREN'S TUMOR FOUNDATION

Welcome to the Foundation's newest staff members!



Michael A. Divers
Vice President, Major Gifts and Major Events
mdivers@ctf.org



Carey Milligan
Accountant
cmilligan@ctf.org



Hyerim Lee, PhD
Science Project Leader,
hlee@ctf.org

Jennifer White
NF Walk Coordinator
jwhite@ctf.org



NF CAMP: Where Kids Can Just Be Kids

Nestled in the Emigration Canyon of Salt Lake City, Utah, Camp Kostopulos recently hosted 60 NF Heroes for two one-week NF Camp sessions in July. NF Camp is six days of summer fun - waterslides, zip lines, horseback riding, canoeing, and more. After all of the surgeries, MRIs, and doctor appointments, NF Camp is a welcome break that allows kids to just be kids.

At NF Camp, our NF Heroes are surrounded by other NF Heroes facing similar issues. This makes them feel a part of something; a team, a community. While the Foundation works hard to fund the best research and build the NF Registry, it also offers NF

Heroes ages 12-21 the chance to build a community at NF Camp. CTF provides multiple outlets that are great support for NF parents such as state chapters, NF Walks, and the NF Forum. But the support that young adults really need is each other.

Being a kid these days isn't always easy, especially if you have neurofibromatosis. Through NF Camp, the Children's Tumor Foundation offers NF Heroes the opportunity to forget their troubles for a while and return home feeling happy, strong, proud, and empowered.



NF Camp Director Julie Pantoliano, second from right, with NF Heroes at Camp Kostopulos in Utah

For more information about NF Camp please visit www.ctf.org/NFcamp or contact Julie Pantoliano at jpantoliano@ctf.org.

STORIES OF NF:

PJ Verona



My name is Paul "PJ" Verona, I'm 28 years old, from Chester, New Jersey, and I have NF1.

I was diagnosed with neurofibromatosis at an early age and the disorder has manifested itself as multiple café au lait spots and benign cutaneous growths that cover my arms, legs, and torso. These abnormal growths are not painful but are removed with minor surgery when they grow too large.

I graduated from Franklin and Marshall College in 2009 with a BA in neuroscience and Italian. After graduating, I moved to Padova, Italy where I worked as a Research Assistant in an immunology lab studying tumor suppression and progression.

Upon returning home, I decided to go back to school for a PhD in Clinical Anatomy. However, as part of my curriculum, I was required to perform physical exams on patients and realized that I belonged in medicine as opposed to research and teaching. Putting the doctorate degree on hold, I applied to medical school.

Currently, I am studying at St. George's University School of Medicine in Grenada, West Indies. I still have several years left, but whatever I end up specializing in, I want to incorporate NF into my practice.

JOIN THE NF REGISTRY AND YOU CAN HELP END NF

ANNA HARLAND
Havertown, PA
Lives with NF1

**I joined the
NF Registry
because...**

"THERE IS POWER IN NUMBERS."

www.nfregistry.org

REGIONAL NEWS

Great Events from Across the NF Community

The Foundation has a presence in nearly all 50 states and facilitates local patient support groups, medical symposia, and fundraising events. Learn more about the Children's Tumor Foundation Chapter in your area by visiting www.ctf.org/communityrelations.

UTAH

CTF's Utah Chapter hosted their Annual Women's Day on May 31st in Salt Lake City. It was an afternoon of sharing and support by the local women of the NF community.



CALIFORNIA

On June 14th, the California Chapter of CTF, along with California NF, hosted an "Ask the Doctors" seminar at the University of California, San Diego in La Jolla, CA. The event featured a panel of seven NF specialists who spent the afternoon answering attendees' questions, and a "Kids' Club" where NF Heroes and their siblings played.



MISSOURI

To honor his friend Luke who passed away due to NF, Jason Yeager held a fundraiser for the Children's Tumor Foundation. He enlisted the help of Kim Davis and Catalent Pharma Solutions and hosted a bake sale that raised \$3,495 to help further NF research.



MASSACHUSETTS

Bonnie and Richard Banks hosted their annual daylily sale event in Carver, MA and raised over \$3,000 for CTF. Supporters came out in droves to purchase the hybrid selection of homegrown lilies in a gorgeous selection of colors.



CTF AD APPEARS IN OVER 4,000 STORES

Thanks to the generosity of News America Marketing, an advertisement raising awareness of NF and the Children's Tumor Foundation is appearing on shopping carts in over 4,000 stores across America including Kmart, Albertsons, Safeway, Save Mart, FoodMaxx, Vons, Giant Eagle, Ingles, Weis, Piggly Wiggly, Associated Foods, C&S Grocers, and many others. Thanks also to IMS for designing the ad. For more information, please visit ctf.org/helpfightnf.



RHODE ISLAND
 This year's Providence NF Walk was the most successful to date with nearly 100 attendees and \$18,000 raised. The event featured Zumba, face painting, a DJ, and food trucks. Congratulations Ocean State!



MASSACHUSETTS

The 2014 Boston NF Walk was held on Carson Beach in South Boston and featured its first annual "Kids Hero Dash" race, face painting, a visit from SpongeBob SquarePants, lunch, and ice cream donated by JP Licks. This event raised over \$23,000 for NF research.



UTAH

The inaugural "#EndNF with Travis Classic" golf tournament took place at The Ridge Golf Club in Salt Lake City on May 17th. Sixty-eight golfers from as far away as Billings, Montana were present and had a great time on the course with NF Hero Travis Carpenter. They competed for over \$35,000 in team prizes, hole prizes, and other give-aways that were donated from businesses throughout the greater Salt Lake City and Park City communities. Special thanks to Matt Solum for his tireless efforts in developing this outstanding event which raised \$44,000. Look for information on the second annual "#EndNF with Travis Classic" in early 2015.

CALIFORNIA

Alyson and Steve McKenzie hosted an "Evening About NF Research" with Dr. Annette Bakker, CTF's President and Chief Scientific Officer, at Hotel Mdr in Marina Del Rey, CA on July 17th. The event was informational and enjoyable as attendees sipped cocktails poolside while learning about the Foundation's newest initiatives in NF research.



TENNESSEE

On July 26th, CTF volunteer Daniel Smith helped Music City Dream Cars host their first annual "Dream Cars for Charity" event in Nashville. Over 1,000 people attended, and \$1,000 was raised for NF research.



REGIONAL NEWS



OREGON

CTF's Oregon Chapter hosted a Lakeridge Boys Varsity Lacrosse event on April 26th in Lake Oswego OR that raised over \$2,000 for NF research.



TEXAS

The Texas Chapter of CTF, Joyful Beginnings Lutheran Church, and Pollard United Methodist Church in Tyler, Texas sponsored a variety show on March 22nd that featured musicians, vocalists, singer-songwriters, a storyteller, a clown, and a magician. The dinner event included a silent auction and raised \$8,215 for the Children's Tumor Foundation. Over 250 people attended, and Outback Steakhouse was the largest donor giving all of its proceeds from the dinner to the Foundation.



COLORADO

The Colorado Chapter of CTF hosted a Mother's Day Tea for NF on May 10th at the Willow Way Clubhouse in Denver. The event included light hors d'oeuvres and flowers for each attendee. Author Kristi Hopkins gave a speech about her NF journey and signed copies of her book, Thriving with Neurofibromatosis. Jennifer Janusz, Psy.D., ABPP-CN, spoke about the local NF Clinic, and Shelley Pesta, President of the Colorado Chapter, updated everyone on coming events.



CALIFORNIA

On May 15th, CTF's California Chapter participated in the Corporate Giving Team Volunteer Showcase at NetApp, a Fortune 500 technology company in Sunnyvale, CA. Andrew Pritchard, a longtime supporter of the Foundation and its Racing4Research program, hosted this event to raise awareness for NF.



OHIO

Cleveland's Got Sole, an annual sneaker exhibition, was held at The Q Arena and raised \$23,000 for the Foundation. Over 2,300 attendees had the chance to peruse and purchase sneakers provided by various sponsors and vendors. In addition to enjoying the shopping, all attendees were given information about NF.

THE BENEFIT *New York*

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NF News is the official publication of the Children's Tumor Foundation and is published quarterly. All issues are available on our website at www.ctf.org. Please direct any questions or feedback to the editor (listed below).

The Children's Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to finding effective treatments for the millions of people worldwide living with neurofibromatosis (NF), a term for three distinct disorders: NF1, NF2, and schwannomatosis. NF can cause tumors to grow on nerves throughout the body and may lead to blindness, bone abnormalities, cancer, deafness, disfigurement, learning disabilities, and excruciating and disabling pain. NF affects one in every 3,000 people, more than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's disease combined. The Children's Tumor Foundation funds critical research into neurofibromatosis. In addition to benefiting those who live with NF, this research is shedding new light on several forms of cancer, brain tumors, bone abnormalities, and learning disabilities, ultimately benefiting the broader community. For more information, please visit www.ctf.org.

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