

NF NEWS

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION
SPRING 2017

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May is NF Awareness Month!

Every year at this time, the Children's Tumor Foundation harnesses the spirit, energy, and passion of the NF community, and channels it into NF Awareness Month. These 31 days are focused on driving NF awareness, educating the community, and raising money to support the groundbreaking NF research supported by CTF.

All year long, you let the world know that those living with NF are fighters. The essence behind "I Know a Fighter" and "Born a Fighter" shows in every tee-shirt worn and photo shared. We delight in sharing the pride and joy Awareness Month brings, and celebrating the courage shown every day by our NF Heroes. Keep reading for the many ways to get involved this year.

FROM the President

Annette Bakker, PhD



When one talks of raising awareness of NF, there are multiple audiences we have in mind. The most prevalent is the broader public who may not have heard of NF, but who absolutely need to. Throughout the month you'll see hundreds of buildings and icons across the United States and around the world "Shine a Light on NF," turning their lighting blue and green in honor of the NF cause. There will be media stories about our NF heroes, proclamations by civic leaders, and community events from sweet tea stands to NF Walks. By the end of May, we want more people to have heard of NF than when the month started. Knowing our NF family, this is a goal we will accomplish.

biotech companies. Over the last five years, we have steered the Foundation's research portfolio toward funding collaborative science – bringing together 'dream teams' of the leading researchers in the world, and incentivizing them to share their unpublished data right away. All these initiatives are aimed at accelerating the pace to effective treatments. The CTF Synodos projects are dramatically increasing the depth of NF knowledge, and illustrate the great promise in our model of open-source data sharing and measurable real-time impact goals. We're also building on our NF Preclinical Initiatives, as we both celebrate and monitor closely the incredible success of the MEK clinical trial, which was informed by the successful preclinical testing of the Foundation's NF Preclinical Consortium. CTF is laser-focused on seeing that this and other promising treatments make their way to approval.

We are encouraged, because we now know more about NF than we ever have before, and more researchers are working on it than ever before. Hundreds of NF experts will soon gather in Washington, D.C. for the annual NF Conference, and out of that critical meeting we expect even greater collaboration and advancement toward treatments for NF.

May is NF Awareness Month, and this issue of NF News is full of terrific calls-to-action on how to tell the world about NF as well as the important work of the Children's Tumor Foundation. Raising awareness is essential! Only when people know what NF is, will they care. So we are confident: the month ahead promises to be full of extraordinary energy and essential education, and the NF community – you, our dear readers, as well as all our NF friends and allies across the globe – will ensure that more people learn about NF, more patients receive the care they need for NF, and more funds are raised for research for NF. At the Children's Tumor Foundation we are both proud and honored to have your trust and confidence as together we lead this global effort.

Another audience on whom we focus is the broader NF community, particularly those not yet engaged beyond their immediate surroundings. For far too many, NF can be isolating, and it is our responsibility, and our mission to ensure that all who live with NF know there are resources to help them through this NF life. Whether it's helpful educational materials on ctf.org, the nationwide reach of the NF Clinic Network, the promise of the NF Registry, or local symposia, we can and should help bring those with NF closer to our community. It has an immediate impact on one's life to know that there are others in the same battle, ready to share and help.

Importantly, we are also working to increase knowledge of NF within the research community, including with pharmaceutical and

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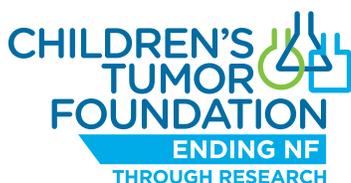
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MEK Clinical Trial Published in *New England Journal of Medicine*

The clinical trial for the MEK inhibitor selumetinib was written up in the December 29, 2016 issue of the prestigious *New England Journal of Medicine*. More than 70% of trial participants have seen tumor reduction of at least 20% in size, a first in NF research, and the most promising compound to date to shrink inoperable plexiform neurofibromas.

This highly successful clinical trial is the result of a major financial investment from the Children's Tumor Foundation NF Preclinical Consortium, in which it was demonstrated that MEK inhibitors (MEKi) have a massive impact on tumor volume.

The trial is now in its registration phase (the last step before submission to the FDA for approval), showing continued positive results, bringing us one step closer on the road to effective, approved treatments for NF.

Focusing on Treatments for Cutaneous Neurofibromas

The Neurofibromatosis Therapy Acceleration Program (NTAP) hosted a Cutaneous Neurofibroma (cNF) Summit in November 2016. Their goal was to identify and address the key questions for understanding and treating cNFs. The participants, from academia, industry, and government agencies, included experts in dermatology, surgery, skin cancer, regenerative medicine and tissue repair, wound healing, genetics, and immunology. CTF also provided some of the seed funding for NTAP and remains involved with its cutaneous project.

This project follows a five-year Children's Tumor Foundation initiative to collect and fully characterize a set of cNF (also called dermal neurofibroma) samples. After starting our biobank in 2013, last year CTF funded the full genomic characterization of these cNFs to provide the first published comprehensive open dataset. The data is openly available and has been published (Gosline SJ et al. A high-throughput molecular data resource for cutaneous neurofibromas. *Sci Data*. 2017 Apr 11;4:170045).



PHILIP MOSS is enrolled in the MEK inhibitor selumetinib clinical trial at the National Institutes of Health. Results, as of January 2017, show a **46% REDUCTION** in the size of Philip's tumor!



2017 NF Conference

The best and the brightest in the NF field will convene once again in Washington, DC on June 10th to the 13th for the 2017 NF Conference. This annual meeting is the most important NF scientific event in the world, drawing more than 300 scholars worldwide, from across a wide range of scientific disciplines and clinical backgrounds.

Register today!
ctf.org/nfconference

Clinical Research Awardee Receives \$1.5 Million

Department of Defense award to continue research that originated with CTF funding

Dr. Ana-Maria Vranceanu, clinical psychologist at Massachusetts General Hospital and Associate Professor at Harvard Medical School, was awarded a Clinical Trial Award from the Department of Defense for her proposal entitled “Resiliency Training for Adults with NF1, NF2, and Schwannomatosis; A Randomized Controlled Trial via Live Video.” Along with her team, which includes Dr. Scott Plotkin and Ms. Vanessa Merker, she plans to compare two resiliency interventions, both delivered in groups via a secure live video platform, and see which one works better in improving quality of life and psychological functioning in 224 adults with NF. The long term goal is to make

evidence-based psychosocial interventions available to the NF population. Dr. Vranceanu was able to secure this DOD grant because she acquired strong data on the feasibility, acceptability, and preliminary efficacy of her program through a clinical trial pilot grant she received from the Children’s Tumor Foundation.

“Without funding from CTF, I would not have been able to conduct the preliminary research that was key in securing this DOD grant award. I am thankful to CTF for their support, and am thrilled to be able to continue this important line of work. Using the same model, I am hoping to extend my research to adolescents with NF and adults with NF2 who are deaf, using preliminary data from ongoing CTF-funded pilot studies.”



“Without funding from CTF, I would not have been able to conduct the preliminary research that was key in securing this DOD grant award.”

—DR. ANA-MARIA VRANCEANU

NF

Q&A

Navigating the NF landscape can be complex; there are appointments and tests to keep track of, developments in research to read up on, and general self-care to indulge in. Have you ever had a question about NF that you forgot to ask at your last doctor’s appointment? We’re here to help!

Q: What is a clinical trial and why should I join one?

A: A clinical trial is a type of research study in which an intervention is given to participants and the subject’s response is assessed. This intervention can include, but is not limited to, medications, surgery, or psychosocial interventions.

Participating in clinical trials is a decision only you can make with guidance from your trusted healthcare provider. A few reasons to consider participating:

- **Personal benefits.** Clinical trials are on the cutting edge of treatment and can, in some cases, result in improved

personal health and quality of life.

- **Community benefits.** Clinical trials can provide the NF community with more information about how NF affects people differently.
- **Better Research.** Clinical trials, even when they don’t result in a new treatment, guide the direction of research and give scientists focus by providing information and guidance on the direction of future research.

The best way to find out about current clinical trials is by talking to your NF doctor! Your healthcare provider will have the best understanding of open clinical trials and whether they are appropriate

for you. You can also join the NF Registry. As a member of the Registry, you may be contacted by researchers, with your permission, to be part of a study. The NF Registry website also includes a listing of open clinical trials. For information about the NF Registry, visit nregistry.org.

Currently there is no cure for NF. We have come a long way in our understanding of neurofibromatosis but there is still much to learn. This is what makes funding and participating in clinical trials so important.

Kate Kelts, the Children’s Tumor Foundation’s Patient Support Coordinator, is a registered nurse with 11 years working with the NF community.

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.



David Viskochil, MD, PhD

A Phase II Trial on the Effect of Low-Dose versus High-Dose Vitamin D Supplementation on Bone Mass in Adults with Neurofibromatosis Type 1 (NF1)

David Viskochil, MD, PhD, University of Utah

Low bone density and vitamin D insufficiency occur frequently among people with NF1, but there are no proven preventive strategies in NF1 patients. This study is designed to assess the efficacy of oral vitamin D3 and calcium therapy to prevent abnormal loss of bone mass in adults with NF1. A two-year prospective double-blind trial of two different doses of daily vitamin D supplementation in adults with NF1, who are insufficient in serum 25(OH)-vitamin D [25(OH)D] at the time of enrollment, will be conducted. The CRA grant from CTF will supplement the investigators' Clinical Trial Award from the Department of Defense (DoD: #W18XWH-12-1-0487).

The grant amount is \$146,267.



Karin Walsh, PsyD

Reliability and Validity of Computerized Cognitive Outcome Tools in NF1

Karin Walsh, PsyD, Children's National Medical Center

Clinical trials targeting cognitive and learning impairments in children with NF1 have yielded mixed results to date, with methodological weaknesses thought to be partially responsible for these inconsistent outcomes.

This CRA grant will support a proposal of the REINS (Response Evaluation in Neurofibromatosis and Schwannomatosis) initiative's Neurocognitive Committee for the systematic review of current cognitive outcome measurement tools, and make recommendations for the most psychometrically sound (reliable, sensitive), feasible, and appropriate instruments for use in clinical trials. It will establish NF-specific normative data, test-retest reliability, and validity of several current, novel computerized cognitive test batteries (Cogstate and NIH Toolbox) to support recommendations for appropriate clinical-trial endpoints. The grant award amount is \$150,000.

Clinics accepted into the NF Clinic Network

The Children's Tumor Foundation is happy to announce that two more clinics have been accepted into the NF Clinic Network. All applications for the clinic network are reviewed by the CTF Clinical Care Advisory Board, and accepted or declined based on several factors, including NF expertise, clinic volume, multidisciplinary approach, research efforts, and involvement with CTF.

Lucile Packard Children's Hospital, Stanford Palo Alto, California

Clinic Directors: Cynthia Campen, MD and David Stevenson, MD

Clinic Coordinator: Samantha Ingerick, NP

Dr. Campen is a board-certified child neurologist and pediatric neuro-oncologist with particular expertise in treating optic pathway glioma and other brain tumors, as well as general expertise in the neurologic complications of NF. Dr. Stevenson is a board-certified geneticist previously at the University of Utah who specializes in the musculoskeletal manifestations of NF1 and related conditions.

The clinic primarily follows pediatric patients, but collaborates closely with adult-care providers.

Moffitt Cancer Center Tampa, Florida

Clinic Directors: Xia Wang, MD, PhD and Sepideh Mokhtari, MD

Clinic Coordinator: Ruth Alipio

Dr. Wang is board-certified in Clinical Genetics and Internal Medicine. Her research efforts have focused on breast cancer and other cancers in NF1. Dr. Mokhtari is board-certified in Neurology and Psychiatry, and is the Director of Neurologic Services at Moffitt Cancer Center. The clinic primarily follows adult NF patients.

For more information about the new clinics, or if you are looking for an NF clinic or doctor, please visit the "Find a Doctor" section of the Children's Tumor Foundation website at www.ctf.org. This site includes providers that are part of the clinic network, as well as a separate listing of other NF specialists. To suggest a new provider, please visit ctf.org/nfspecialists.



A Mother's Love

Liz and Sarah Rodbell

In honor of Mother's Day this year, we asked Liz Rodbell to tell us about her daughter Sarah, who is the 2017 NF Ambassador.

"As I watched Sarah deal with [her NF diagnosis] I saw something very special come forward. It was her desire to help others in any way possible, those in the NF community and, really, in everyday life. Her dedication and perseverance through adversity has only made her stronger and a true leader. She has inspired me to help in any way possible, supporting her along the way with the goal of a cure."

Read more from Liz about her daughter at ctf.org/blog.

Cupid's Undie Run Putting the Hilarity in Charity

February marked the eighth consecutive Cupid's Undie Run to benefit the Children's Tumor Foundation. Everyone's favorite Valentine's-themed party has again shown us all what an inspired group of generous people can do for the NF cause. Cupid's has grown by leaps and bounds from 2010, when participants raised \$10,000, to now, in 2017, when they've brought their eight-year total to more than \$10 million.

In 36 cities across the US, plus 14 in Australia, Cupid's Undie Run is a fun and unique way to raise money exclusively for NF research. Presented nationally by Quicken Loans, Bombas, and MeUndies, Cupid's Undie Run is a great time, not only for those living with NF, but also for those who are unaffected and want to make a difference.



Flashes of Hope Big Shots and Little Stars

Since it was founded in Cleveland in 2001, Flashes of Hope has photographed close to 60,000 children fighting cancer to help them look and feel attractive and invigorated, boosting their confidence as they cope with the depths of the disease.

'Big Shots & Little Stars' is the charity's most impactful annual fundraiser, raising money for research to accelerate a cure for children's cancer. The night culminates with a strut down a fashion runway spanning the floor of the Quicken Loans Arena. Cleveland-area business leaders, civic leaders, and Cavalier basketball players partner with the children

and escort each of them down the runway for a moment in the spotlight.

"We meet and photograph a lot of children throughout the year, and we are always amazed by their bravery, their courage, and their spirit, in spite of everything they're going through," said Allison Clarke, President of

Flashes of Hope.

Thanks to this event, Flashes of Hope made a donation of \$650,000. The Children's Tumor Foundation extends our utmost thanks to Flashes of Hope and its founders, Kip and Allison Clarke, for their continued support in funding NF research.



stories

OF NF

Leyla Ghassemi

I was born in Iran to a loving family who never saw my NF as an obstacle to achieving higher goals and success in life. My dad was a general surgeon and my mother was a homemaker. When I was two, my mom noticed little bumps under my right arm, and I was scheduled for a biopsy shortly after. That was when I was diagnosed with NF1.

We moved to Seattle where, after graduating high school, I decided to study Computer Science. I started my higher education at a local community college, then transferred to Seattle University. I completed my masters in Technical Management in 2011. Studying computer science was not

I am someone who loves to take a look at a problem, break it down, and come up with a solution. My job at times can be challenging, mostly when I am put on a project that is out of my comfort zone. But at the end of the day, these challenges have given me a better understanding of how I can solve problems.

Living with NF is challenging. You can have really good days and really bad days. Not everyone you meet will know or understand what you have, and may even make comments out of ignorance. I believe we should be our own advocates and educate people about NF. Let people know that with all of our challenges, we can live normal lives and follow our aspirations.

To parents: My parents raised me with the belief that I was no different than my siblings or other children, and that I would be able to do anything, as long as I put my mind to it. So, believe in your children's inner strength and natural abilities, and help them achieve their dreams. They are a lot stronger than

you think. Allow them to face challenges and support them as they find their own way to achieve their goals.



an easy task but I was able to achieve it with the support of my family.

“ Believe in your children's inner strength and natural abilities, and help them achieve their dreams.

—LEYLA GHASSEMI

Vincent Timko

My son is a true hero. Vincent was born in March 2010 and diagnosed with NF later that fall. First came surgery, at 6 months old, to remove a plexiform neurofibroma from his bladder, followed by countless doctor visits, ultrasounds, and needle pokes. He is now on his second drug trial to shrink a plexiform on his sciatic nerve that runs down to his knee. At the age of 6, he has already had 16 MRIs.

has had his ups and downs, but overall done really well. This past December we had our first MRI since starting the medicine, and his tumor has decreased by 14%! We are thrilled with this result, because in the 17 months prior to starting the trial, his tumor grew 104%. We are definitely moving in the right direction, and Vincent takes it all in stride. Vincent loves to play Legos and Minecraft, and loves his chocolate.

—Claudia Timko,
Vincent's mother

But despite all of that, he's a happy, funny, loving little boy, who goes into the MRI room with a smile on his face. He truly amazes everyone. As a family, we (his 10-year-old sister, Dad and I) try to raise awareness by participating in the Atlanta NF Walk as Team Vincent's Victors. I've also participated in the Cupid's Undie Run. And we all proudly wear our Fighter T-shirts!

Vincent is currently enrolled in the AZD6244 Clinical Trial, which involves traveling from Atlanta to Philadelphia each month. Vincent



MAY is NF Awareness Month!

Visit ctf.org to learn more about all the ways YOU can take action to End NF!



WEAR

our exclusive "I Know A Fighter" and "Born A Fighter" t-shirts



SHINE

a Light in your community and add to the growing list of landmarks that will glow in blue and green



CHANGE

your profile picture to one that celebrates NF Awareness



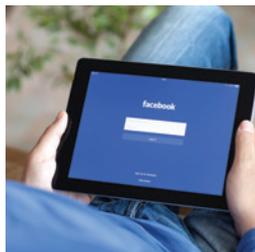
TAKE

a photo that shows "Where in the World do you End NF?"



TAG

your photo(s) on social media with #EndNF



LIKE

Children's Tumor Foundation on Facebook



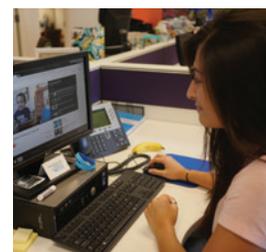
SHARE

exclusive NF Awareness Month graphics



PARTICIPATE

in an NF event in your community



WATCH

our NF Awareness Month Videos



EDUCATE

using informative fact sheets



JOIN

the NF Registry if you or your child has NF



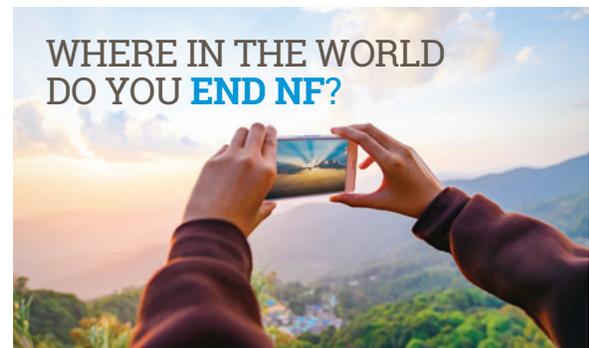
DONATE

to fund the cutting-edge research that will end NF



COMMUNICATE

Spread the word and increase awareness about NF!



WHERE IN THE WORLD DO YOU **END NF?**

Raising awareness for NF can happen anytime, anywhere. Whether you're on vacation, at work, at school or just hanging out in your front yard, we know you're on call 24/7/365, telling others what NF is, how it impacts your life, and the significance of funding research. Enter the 2017 NF Awareness Month photo contest and show us where in the world do you end NF!

Email media@ctf.org with your entry. Please include a few sentences about when and where the photo was taken. Contest ends May 31, 2017.

You probably know people who have not yet heard of neurofibromatosis or know little about it, but they can appreciate the strength and perseverance of our NF Heroes. During the month of May, invite everyone you know to join us – share the list above and ask them to get involved. We need the world to hear us loud and clear – it is time to End NF!

And don't forget: May 17th is World NF Awareness Day!

Download your NF Awareness Month resources at ctf.org/nfawareness

THIS IS NF

This unique and inspirational photo series, by award-winning photojournalist Craig Warga, is about people living with neurofibromatosis - not just living with NF, but succeeding and thriving in one's chosen vocation. The NF story can be one full of hurdles - diagnosis, symptoms, doctor appointments, MRI scans, surgeries, and/or clinical trials. With this photo series we're telling a side of the NF story that isn't often told - the passion that those living with NF bring to their daily lives - their work, their goals, the things they want to get out of life, with or without NF. Mr. Warga, who has photographed some of the most famous people in the world, is also an NF parent who set out to inspire his young son, who lives with NF1.

Visit ctf.org/thisisnf to view the rest of the series, and prepare to be inspired as well!

“ I hope someday I'll get mobility back in my right arm and have less pain. But I also want people to know that just because I have an illness and can only use one arm right now, it has not stopped me from doing my job and living out my dream as a photographer. ”

—**MARISA MCGRODY**
37-years-old, lives with neurofibromatosis type 1 (NF1) and works as a photographer.

CELEBRITIES SUPPORT THE FIGHT TO END NF



MIRANDA LAMBERT
NF Hero Nicki Strandberg had the chance of a lifetime – to meet one of her favorite country singers Miranda Lambert and tell her what it means to be a fighter.



NICK FOLK
These cleats were made to “kick” NF outta here! Former Jets Kicker Nick Folk designed these awesome blue-and-green Nike cleats with his cousin, NF Hero Blake Robinson, in support of the Children's Tumor Foundation

GEAR UP WITH YOUR OWN FIGHTER TEES AND CTF-BRANDED SWAG! Visit ctf.org/store today.

Looking to get into a SOLD OUT race?

The Children's Tumor Foundation NF Endurance team is an official charity partner at the Marine Corps Marathon (10/22), the Bank of America Chicago Marathon (10/8), and the TCS New York City Marathon (11/5).

These races are sold out, but the Children's Tumor Foundation has your entry into these races, plus many more! When you sign up with the team, you will receive a CTF dri-fit shirt, free entry into the race, a personalized training plan, a fundraising website, and a connection to an NF Hero. Join us!

UPCOMING EVENTS

Santa Barbara Wine Country Half Marathon

May 13, 2017 • Santa Barbara, CA

Rock'n'Roll San Diego Marathon, Half, Relay & 5K

Jun 3-4, 2017 • San Diego, CA

Summer Solstice 10K and Kids Race

Jun 16, 2017 • Spokane, WA

Napa-to-Sonoma Wine Country Half Marathon

Jul 16, 2017 • Napa/Sonoma, CA

Panasonic NYC Triathlon

Jul 16, 2017 • New York, NY

Transamerica Chicago Triathlon

Aug 26-27, 2017 • Chicago, IL

Bank of America Chicago Marathon

Oct 8, 2017 • Chicago, IL

Marine Corps Marathon

Oct 22, 2017 • Quantico, VA

TCS New York City Marathon

Nov 5, 2017 • New York, NY

California International Marathon

Dec 3, 2017 • Sacramento, CA

Sign up today at nfendurance.org.



As members of the NF Endurance team at the **CALIFORNIA INTERNATIONAL MARATHON** on December 4, 2016, Dawn Lowell, Michelle Piner, and a team of 60 athletes raised \$52,000 in honor of Dawn's daughter Ava and Michelle's son Timmy, both living with NF1.

Since 2009, Kristina Rath and her daughter, Jane, have raised over \$140,000 for the Children's Tumor Foundation. And they are still running! "CTF is a wonderful group dedicated to improving the health and well-being of individuals and families affected by NF," says Kristina.

The 2016 Bank of America Chicago Marathon was a resounding success, raising over \$80,000 to support NF research. The team was led by top fundraisers Carolanne Owenby (\$25,000), Tara Rogers (\$8,200), Morgan Phelps (\$7,500), and Joe Keller (\$5,500).



I have a full race schedule, one that includes the Marine Corps Marathon this year. I'm thrilled that the Children's Tumor Foundation is finally an official charity partner of the race. I hope we can build a huge team for the event this year!

—KRISTINA RATH, NF ENDURANCE ATHLETE AND NF MOM



UPCOMING WALKS

May 20, 2017
Orlando, FL
Staten Island, NY

May 21, 2017
Cincinnati, OH
Providence, RI

Jun 3, 2017
Kernersville, NC

Jun 10, 2017
Richmond, VA

Jun 17, 2017
Philadelphia, PA

Jun 24, 2017
Boston, MA
Casper, WY
San Jose, CA

July 22, 2017
Concord, NH

Jul 23, 2017
Portland, OR

Aug 19, 2017
Denver, CO

Aug 26, 2017
Salt Lake City, UT

Sep 9, 2017
Rochester, NY

Sep 16, 2017
Idaho
Iowa
Maine
New Jersey

Sep 17, 2017
Addison Oaks, MI
Moorhead, MN

Sep 23, 2017
Chicago, IL
Kansas City, KC
Las Vegas, NV
Seattle, WA

Sep 24, 2017
New York City

Sep 30, 2017
Putnam, CT
Houston, TX

Oct 1, 2017
Washington, DC

Oct 7, 2017
Phoenix, AZ

Oct 14, 2017
San Antonio, TX

Oct 21, 2017
Dallas, TX
Atlanta, GA

Oct 22, 2017
Long Island, NY

Oct 28, 2017
Los Angeles, CA

Nov 11, 2017
San Diego, CA

Sign up today at
nfwalk.org

TEAM SPOTLIGHT

Team Dreaming for Danielle

"Our family started our team, Dreaming for Danielle, for the 2014 Houston NF Walk, when we found ourselves in a very dark place. We were weighed down with worry, fear, and anxiety about our oldest daughter Danielle's NF1 diagnosis. Luckily, we found CTF and were inspired to do something. We traveled to Dallas to participate in their NF Walk. Then we co-organized Houston's first NF Walk in 2015, and haven't looked back since! Fundraising, being a part of the NF community, and focusing on a cure, has been life changing for our family. Our fears and anxiety have been quieted with hope and purpose. We no longer carry the weight of NF on our own shoulders, but now hit it head on with our team, Dreaming for Danielle. Watch out NF, because we dream BIG, we dream for a CURE!"

— Morgan Clayton, mom to NF Hero Danielle, the inspiration for Team Dreaming for Danielle



NFWALK



"Instead of presents this year, I want donations for my NF Walk. I want everyone to come for the Walk so we can raise money to find a cure for NF." —EVELYN FRIAS, NF HERO



No amount of rain could dampen the spirits of the NF Heroes, their family, friends, volunteers, and community supporters at the Boca Raton NF Walk in December 2016.

Participants enjoyed a day filled with music, food, fun, camaraderie, and most importantly, hope. The annual event, organized by Walk Chair Rasheena Taub, had a record-breaking year, raising more than \$81,000 for NF research, and hosting more than 340 dedicated participants and supporters.

An NF Hero with a heart of gold, Evelyn Frias celebrated her 9th birthday at the Walk. She had just one request: "Instead of presents this year, I want donations for my NF Walk. I want everyone to come for the Walk so we can raise money to find a cure for NF."



The Florida Atlantic University baseball team hit the pavement with Team Taub in honor of NF Hero Ari Taub.

Regional NEWS

The Foundation has a presence across the United States and facilitates local patient support groups, medical symposia, and fundraising events. Learn more about the Children's Tumor Foundation in your area by visiting www.ctf.org.

NEW YORK

Tappan Zee High School hosted the inaugural "Two Counties, One Cause" boys' basketball tournament fundraiser on Saturday, January 14th. The tournament featured six teams, three from Westchester County, and three from Rockland County. Tappan Zee High School head basketball coach George Gaine, along with acting athletic director, Chris Rastelli, were the driving forces behind the creation of the six-team event. The host team, Tappan Zee, took home the win.



The tournament was organized in honor of Coach Gaine's 5-year-old daughter Brielle, pictured with her cousin, Cameron

“The outpouring of support we have received, not only from our administration, but the participating schools, our team parents, current and former players, and the community as a whole, has been awe-inspiring,” said Coach Gaine, now in his 14th year at the helm of Dutchmen basketball.

NORTH CAROLINA

On February 2nd, the Nelson Family held 2017's first "Sweet Tea for Sophie" event. Partnering with the Kendra Scott Gives Back program, store associates set up an official "Sweet Tea for Sophie" stand with their signature sweet tea, plus donated additional sips and sweets. For every purchase made, they donated 20% to the Children's Tumor Foundation, raising close to \$500. The events were started by the Nelson's two sons in honor of their sister, Sophie, who has NF1. Last year there were over 35 stands in 7 different states, and this year they are looking forward to expanding, with more stands all across the country.



COLORADO

The National Hockey League's Colorado Avalanche hosted the Colorado Children's Tumor Foundation community for its game against the Vancouver Canucks, on January 25, 2017 at Denver's Pepsi Center. Sixty-three CTF friends and family gathered to enjoy the exciting contest, and some even took part in a pre-game skate on the ice! We would love to extend our thanks to Kroenke Sports (parent company of the Avalanche, the NFL's Los Angeles Rams, the NBA's Denver Nuggets, and the National Lacrosse League's Colorado Mammoth) for supporting this fantastic evening!





CALIFORNIA

Javita Coffee Company hosted two “Do It Yourself” events: “Paint Night” and “Super Saturday Wellness,” bringing together members of the Javita Company and their guests to support the Children’s Tumor Foundation and NF research. NF mom Karlie Savage was there to talk about her son, NF Hero Ryder Savage. The two events raised \$2,500.

NEW YORK

Cold nights did not keep the upstate New York NF community from coming together! Families bundled up and gathered for two NF Community Nights Out - one in Buffalo at a local pub, and one in Rochester, at our community partner’s restaurant, Tandoor of India. There were 12 families at each gathering, and bonds were formed over food and laughter. Even though NF can be challenging, being part of a loving NF community provides support and understanding. These were just the first NF community gatherings of many to come!



Raj Singh and Job Valluthamannunkal of Tandoor of India with NF Heroes Nora and Adriana



From L to R: Austin Auflick, founder of Race Armada Texas, Frank Lee, owner and founder of Euroworld Motorsports, and Chantell Jent, Euroworld Motorsports brand manager

TEXAS

For the third consecutive year, Euroworld Motorsports honored the Children’s Tumor Foundation at their annual holiday party, “Cars for a Cause.” Euroworld Motorsports continues to be a wonderful community partner and has yearly shown their support at this party and at the Houston NF Walk. The silent auction raised more than \$8,000 for the Foundation.

Make a difference in your community in the fight to end NF by creating your own fundraiser! Visit ctf.org and get started today!

Doing Nothing is Not An Option

In January 2016, Diane Owens, an NF Endurance marathon mom, found herself in a hospital bed, suddenly paralyzed. Her diagnosis was Guillain-Barré syndrome, a rare disorder in which your body's immune system attacks your nerves. It began with weakness and tingling in her extremities, which quickly spread, eventually paralyzing her entire body. Diane knew that she could not let this unexpected illness keep her from delivering on her goals to raise money for NF research. Only two weeks earlier, she had declared she would race three marathons in honor of her son, NF Hero Alex. Although the doctors told her

she would not run again, this amazing woman showed them that she could and she would. It was not easy, but Diane took her first steps one month after the onset of her illness and began running again just two months later. Diane walked a 5K on April 30 and completed three legs (15 miles) of a 200-mile relay in September, just under her projected pace. She went on to finish the California International Marathon in early December and raised over \$17,000 for NF research in 2016, bringing her family fundraising total to right around \$100K over three years. It's amazing what people are capable of when they have determination and passion.



“Despite the high likelihood that I would suffer some degree of permanent paralysis, I decided ‘doing nothing’ for my son was not an option.”

—DIANE OWENS, NF ENDURANCE ATHLETE AND NF MOM

NF CAMP

NF Camp is for young adults between the ages of 12 and 22 living with NF, offering them the opportunity to grow, laugh, and create their very own NF community of peers. Join us for our 21st year of NF Camp! Camp activities include the ultimate team-building event (Survivor Day), a ropes course, talent show, and horseback riding, as well as off-site trips to places like the water park and amusement park, and so much more!

This year, for the first time, we will be hosting the program for 3 weeks, making more room for new campers and new memories!

Dates:
July 8-14
July 15-21
July 22-28

NF Camp takes place at Camp Kostopulus in Emigration Canyon, Utah. For more information and to download the application please visit www.ctf.org/camp.

JOIN THE **NF** REGISTRY AND YOU CAN HELP **END NF**



JOANNE PASTEL
Minneapolis, MN
Daughter Jacqueline lives with NF1

“I joined the registry because...

I want to fight NF.”

www.nfregistry.org



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FOR MORE INFORMATION CONTACT
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New Faces at Children's Tumor Foundation



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NF News is the official publication of the Children's Tumor Foundation. All issues are available on our website at www.ctf.org. Please direct any questions or feedback to 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 causes tumors to grow on nerves throughout the body and may lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and cancer. NF affects 1 in every 3,000 births across all populations equally. There is no cure yet – but the Children's Tumor Foundation mission of driving research, expanding knowledge, and advancing care for the NF community fosters our vision of one day ending NF. For more information, please visit www.ctf.org.

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