

## Searching for Answers:

*First Optic Pathway Glioma Multicenter Clinical Study co-funded by CTF and Gilbert Family NF Institute*

The Children's Tumor Foundation and the Gilbert Family Neurofibromatosis Institute will co-fund a five-year collaboration involving 25 NF clinics in a study of optic pathway glioma (OPG) in children with neurofibromatosis type 1 (NF1). 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. The treatment is chemotherapy, so it is vital to know when this is necessary and when it can be safely avoided.

The decision to start therapy is a challenge for clinicians because the effects of OPG are highly unpredictable. OPGs are not typical tumors. Half to two-thirds show minimal tumor progression. When they do progress, they tend to grow slowly. They sometimes shrink without treatment. Some clinicians advocate treatment when there is either tumor growth seen on an MRI or visual deterioration. Other clinicians reserve treatment only for patients that clearly have visual deterioration.

This multicenter collaboration, chaired by two top principal investigators in the field, Michael Fisher, MD, and Robert Avery, DO, MSCE of the Children's Hospital of Philadelphia, is an observational study. This means that there is no new treatment being tested; each enrolled patient's doctor will decide whether to recommend conventional treatment. Patients will have their vision checked periodically during the study and, if treated, after treatment for a period of three years. Some centers will begin enrolling this spring, with the others to follow. Please look for more about the OPG Consortium at [ctf.org](http://ctf.org).

## Synodos for NF1 Kick-Off Meetings:

*The Children's Tumor Foundation brings together interdisciplinary teams of neurofibromatosis experts*

A group of world-class scientists and clinicians from various disciplines gathered in Minneapolis, Minnesota, in January for the first of two Synodos for NF1 kick-off meetings. Synodos for NF1 brings together multidisciplinary teams of scientists, clinicians, technicians, patients, and other neurofibromatosis (NF) experts from world-class labs at academic and medical centers. These scientists have pledged to work together and share unpublished information, datasets, and results, thereby accelerating the drug development process.

*Continued on page 4*



## You Met the Match!

Thank you to the hundreds of donors, families, and corporations who contributed to the Synodos for NF1 Matching Gift Fund. In 2014, Jim Bob and Laurée Moffett pledged to match contributions toward Synodos for NF1 dollar-for-dollar up to \$2.5 million. It is with tremendous gratitude that we announce that the match was met in early 2016. Thank you Jim Bob and Laurée for making Synodos for NF1 a reality!

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[nfregistry.org](http://nfregistry.org)

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## LETTER FROM THE PRESIDENT

***Annette Bakker, PhD***



As we begin 2016, I wish all of you much happiness and success in the New Year. I want to express my pride and gratitude for your accomplishments in the year now behind us. The neurofibromatosis (NF) community has never been stronger. The dedication of our researchers, clinicians, volunteers, advocates, generous donors, and especially of our NF Heroes, has resulted in increased funding, exciting research, greater awareness, and stronger collaborations.

Synodos for NF1, which will focus on low grade gliomas and preclinical acceleration, is now a reality thanks to the philanthropic leadership of Jim Bob and Laurée Moffett. Because of the efforts and generosity of many of you, the Moffett's extraordinary \$2.5 million matching gift has been met.

This past year we saw a phase II registration trial for the MEK inhibitor selumetinib, the most promising compound to date to shrink inoperable plexiform neurofibromas. The Children's Tumor Foundation (CTF) was critical in funding preclinical testing of this compound, and hopes are high that it will become the first ever FDA-approved NF treatment. The Foundation's investments in research initiatives are attracting follow-on funding from the likes of the NIH and the NF-dedicated Congressionally Directed Medical Research Program (CDMRP). This is a testament to the quality and promise of the research you have supported, and surely increases the possibilities of more promising potential NF treatments in the pipeline.

We are eager to get specialized NF care to more patients around the country, and we're proud to have added three new clinics in 2015 to our now fifty-member NF Clinic Network. In addition, we have launched a new Community Building and Patient Engagement initiative to more closely engage patients. This initiative will integrate the patient voice into all phases of research and development at the Foundation. In December, our friend and 2015 CTF Ambassador Jeff Hanson won the NASCAR Foundation's Betty Jane France Humanitarian Award. Through the collective efforts of Jeff, his family, and all of your votes, Jeff brought home the \$100,000 prize for CTF. Amazing stuff!

As we move into 2016, the spirit of working together continues. An exciting new Optic Pathway Glioma Consortium that has been in preparation since 2014 is launching. This collaboration is co-funded by CTF and the Gilbert Family Neurofibromatosis Institute, and enormously impacts patients and their treatment.

As we prepare for May NF Awareness Month, there are many ways for you to become involved in your community, from NF Walk to helping our friends from Cupid's Undie Run. Thank you for joining forces with us in the fight to end NF!

Warmest wishes,

## CLINICAL RESEARCH AWARDS

The Children's Tumor Foundation's Clinical Research Award (CRA) program supports early stage pilot clinical trials of candidate therapeutics or interventions for the treatment of NF1, NF2, and schwannomatosis manifestations. These awards support innovative clinical trial enabling studies.



**Ana-Maria Vranceanu, PhD**, a Clinical Research Award (CRA) recipient in 2013 and 2014, has been awarded a third CRA to adapt a psychosocial support method so that it can be offered to people with NF2. This population can experience significant social isolation as well as anxiety and depression, unemployment, or divorce or separation from significant others. The Relaxation Response Resiliency Program (3RP) has been found effective for improving Quality

of Life (QoL) in NF1 and schwannomatosis populations in Dr. Vranceanu's previous CTF-funded research. With the new grant, Dr. Vranceanu's team will test 3RP delivered via Skype and using Communication Access Realtime Translation (CART). If effective, she plans to implement this approach for the broader population of NF2 patients. Dr. Vranceanu is an Associate Professor in Psychology working at Massachusetts General Hospital and at Harvard Medical School. The grant award amount is \$149,836.

**Gena Heidary, MD, PhD**, a neuro-oncologist at Boston Children's Hospital, received a CRA to conduct a study of visual field outcomes in NF1-related optic pathway glioma (OPG). Her project builds on a multicenter study of NF1-OPG outcomes, funded jointly by CTF and the Gilbert Family Neurofibromatosis Institute. Dr. Heidary's work will examine whether visual field testing, which measures peripheral vision, is a valuable addition to conventional visual acuity testing for measuring visual outcomes in children with OPG. The grant amount is \$150,000.



## MORE CLINICS ACCEPTED INTO THE NF CLINIC NETWORK

Three additional NF clinics have been accepted into the NF Clinic Network (NFCN) bringing the total to 50 NFCN Affiliate Clinics in the United States. As our network continues to expand, the Children's Tumor Foundation is making every effort to increase access to and improve the quality of NF care throughout the country.

Congratulations to the most recent clinics accepted into NFCN:

- **Children's Hospital of Orange County in Orange, CA** with Clinic Director Neda Zadeh, MD, and Clinic Coordinator Narda Hernandez.
- **Connecticut Children's Medical Center in Farmington, CT** with Clinic Director Francis DiMario, MD, and Clinic Coordinator Alyssa White, RN, BSN.
- **Kentucky Neuroscience Institute through the University of Kentucky in Lexington, KY** with Clinic Director Donita Lightner, MD, and Clinic Coordinator Kim Osborne.

All Affiliate Clinics must submit an annual report that demonstrates that the clinic provides appropriate NF care through implementation of current consensus clinical care guidelines for NF. As part of this reporting process, Affiliate Clinics are eligible to apply for NF clinic stipends, which provide funding for hosting medical symposia and/or professional attendance at the annual CTF NF Conference, which gathers NF experts and researchers from all over the world.

CTF welcomes the newly appointed clinics who join our other NFCN colleagues in striving to provide excellent patient care and support to families throughout the country. To learn more please visit [ctf.org/nfcn](http://ctf.org/nfcn).

## IMPORTANT 2016 DATES FOR NF RESEARCHERS

<b>April 18</b>	<b>Drug Discovery Initiative Award (A) application deadline</b>
<b>June 18-21</b>	<b>NF Conference, Austin, Texas</b>
<b>June 20</b>	<b>Clinical Research Award Letter of Intent due</b>
<b>September 19</b>	<b>Clinic Award applications due</b>
<b>September 26</b>	<b>Drug Discovery Initiative Award (B) application deadline</b>

To learn more go to [ctf.org/research](http://ctf.org/research).

## Synodos for NF1 Kick-Off Meetings *continued from cover*

Synodos for NF1 is made up of three separate consortia based on the original Synodos model. Gathered in Minnesota were the two teams that form the Preclinical Acceleration component. These two teams will focus on the development of a swine model that will inform and help develop clinical trials in humans. A genetically modified swine model will closely resemble a human's response to a potential treatment. These two teams share the goal of accelerating the path to a cure, but will use different technologies and target different genetics to mimic NF1.

The Minnesota meeting had an inspirational beginning when Laurée Moffett, Synodos for NF1 lead benefactor, personally thanked the Synodos teams for the work that they are doing to find treatments for NF1. Following her remarks, patient advocate Renie Moss beautifully told the story of her husband and their two children, who are living with

**“It gives me energy and hope to know that you are willing to come together and collaborate. And I hope that you will see the face of the patient on your darkest days and it will motivate you to keep up the fight. Because we’re counting on you, we really, really are.”**



—RENIE MOSS, Synodos for NF1 Patient Advocate speaking to the Synodos for NF1 researchers in their first group meeting in Minneapolis, Minnesota

NF. She motivated the researchers to let “the face of the patient” inspire them throughout the incredibly difficult task upon which they are embarking.

The third Synodos for NF1 team, the Low Grade Glioma (LGG) component, gathered at the Children’s Hospital of Philadelphia for their kick-off meeting in February. Low grade glioma is the most common childhood brain tumor affecting children with NF1, and this group plans to transform the understanding of the cellular and molecular underpinnings of these unique tumors.

## THE SYNODOS FOR NF1 INVESTIGATORS

### Preclinical Acceleration – Project 1



**Co-leader**  
**David Meyerholz, DVM, PhD**  
University of Iowa



**Co-leader**  
**Jill Weimer, PhD**  
Sanford School of Medicine



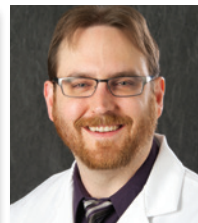
**Christopher Rogers, PhD**  
CSO of Exemplar Genetics



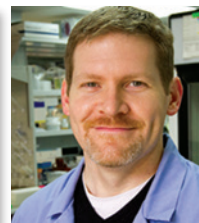
**Jessica Sieren, PhD**  
University of Iowa



**Dawn Quelle, PhD**  
University of Iowa



**Benjamin Darbro, MD, PhD**  
University of Iowa



**Adam Dupuy, PhD**  
University of Iowa

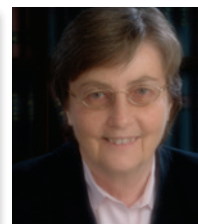
### Preclinical Acceleration – Project 2



**Co-leader David Largaespada, PhD**  
University of Minnesota



**Co-leader Christopher Moertel, MD**  
University of Minnesota



**Gunda Georg, PhD**  
University of Minnesota



**Mark Kirstein, OD**  
University of Minnesota



**Nancy Ratner, PhD**  
Cincinnati Children’s Hospital Medical Center



**Brigitte Widemann, MD**  
National Cancer Institute



**Eva Dombi, MD**  
National Cancer Institute

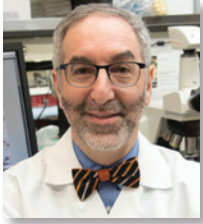


**Adrienne Watson, PhD**  
Recombinetics, Inc.



**Jon Hawkinson, PhD**, University of Minnesota

## Low Grade Glioma



**Co-leader David Gutmann, MD, PhD**  
Washington University in St. Louis



**Co-leader Michael Fisher, MD**  
Children's Hospital of Philadelphia



**Stephan M. Pfister, MD**  
German Cancer Research Center, DKFZ and Heidelberg University Hospital



**David T. Jones, PhD**  
German Cancer Research Center, DKFZ and Heidelberg University Hospital



**Olaf Witt, MD**  
German Cancer Research Center, DKFZ and Heidelberg University Hospital



**William A. Weiss, MD, PhD**  
University of California, San Francisco



**Joanna Phillips, MD, PhD**  
University of California, San Francisco



**Adam C. Resnick, PhD**  
Children's Hospital of Philadelphia



**Angela J. Waanders, MD**  
Children's Hospital of Philadelphia

## Adults with NF

The Children's Tumor Foundation is dedicated to providing support and resources for individuals with NF of all ages. In an effort to expand our adult-focused programs, last fall we distributed a survey to assess interest in support opportunities for adults. Thank you to all who participated!

Below are some highlights of the survey results:

- Individuals who responded ranged from ages 18 to 70, with a majority between the ages of 36 and 50.
- Most individuals who responded have a diagnosis of NF1, but there were respondents with NF2 and schwannomatosis represented as well.
- 60% indicated that they do not have opportunities to connect with other adults with NF.
- The events that were most attended, according to respondents' feedback, were a local NF Walk or local medical symposium.
- A vast majority of adults with NF say that they are likely or very likely to participate in a meet-up at a local NF Walk event, an adult online chat/support group or other social media, or a breakout session at the NF Family Forum.

The results of the survey were helpful in further developing the following ideas to support adults with NF.

### AN ADULT MEET-UP AT THE NF FORUM

Join us in Austin, Texas at the patient and family symposium on June 17-19, 2016. Look for the welcome area specifically for adults with NF to discuss adult resources and connect with other adults. To register go to

[ctf.org/nfforum](http://ctf.org/nfforum).

### PLAN AN EVENT IN YOUR AREA

If you know of an upcoming event, contact the organizer to see if you can assist in an adult meet-up during or following the event. Or, plan your own. Be creative! CTF can assist you in marketing your event. Contact your regional CTF representative at [ctf.org](http://ctf.org).

### PARTICIPATE IN AN ADULTS WITH NF WORK GROUP

It's important to discuss additional ways to support one another and bring ideas to your own state. If you are interested in participating please contact Sheila Drevyanko at [adultswithnf@gmail.com](mailto:adultswithnf@gmail.com).

The Children's Tumor Foundation is exploring additional ideas for adults. We will keep you posted as they come to fruition.

*Adults with NF gather at the 2015 NF Forum.*



### REGISTRY DATA PRESENTED AT REINS WINTER MEETING

Annette Bakker, PhD, CTF President and Chief Scientific Officer, presented the results of the first analysis of data from the NF Registry. The focus of her presentation was the finding that NF Registry data, contributed directly by patients, closely matches physician-reported records for the items covered. This proves that patients can be relied upon to report their own data accurately—and that a global patient-centered registry has unique ways to serve in the search for better lives for our community.

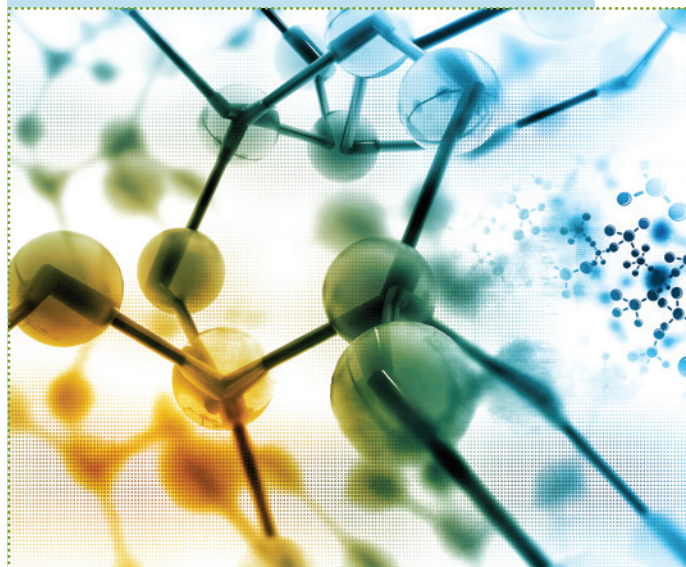
Dr. Bakker's presentation took place at the winter meeting of the Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS) group in Bethesda, Maryland. REiNS, which is supported by the Children's Tumor Foundation, seeks to build consensus on clinical outcome measurement so that comparisons can be made from one study to the next.

The analysis included data collected from 4,690 NF patients from 71 different countries, who joined the NF Registry between June 2012 and October 2015. Data was examined by an epidemiologist, Robert Holzman, MD, working with CTF consultant Mindell Seidlin, MD, and several members of the CTF research staff. The records were from 4,020 people with NF1, 579 people with NF2, and 91 people with schwannomatosis.

The NF Registry found that 35% of people with NF1 reported having plexiform neurofibromas. This is consistent with the average percentage of NF1 patients with plexiforms reported in published medical studies, which is 33%. Similar matching data was found for other NF1 manifestations, such as optic pathway glioma (19% in the Registry, 11% in published reports); malignant peripheral nerve sheath tumors (MPNST) (2% in the Registry and 4% in published reports); and learning disability (51% in the Registry and 62% in published reports).

The NF Registry is designed to serve all patients and researchers in NF. It is a voluntary online registry that uses a secure system for collecting patient data via surveys. Based on participant answers, registrants can receive information about relevant clinical trials, view trends and averages to see how they are like and unlike other people with NF, and take an active role in finding new treatments. The NF Registry has already been shown to speed clinical trial recruitment. So far 22 clinical trials have found participants through the NF Registry.

If you or your child are living with NF1, NF2 or schwannomatosis, please join the NF Registry at [nfregistry.org](http://nfregistry.org)



### Body Donation Program Opens for NF2 and Schwannomatosis

Carefully preserved NF tissues are essential for research, but can be difficult to obtain outside of major medical institutions. To solve this critical research need, CTF began “biobanking” tissue from NF patients. Originally set up to collect dermal neurofibroma surgical samples, the CTF biobank was broadened last year 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.

The Foundation recently received approval to begin banking tissue from people with NF2 or with schwannomatosis. CTF's procedure for NF2 and schwannomatosis body donation will ensure that NF2 and schwannomatosis tissue be made widely available, promising to speed treatment development for these rare forms of NF.

Anyone interested in learning more about the body donation program for NF1, NF2, or schwannomatosis research is invited to contact the Clinical Program Director, Pam Knight, at (646) 738-8555 or [pknight@ctf.org](mailto:pknight@ctf.org).

## MEET AN NF HERO: *Sophie Dillard*

My daughter Sophie is my hero. She's 12 years old and was diagnosed with NF1 when she was 9. She had brain surgery twice last year; in March she had a two-centimeter brain tumor removed from her parietal lobe, at which time they noticed problems with her arteries and blood vessels. One month later she was diagnosed with moyamoya and had cerebral vascular brain bypass surgery in June. She also recently had surgery on her elbow.

Despite everything she's been through, Sophie remains a happy child who loves soccer, softball, swimming, and hanging out with friends. Her favorite class in school is science, favorite food is steak, favorite book is *Smile* by Raina Telgemeier, and her favorite movie is *Camp*.

Nothing else to say except this kid is simply amazing! She inspires me like no other with her perseverance and stellar attitude! She is a fighter through and through!

—**Trudi Dillard, Sophie's mom**

### QUESTIONS FOR SOPHIE:

**What advice do you have for others facing similar challenges?** Try to remember that there is always someone going through something worse than you. Lean on your family, friends, and other NF fighters who have towed the line.

**What's a success or accomplishment you're really proud of that happened this year?**

I graduated from the sixth grade with my class, many of whom I have known since birth. I missed about four months of school because I had three major elbow surgeries and two major brain surgeries. But I did it! I'm now in the seventh grade and getting As and Bs.

**What are you most looking forward to in 2016?**

Hopefully no more surgeries! There will be still be many scans and doctor appointments for which we travel 12 hours, round trip, but I've come to accept that it's just my path in life and it's what will keep



me alive and healthy. No one can walk in my shoes but me.

**What's one song that you never skip on your playlist?** I love the song "Brave" by Sara Bareilles. It gave me strength when I was weak and afraid. It's my personal fight song, and all my friends say it reminds them of me.

## STORIES OF NF **The Grisham Family**

My uncle, Darin, has had neurofibromatosis since he was a child and has tumors that affect the nerves in his face. A few years ago, he experienced severe swelling along the side of his head that required surgery to reduce it. He and his wife, Elizabeth, have two beautiful, smart, caring kids, Calvin and Autumn, both of whom also have neurofibromatosis.

Calvin, age seven, and Autumn, age six, both have optic gliomas. Calvin's tumors are on both eyes, and Autumn has a large one where the two optic nerves split. It has affected her vision, and doctors say she will eventually lose her sight. She recently began chemotherapy to reduce the size of the tumor.

Both kids are such trouper; they never complain about their numerous MRIs, needle sticks, and doctor appointments. I hear such great things from their parents and I follow their medical journey through Elizabeth's blog on [CaringBridge.org](http://CaringBridge.org).

Calvin lives to be a firefighter; he's wanted to be one since he was two years old. Anything that has to do with fire trucks, ambulances, or rescues, he'll be there with his bunker gear on!



He also loves riding his tractor and helping everyone he meets.

Autumn likes a variety of things, including coloring, cooking, climbing on the play structure that the Make-a-Wish Foundation revitalized for her, and watching the movie *Minions*.

Darin's hobbies are barbecuing and making beef jerky; he has more than 40 flavors now! He also loves to fish and camp. If his three brothers (one of whom is my dad) lived closer, I'm sure they'd spend lots of time together!

I'm so proud of my family of fighters. I look forward to visiting them one day, and I send them love always!

—**Bonny Beaty, niece of Darin and cousin of Calvin and Autumn**

## Children's Tumor Foundation's Jeff Hanson

### Wins NASCAR Foundation's Betty Jane France Humanitarian Award

World-renowned artist and Children's Tumor Foundation 2015 Ambassador Jeff Hanson is the 2015 winner of the NASCAR Foundation's Betty Jane France Humanitarian Award, presented by Nationwide Insurance. The award embodies the NASCAR Foundation's Founder Betty Jane France's unwavering commitment to philanthropic causes and recognizes those whose generosity and compassion have positively impacted the lives of children in their community.

Jeff is a 22-year-old philanthropic artist who is visually impaired due to an optic nerve glioma related to NF1. Though legally blind, the Kansas native has painted and donated more than \$2 million in acrylic canvases to more than 100 charitable causes since 2006.

Nominated by Racing4Research Director Jill Beck, Jeff and the Children's Tumor Foundation received the most online votes out of four finalists who competed in a nationwide contest that lasted for nearly two months. In honor of Jeff's win, the Children's Tumor Foundation receives a \$100,000 donation from the NASCAR Foundation.

*"I am so unbelievably honored to have received the Betty Jane France Humanitarian Award," said Hanson. "Mrs. France is an amazing role model, and I'm proud that my efforts on behalf of the Children's Tumor Foundation have been recognized with an award named in her honor. The money that we receive from the NASCAR Foundation will be used to launch an exciting new research program aimed at improving the lives of people like me who live with NF, and help us get a little closer to finding a cure."*

—JEFF HANSON, 2015  
Betty Jane France  
Humanitarian Awardee

### THANK YOU

- For voting daily for fifty-eight continuous days without wavering.
- For reminding your friends, family, and social network to vote.
- To our Racing4Research partners and friends—drivers, teams, and sanctioning bodies—for showing their support for CTF.
- To race car driver Kenny Wallace, for your unmatched efforts on behalf of CTF.
- To Jeff Hanson, for your amazing talent and support of CTF.
- To the NASCAR Foundation, the France family, and Nationwide Insurance for this amazing recognition.



Together, we won \$100,000 for NF research, and together we will end NF!





**Little Heroes 5K**

Join our team! If you're interested in hosting a Little Heroes 5K in your area, please complete the form at [ctf.org/5KDirector](http://ctf.org/5KDirector) or email us at [nfendurance@ctf.org](mailto:nfendurance@ctf.org).

**Get Muddy for a Meaning**

Tough Mudder is a team-oriented obstacle course designed to test teamwork, physical strength, and mental grit. Tough Mudder puts camaraderie above rankings. It's not a race, it's a team challenge in which Mudders forget their course time and help their fellow Mudders complete the course.

This year, the NF Endurance Team is a proud charity partner, and we have spots available in every event across the country! If you're eager to show your strength, defy gravity, take risks, and work together, contact NF Endurance Team Manager Angela Dumadag at [adumadag@ctf.org](mailto:adumadag@ctf.org).



**HEART OF A CHAMPION: Kristina Rath**

Kristina Rath, longtime NFE participant and CTF advocate, has been awarded the first annual Garrett Baumann Heart of a Champion Award. Each year this award will be given to a person who exhibits the courage and tenacity of Garrett Baumann, a young man with NF2 who is the heart of Team Garrett. Kristina joined NF Endurance after her daughter

Jane was diagnosed with NF1, and has since run ten half marathons and eight full marathons, raising more than \$110,000 for the Children's Tumor Foundation.



**Join us for an IRONMAN event in 2016**

The Children's Tumor Foundation is partnering with four IRONMAN events in 2016. If you've ever thought about taking the next step in your endurance journey to help end NF, consider joining one of our IRONMAN teams! Our staff and coaches will be here to help you every step of the way. Questions? Contact us at [nfendurance@ctf.org](mailto:nfendurance@ctf.org).

- IRONMAN Hawaii 70.3** | June 4, 2016
- IRONMAN North Carolina 70.3** | October 22, 2016
- IRONMAN North Carolina** | October 22, 2016
- IRONMAN Florida** | November 5, 2016



**IRONMAN Florida athlete Seth Habberfield:**

*"I would highly recommend signing up with CTF for IRONMAN Florida or any IRONMAN event, for that matter. My NF Hero was Ava Lowell, and she was a huge support during my training and the race itself. My wife and I thought that the fundraising would be tough but it turned out to be really easy with a little bit of creativity. The entire team of athletes are constantly posting about the fundraising they are doing in their part of the country and are always willing to help with new ideas. The best part of being on the NF Endurance Team is knowing that the money you are raising is actually going to help find a cure for NF! Sign up for the best experience of your life!"*

**UPCOMING EVENTS**

- 3/20 - **New York City Half Marathon**  
New York, NY
- 4/9 - **Little Heroes 5K of Tennessee**  
Chattanooga, TN
- 4/10 - **Hapalua Half Marathon**  
Honolulu, HI
- 4/24 - **Big Sur Marathon**  
Big Sur, CA
- 4/24 - **London Marathon**  
London, England
- 5/1 - **TD Five-Boro Bike Tour**  
New York, NY
- 6/17 - **Summer Solstice 10K and Kids Run** | Spokane, WA
- 7/24 - **New York City Triathlon**  
New York, NY
- 8/28 - **Chicago Triathlon**  
Chicago, IL
- 10/9 - **Bank of America Chicago Marathon** | Chicago, IL
- 11/6 - **TCS New York City Marathon**  
New York, NY
- 12/11 - **Honolulu Marathon**  
Honolulu, HI

Don't see an event listed? You can also sign up to Choose Your Own Event!  
Visit [nfendurance.org](http://nfendurance.org) for more information.



### Seattle

The second annual Seattle NF Walk was held on a sunny September morning in beautiful Point Defiance Park. More than 150 people were in attendance and raised

more than \$68,000 for NF research. The Walk took place on Owen Beach, and walkers were given the choice to walk along the water or follow along a scenic 5K trail. Everyone, including the adults, enjoyed being able to pose with Wonder Woman and Superman, who helped make the Walk a little more fun.



### Philadelphia

Despite the doom and gloom of the meteorologists, the Philadelphia NF Walk managed to have what was one of our most successful Walks yet! In spite of the rain, nearly 500 people came out to raise \$65,000 for NF research! Thank you to our volunteers, donors, sponsors, some “super” special guests, and of course all of the walkers; and a very special thank you to this year’s Gold Sponsor, Steamfitters’ Local Union 420!



### Central Jersey

This year’s Central Jersey NF Walk and Run was an incredible day at its new location in Veterans Park in Hamilton Township. New this year was a DJ to keep the party going, a silent auction with some awesome prizes, a fire truck, and special appearances by Supergirl, Spider-Man, and the Flash! Not only was it a fun day for the whole family, but a very special donor gave \$50 to CTF for every person who registered—all in all, the event made more than \$75,000!



### Houston

The first annual Houston NF Walk was a major success! Under the leadership of Bethany Bell, Morgan Clayton, and Hana Kosarek, the event was attended by almost 600 people and raised more than \$80,000 toward crucial NF research. The most memorable aspects of the Walk were the Buffalo Wild Wings eating contest, an amazing silent auction, visits from superheroes and princesses, and a moving speech by local NF Hero Tiger Coffman.



### Boca Raton

“Start Together, Finish Together” was the theme for the 2015 Boca Raton NF Walk, and more than 250 walkers finished together, raising more than \$62,000 for NF research. A day of love, learning, and community was celebrated by everyone in the NF family—NF Heroes, their siblings, and their supporters. Walkers had an amazing time dancing, doing crafts, reading, and playing games.

ished together, raising more than \$62,000 for NF research. A day of love, learning, and community was celebrated by everyone in the NF family—NF Heroes, their siblings, and their supporters. Walkers had an amazing time dancing, doing crafts, reading, and playing games.



### Los Angeles

The tenth annual LA Walk was held on October 25th and was attended by 500 people, making it the best LA Walk so far, and everyone had a blast. There was a pizza truck, snow cones, pumpkin decorating, an air-brush artist making custom hats and shirts, and much more. The event raised nearly \$125,000, and everyone is looking forward to how much it’s sure to grow next year! For 2016, the committee is planning a twilight/night walk on the backlot of CBS Studio Center with lots of glow-in-the-dark kids’ activities.

## NF Organizations Work Together with One Goal: TO END NF

The NF community is fortunate to have many passionate people and organizations dedicated to finding a cure for NF, and a number of them came together in early December in Washington, DC to participate in a congressional briefing - as one voice, united against NF. CTF President and CSO, Annette Bakker, was among the speakers on Capitol Hill who addressed an overflow crowd. After the briefing, the NF organizations met to discuss shared interests and initiatives, and how best to coordinate efforts in Washington, DC and in communities throughout the United States. This collaborative vision has resulted in success in securing continued NF funding of the CDMRP. Everyone at the meeting pledged to continue to align efforts whenever possible. Another meeting is planned for March 2016 in NYC, at which NF advocacy efforts and patient initiatives such as the NF Registry will be discussed. CTF is proud to be a part of this effort to bring everyone together, as we jointly work to improve the lives of NF patients and their families.



*Barbara Franklin (Advocare NF2), Simon Vukelj (CTF), Cindy Hahn (Texas NF), Kim Bischoff (Neurofibromatosis Network), Jennifer Bischoff (Neurofibromatosis Network), Connie Sorman (CTF), Chris Mings (Littlest Tumor Foundation), Annette Bakker (CTF), Katrin Patience (Littlest Tumor Foundation), Steve Kendra (NF Team Foundation), Tracy Wirtanen (Littlest Tumor Foundation), Diana Haberkamp (Neurofibromatosis Midwest)*

## CTF Advocacy Secures \$15 Million in Federal Funding of NF Research

*Thanks to the dedicated and passionate outreach of the NF community - letters and emails, calls and visits - \$15 million was secured to fund the Congressionally Directed Medical Research Program-Neurofibromatosis Research Program (CDMRP-NFRP) for fiscal year 2016. The CDMRP-NFRP, managed by the Department of Defense, provides crucial funding that helps fuel the NF Clinical Trials Consortium. For over 19 years, this funding has been essential to the great strides that have been made in NF research, and it is your participation in the NF advocacy process that has ensured that this progress continues. Our work is not yet done, however! CTF's advocacy work for fiscal year 2017 has begun. Visit [ctf.org/advocacy](http://ctf.org/advocacy) to learn how you can support the NF fight in Washington, DC.*

## Registration Open 2016 NF FORUM

The NF Forum is a patient and family gathering that features:

- NF clinical and research updates
- Sessions on the personal and social challenges of living with NF
- Interactive Q&A sessions with NF specialists
- Fun activities, meals, and social time with new friends and old

[ctf.org/nfforum](http://ctf.org/nfforum)

**JUNE 17-19 JW MARRIOTT  
AUSTIN, TEXAS**

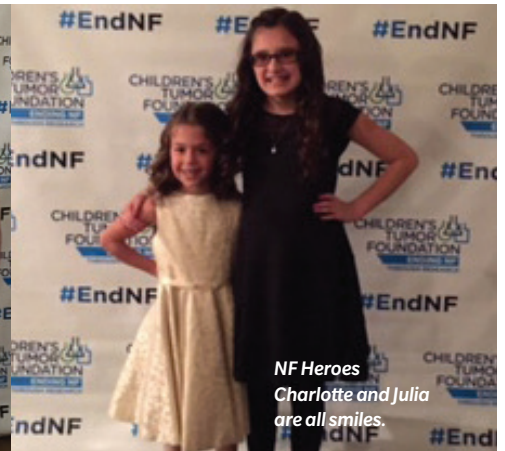
# REGIONAL NEWS

## NEW YORK

A huge thank you to Cristina Spoto, Lisa Arena, Jill Hannity, and Laura Perfetti for the dedication, time, and effort they put toward Cocktails for a Cure. It paid off! This committee put together a gorgeous night at Coindre Hall in Huntington, Long Island, and hosted 300 guests, a raffle, a diamond dig, and a silent auction. More than \$130,000 was raised for NF research. Congratulations to all!



(from left to right) Cristina Spoto, Jill Hannity, Lisa Arena, and Laura Perfetti, the Cocktails for a Cure committee.



NF Heroes Charlotte and Julia are all smiles.

## UTAH

On November 27th several Utah CTF families and their NF Heroes quickly assembled to sell "Chuck-A-Pucks" and raise NF awareness at the Utah Grizzlies hockey game. Thank you, Utah Grizzlies Hockey, for your continued support of CTF and our Utah area families!



## NEW JERSEY

Nothing is more inspiring than watching young people support each other. Wayne Valley High School of New Jersey hosted an after school Dodgeball to End NF Tournament with the help of Coach Kotlarz and the Emolo Family, in honor of fellow student Robert Emolo. With more than ten teams participating and more taking part as spectators, these dedicated students came out to support a friend. With lots of spirit, crazy team names, and matching shirts, everyone got in on the action.

## CALIFORNIA

The Merced Elks Golf Association hosted their third annual golf tournament in honor of NF Hero Dakota Anderson on October 17th in Merced, California. The event raised more than \$6,500 for NF Research.



## MASSACHUSETTS

A big thank you to the students of the Minnechaug Regional High School! They presented a check to CTF in the amount \$1,714 on January 15th after the Celebrate Life Club held a walk-a-thon in honor of Celia LaBabera of Willbraham, Massachusetts, who lives with NF2.

## COLORADO

The annual NF Gingerbread Event was held on December 6th at the Crowne Plaza Hotel in downtown Denver, with 60 individuals attending. Santa took pictures with the families and gave the kids gifts while everyone decorated gingerbread houses and enjoyed appetizers from Chili's. This event is a wonderful holiday tradition!



## FLORIDA

Mark and Hannah Ehrli hosted their fifteenth golf fundraiser at the Bayhill Golf Course in Orlando, Florida, sponsored by Wireless Zone and Planet Hollywood. To date the Ehrli family has raised more than \$350,000 for the Children's Tumor Foundation. Their son Joe has NF1 and currently is a junior at the University of Central Florida.



Mark and Joe Ehrli alongside legendary golf champion Arnold Palmer.



## ILLINOIS

What do you do when your New Year's resolution is to run more, but you don't actually like to run? You join CTF for the first annual CTF 1K—because even 1K is more than no Ks. On January 16th a group dedicated to keeping their resolutions met at Schoolyard Tavern & Grill in Chicago to run...but not too far. After the race, the group toasted their dedication and commitment.



## CALIFORNIA

On October 21st the Wall of family (Team Grace) promoted the LA Walk on LA's local KCAL 9 news in a live interview. Ted, Laura, and Grace did a great job talking about the event and spreading awareness. Five-year-old Grace got a glimpse of the news behind the scenes and she loved it!

**COLORADO** The biannual NF Symposium in Denver, Colorado, was attended by more than 60 participants and was hosted by CTF & Denver Children's Hospital on Sunday, October 18th. Speakers provided education, updates, and insights into NF. Topics addressed included headaches, natural pain management, IEPs, NF 101, and more. Many useful recommendations and fresh ideas were discussed to improve the quality of life for anyone affected by NF. Following the speaker's presentations, a panel of adults living with NF answered questions and shared personal experiences with the audience. The kids enjoyed a workshop of their own with crafts, games, and even a tour of the hospital.



## UTAH

Nearly 150 adults and children gathered at Discovery Gateway Children's Museum for the Sixth Annual Utah NF Symposium on Saturday, October 24th. Dr. Juliann Allred, University of Utah neurologist for the Utah Adult NF Clinic, presented on different types of headaches and how to avoid headache triggers. Everyone enjoyed the event and appreciated the updates on NF research.





**“I love NF camp because, in this huge world that we live in, I don’t feel so alone or different from the rest.”**

**—HUNTER JACKSON**

## NF CAMP

*Building Community in Young Adults with NF for 20 years*

This year marks the 20th anniversary of CTF’s NF Camp, a week-long opportunity for young adults ages 12 to 22 to meet others who are living with NF1, NF2, or schwannomatosis. When teens and young adults arrive 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 life.

NF Camp takes place at Camp Kostopulos (Camp K) in Emigration Canyon, Utah on 25 beautiful acres in the canyons outside Salt Lake City. This campground caters to individuals with special needs and provides a wide array of recreational activities accommodating all ages and abilities.

This year, campers can choose to attend either July 16-22 or July 23-29, 2016. If you would like to sponsor a camper, or learn more about attending NF Camp, please visit [ctf.org/camp](http://ctf.org/camp).

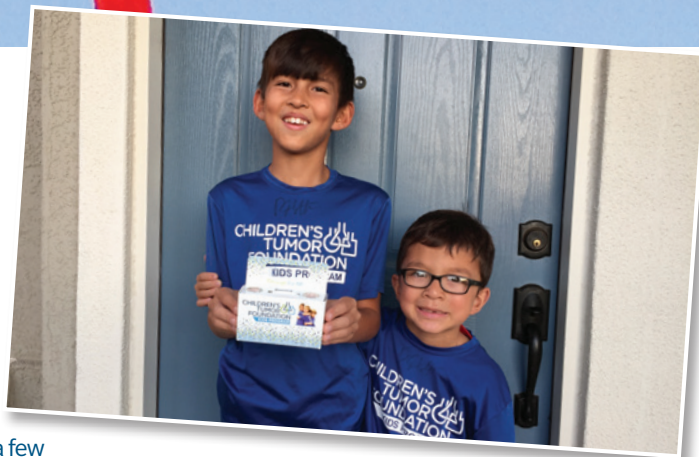
## • MAY IS • NF AWARENESS MONTH •

### COUNTDOWN TO MAY NF AWARENESS MONTH

Counting down until May 1st, we are releasing new tools to help you get a head start on the action! Here are a few things you can do now to help spread NF awareness in your community this May:

- **Change for NF** is an exciting new coin-collecting program for kids...because every penny counts in the fight against NF! Our staff can help you execute a Change for NF fundraiser in your child’s school this May. For more information and to get started contact Angela Earle at [aearle@ctf.org](mailto:aearle@ctf.org).

- **Shine a Light on NF** brings NF awareness into the community by lighting up buildings, bridges and monuments in blue



and green. In 2015, you went into your community and lit up 40 landmarks! This year, we have created tools to make outreach even easier. Download information at [ctf.org/shinealight](http://ctf.org/shinealight) and hit the pavement!

- **Wear it for awareness!** Be sure to add an awareness-raising item to your wardrobe! Visit the CTF store at [ctf.org/store](http://ctf.org/store).

- **Join a CTF event this May**--or organize one of your own! Be sure to countdown with us at [ctf.org/nfawareness](http://ctf.org/nfawareness).

## MEET THE STAFF

Jill Beck

**HOMETOWN:** La Crescenta, California

**CURRENT TOWN:** Carlsbad, California

**EDUCATION:** BS Industrial Design, ArtCenter College of Design

**YOUR WORK WITH THE FOUNDATION:** I am

Director of the RacingResearch program. I began working with CTF in early 2008, when my daughter was just an infant. I look at her as a tangible reflection of how much my position at the Foundation has evolved over the years, growing and changing just as she has. In my early years at CTF, in addition to my role with R4R, I did the design work for the Foundation. Those needs are now well managed by the Foundation's communications team and, happily, I am still able to exercise my creative side by handling the design needs for R4R, including designing the race cars. With my focus squarely on Racing4Research, I have been able to expand it from a single event to a nationwide, multi-event program. It's exciting to see the joy that this program brings to families living with NF, including my own.

**YOUR FAVORITE EXPERIENCE WITH THE FOUNDATION:** It's hard to choose one! Daytona 2009 was our first full-blown "CTF-at-the-track" race and I'll never forget the tears in my eyes watching our NF Heroes sign the car, with smiles from ear to ear. That's what it's all about. I'm incredibly proud of the Art Car program, which has done so much to raise awareness of the Foundation and NF. Winning the \$100,000 NASCAR Foundation Betty Jane France Humanitarian Award in December was the cherry on top of what's been an amazing ride so far with the Hanson family and our CTF racing family.

**FAVORITE HOBBY:** Travel. Aquarist. Obsessive interior designer. Watching NFL football—GO CARDS!

**FAVORITE BREAKFAST FOOD:** Bacon!

**IF YOU COULD HAVE ANY SUPERPOWER, WHAT WOULD IT BE?** Teleportation

**GO TO KARAOKE SONG:** "Don't Stop Believin'"

**WEIRDEST THING YOU'VE EVER EATEN:** Rattlesnake. Tastes like chicken.



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](http://www.ctf.org). Please direct any questions or feedback to [info@ctf.org](mailto:info@ctf.org).

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 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](http://www.ctf.org).

### FOUNDATION STAFF

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

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**Salvatore La Rosa, PhD**, Vice President of Research and Development  
**Maria Carela**, Grant Manager  
**Vidya Dhote, PhD**, Basic Science Manager  
**Kate Kelts**, Patient Support Coordinator  
**Pamela Knight**, Clinical Program Director  
**Hyerim Lee, PhD**, Translational Science Project Leader  
**Patrice Pancza**, Program Director, Research  
**Heather Radtke**, NF Clinic and Symposium Coordinator  
**Sarah Rosenberg**, Executive Assistant

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**Jill Beck**, Program Director, Racing4Research  
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**Allison Cote**, Regional Development Coordinator  
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**Angela Earle**, NF Endurance Manager  
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**Kelly Mills**, Regional Development Manager  
**Julie Pantoliano**, Regional Development Manager  
**Kristine Poirier**, Director, Regional Development & NF Walk  
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**Traceann Rose**, Director, Community Building & Patient Engagement  
**Mary Vetting**, Stewardship Manager  
**Lauren Walsh**, NF Endurance Manager  
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**Catherine Blessing**, Human Resources Manager  
**Monique Boucher**, Gift Processing Manager  
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**Margaret Flaccamo**, Fulfillment Coordinator  
**Keena Hutchinson**, Gift Processing Coordinator  
**Latisha Maxwell**, Gift Processing Assistant  
**Danielle Meyer**, Technical Support, National Programs  
**Carey Milligan**, Accountant  
**Rosa Amelia Perez**, Project Administrator

#### Public Education and Communications

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**Alissa Marks**, Marketing Manager  
**Susanne Preinfalk**, Design Director  
**Rebecca Silver**, Public Relations Manager  
**Vanessa Younger**, Communications Manager

## NEW FACES at the Children's Tumor Foundation

Welcome to the Foundation's newest staff members!



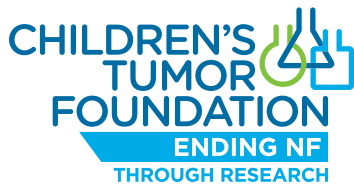
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[www.nfregistry.org](http://www.nfregistry.org)



**JOANNE PASTEL**  
Minneapolis, MN  
Daughter Jacqueline  
lives with NF1