

NF NEWS

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION
SPRING 2020

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So Much to Celebrate!

This is an incredible time of celebration at the Children's Tumor Foundation, and in this newsletter we are thrilled to share exciting news about the recent FDA approval of Koselugo (selumetinib) for NF1, groundbreaking research for NF2, and our worldwide NF awareness campaign that shines a light on neurofibromatosis.

Make NF Visible
Turn to page 10 to read more about our NF Awareness Month campaign, Make NF Visible, and this beautiful new portrait series featuring individuals living with NF.

FROM the President

Annette Bakker, PhD

UPDATE:

COVID-19 Response

The Children's Tumor Foundation has taken the guidance of New York State and New York City and closed the CTF NYC office until the guidelines on social distancing have been lifted. CTF staff, whether in NYC or around the country, are working remotely. We expect that our ability to conduct CTF business during this time will continue. Please note that there may be a delay in the mail and donation processing for letters and items physically received at the NYC address. Online and telephone donations and communications remain unaffected. You can always reach the Foundation at 1-800-323-7938 or 212-344-6633, or email us at info@ctf.org.

Even as we work through this challenging moment together, the innovative research taking place to end NF continues. The coming weeks may see workarounds for meetings, and some postponements. But you have our commitment that our dedication to finding treatments for NF will never be postponed.

Please visit ctf.org/covid19 for the latest CTF updates, where you can also view the recording of a live video chat about the impact of COVID-19 on our community that took place in March with NF experts Scott Plotkin, MD, PhD, and Bruce Korf, MD, PhD, as well as educational experts from within the NF community.

In the coming weeks and months, please be safe and take care of each other and yourselves.



It is a time of great celebration for the Children's Tumor Foundation (CTF) and for the neurofibromatosis (NF) community! In recent years, we have tracked the progress of the MEK inhibitor selumetinib as a potential, first-ever treatment for NF1. On April 13, 2020 the news we had been waiting for was announced, and selumetinib, now packaged as Koselugo, has been approved for NF1 patients with inoperable plexiform neurofibromas! I shed such tears of joy upon this news, knowing that this treatment can now reach all who need it!

But selumetinib is not all we are celebrating. To further speed the drug discovery process, the NF2 Accelerator Initiative is fueling tremendous progress toward treatments for NF2, and the Children's Tumor Foundation has been actively working toward treatments for all types of neurofibromatosis. Thanks to the dedicated research discovery of our Synodos for NF2 project, the FDA has approved an upcoming clinical trial for Brigatinib, a drug treatment which we trust

will bring the same hope and progress to our NF2 community as selumetinib has done for NF1.

May brings NF Awareness Month – another amazing celebration. This year, we want people to see NF and our NF Heroes through our "Make NF Visible" campaign. Throughout the month you will see beautiful portraits of twenty-two NF Heroes (such as the ones on the front and back covers of this newsletter) who live with NF1, NF2, and schwannomatosis. Some of these Heroes are visibly affected by NF, while for others, their NF is invisible to the naked eye.

This month-long celebration is inspired by the extraordinary spirit of patients and caregivers like Stephanie Jaramillo, who you will read about in this newsletter. She and her son Caiden live each day with strength, advocacy, and courage.

While the coronavirus might be keeping us at home, our continued fight to find more treatments for all forms of neurofibromatosis continues to soar. Now more than ever, we must bind ourselves together in a united effort, to shine a light in whatever darkness seems to block our way. We have come so far - let's charge ahead together!

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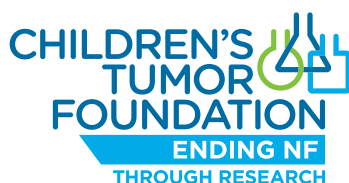
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Director of Medical Affairs Emeritus



FDA has Approved Kosulego (Selumetinib)

For Use in Patients with Inoperable Plexiform Neurofibromas

The U.S. Food and Drug Administration (FDA) has approved Kosulego (selumetinib) for use in patients with inoperable plexiform neurofibromas, a common manifestation in neurofibromatosis type one (NF1).

The FDA's approval of AstraZeneca's and MSD (Merck)'s submission is a major milestone for patients living with neurofibromatosis (NF), a genetic disorder that causes tumors to grow on nerves throughout the body. Affecting 1 in 3,000 people of all populations equally, this announcement is the first ever approved treatment for NF, and portends the potential for the development of treatment options for all NF patients.

Kosulego's approval follows comprehensive clinical testing of the drug in patients at the National Cancer Institute (NCI), a division of the National Institutes of Health (NIH). In those clinical trials, over 70% of NF patients with inoperable plexiform neurofibromas saw tumor size reduction anywhere from 20-60% in size. In addition to both visible and actual tumor reduction, patients reported higher-quality physical function, reduced pain, improved mobility, and enhanced emotional and psychological status.

The first use of MEK inhibitors as a potential treatment for NF tumors came from early-stage discoveries by Children's Tumor Foundation-funded researchers, who showed that MEK inhibitors could significantly affect NF tumor size. Positive early clinical results were first reported at CTF's annual scientific NF Conference in 2015, as well as in subsequent publications in the *New England Journal of Medicine* in 2016 and 2020.

Collaborative efforts among the NCI, the NIH, the NFRP-CDMRP



(Neurofibromatosis Research Program of the Congressionally Directed Medical Research Programs), NTAP (Neurofibromatosis Therapeutic Acceleration Program), and CTF ensured that this 'MEK Story' proceeded expeditiously through proactive and strategic coordination, guaranteeing efficient use of donor/investor funding, including from the federal government.

Another hallmark of this path to approval has been the inclusion of patients throughout the process, including the first ever 'NF listening session' held at the FDA in 2019.

Many other MEK inhibitors are also now in clinical trial, including mirdametinib from

SpringWorks Therapeutics, a company which the Children's Tumor Foundation helped spin off from Pfizer.

"We are so excited for the entire NF community today! This announcement from the FDA about Kosulego (selumetinib) is a tremendous step towards our ultimate dream – approved treatments for all forms of neurofibromatosis," said Annette Bakker, PhD, President of the Children's Tumor Foundation. "We believe that FDA approval of this treatment helps not only a subset of NF1 patients, it opens the door to increased interest in all forms of NF by pharmaceutical companies. We are already experiencing it – the number of companies interested in NF1, NF2, and schwannomatosis is growing rapidly."

KOSELUGO: Stories of the Road to Approval

The Children's Tumor Foundation made a significant investment in the NF Preclinical Consortium, which demonstrated that MEK inhibitors have a significant impact on tumor size in animal models. That work was instrumental in the development of a clinical trial led by Dr. Brigitte Widemann of the National Institutes of Health, who announced at the Foundation's 2015 NF Conference that

over half of the patients in the trial were seeing significant reduction in tumor size of their inoperable plexiform neurofibromas. NF. Over 70% of trial participants saw tumor reduction of at least 20% in size, a first in NF research. These success stories are now a part of the history of Koselugo, (selumetinib), the first ever approved treatment for neurofibromatosis.

NF HERO: Jane Constable / 30% Shrinkage

“I am thankful for the Children's Tumor Foundation's enormous efforts to support the research that led to such a trial. Now that selumetinib has been approved as the first-ever FDA-approved treatment, I am thrilled that now other people with plexiform neurofibromas will have access to and can benefit from selumetinib; proud that Jane was one of the first 24 children in the world to take selumetinib. She has seen it through from a Phase I trial to FDA approval, and her experiences, both good and bad, with the medication have helped guide researchers on how best to use it. I am relieved that all of Jane's hard work—all the trips to NIH, all the blood draws and MRIs and other tests, all the side effects and uncertainty—has paid off and will benefit others.”

—AS TOLD BY JANE'S MOM, KRISTY



BEFORE

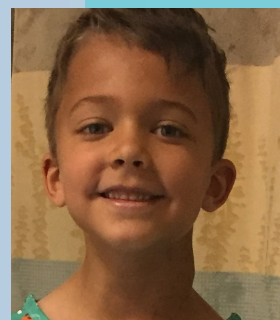


AFTER

NF HERO: Cooper / 21% Shrinkage

“We are so thankful that the Children's Tumor Foundation invested in the science that made the clinical trial for selumetinib possible! We are incredibly thankful that all NF Heroes will now have access to the drug that changed Cooper's life. We shudder to think of what would have happened if Cooper's tumor had continued to grow. Before starting the drug, his tumor was nearly doubling in volume every 18 months. Since starting selumetinib, his tumor has not only stopped growing, it has shrunk 21%! Our hope is that it will be as life-changing for others as it has been for our family.”

—AS TOLD BY COOPER'S MOM, KIRSTA



BEFORE



AFTER

FOR THE FIRST TIME IN HISTORY, THERE IS AN APPROVED TREATMENT FOR NF!

We need your help now more than ever!

This is a time of great celebration - the FDA recently approved the first-ever drug treatment for neurofibromatosis! This new treatment, called Koselugo (selumetinib), is **now approved** for NF1 patients with inoperable plexiform neurofibromas. This is a game-changing moment, and it is here because of an early discovery by Children's Tumor Foundation-funded researchers proving that MEK inhibitor drugs have the potential to affect tumor size.

That pioneering research was funded by donors like YOU – whether through a donation at an event, participation in a walk or run, or a direct gift to the Foundation. **You made this historical moment happen!**

Just look at these before and after photos of young Philip Moss, who was one of the first participants in the selumetinib clinical trial, and who saw the tumor in his neck shrink an incredible 60%!

We are now at a pivotal moment.

facial reanimation (twice), chemotherapy, and radiation. **Today, I am still hard of hearing, but restoration of some hearing has been life changing.**

CTF efforts like the NF2 Accelerator Initiative give me great hope for the future, for myself, and others affected by NF2."

For patients like Edith, the CTF-spearheaded NF2 Accelerator Fund is speeding research toward treatments for NF2. One of these projects is an upcoming, **FDA-approved clinical trial for a drug called Brigatinib**, specifically for patients with NF2. This potential treatment is a direct result of you, our donors, who funded CTF's Synodos for NF2 research consortium, which made the research discovery that led to this breakthrough.

We need this kind of hope for people like **Leslie Neighbours**, who at 27 finally received a diagnosis of schwannomatosis after living with severe nerve pain that grew more and more excruciating every year.

After a recent surgery to remove more than 15 tumors, Leslie described her pain as, **"hot lightning and blowtorch nerve pain ... like repetitive wasp stings."** Even worse, in order to get some relief, Leslie has had to pay



Edith Garrett,
who lives
with NF2

for many of her treatments completely out of pocket.

We need drug treatments for Leslie and all of those suffering from the debilitating pain of schwannomatosis. Thanks to your continued help, CTF's Synodos for Schwannomatosis is focused specifically on developing treatments for this pain!



Leslie Neighbours,
who lives
with schwannomatosis

Right now, there are 68 potential drugs for NF in the pipeline, including a selumetinib clinical trial for NF2. We are on the brink of more treatment options for all types of NF, and we are at this moment because of supporters like you, who took a chance on the Children's Tumor Foundation, and the inspiring scientists we funded.

Koselugo is now the first approved drug for NF. And when there has been a first... there can be a second. And a third.

There is more work to be done - and the time is now!
Please support this life-changing effort at ctf.org/donate.

"Thanks to selumetinib, my son's tumor shrunk more than 60%. Without this treatment, he wouldn't have been able to swallow, or to smile. It has given us back his life."

—Renie Moss,
mom to Philip

NF HERO: Philip Moss 60% Shrinkage



BEFORE

AFTER

The long-awaited FDA approval of this MEK inhibitor drug means that more attention is coming to neurofibromatosis – **and that attention is an opportunity to accelerate drug discovery for ALL manifestations of NF!**

Koselugo is just the first step. We still have no approved treatment for other types of NF tumors, like disfiguring cutaneous neurofibromas, life-threatening meningiomas, or painful schwannomas. We cannot stop until there are treatments for all forms of neurofibromatosis – NF1, NF2, and schwannomatosis.

The millions of people living with all types of NF need your help now.

We need your help to get to approved treatments for people like **Edith Garrett**, who as a 19-year-old college student, was diagnosed with neurofibromatosis type 2.

"I was fully deaf for a year. Fortunately, research was beginning to make drug therapy an option. I joined a preclinical trial for Avastin in 2007. After just a month of infusions, one of my tumors, a vestibular schwannoma, began to shrink. In time, hearing was restored to my left ear.

The last ten years have been full of interventions: brain surgeries,

The NF2 Accelerator Initiative

One year ago, on the occasion of World NF2 Awareness Day, the Children’s Tumor Foundation announced the establishment of a significant research initiative dedicated to finding effective treatments for NF2, along with a substantial investment of \$2.3 million in this bold new effort. Called the NF2 Accelerator Initiative, this three-year undertaking is dedicated to bringing active NF2 treatments to the clinic (and patients) by expanding the clinical drug pipeline for NF2, improving drug selection through the development of innovative testing models, and the development of gene therapy options that address the underlying genetic causes of NF2.

The NF2 Accelerator Initiative is actively creating opportunities in these three areas:

Expanding the Clinical Drug Pipeline for NF2

- Leveraging the discovery and knowledge that came from CTF’s team-science Synodos for NF2 project, we are participating in and co-funding an upcoming phase 2 clinical trial using Brigatinib.
- Offering Drug Discovery Awards to researchers and institutions focused on the next phase of NF2 clinical candidates.
- Offering Young Investigator Awards to early-stage researchers to invest in the expansion of understanding of the processes that drive NF2. These awards will be announced later in 2020.

Improving Drug Selection for NF2

- Expanding the research on NF2 animal models in order to provide

better understanding of how different manifestations of NF2 develop over time.

- Developing image-based animal models for vestibular schwannomas to combat the limited availability of preclinical resources that allow for efficient drug testing.

Investing in Gene Therapy for NF2

Much of NF2 drug discovery and development is primarily focused on inhibiting the processes that are activated as a consequence of the loss of the *NF2* gene. CTF has invested in gene therapies in the past, but in 2019 committed to funding a very exciting gene therapy proposal that has the ability to be a real treatment option for patients with NF2.

To support the NF2 Accelerator Initiative, please visit: ctf.org/endnf2

NF2 Accelerator Initiative Research Grants

In 2019, CTF launched the NF2 Accelerator Initiative, which included a request for applications for new NF2 drug-testing proposals. We are pleased to share the news of two grantees from this endeavor and summaries of their projects below.



Elisabeth Castellanos-Perez, PhD (*Fundació Institut d’Investigació en Ciències de la Salut Germans Trias i Pujol in Spain*) will evaluate the use of antisense oligonucleotides (ASO) as personalized therapy

for NF2 patients. Since ASOs can correct point pathogenic variants (mutations) that prematurely truncate proteins or prevent proper mRNA splicing, they present a conceptually viable approach to overcome the effects of NF2. Approximately 45% of pathogenic variants detected in the *NF2* gene could be potentially treated with antisense therapy. Dr. Castellanos-Perez’s team is well-experienced in using ASOs and has successfully applied them in a previous NF2 study. In the current project, they propose to test ASOs in reducing the severity of truncating NF2 pathogenic variants in patient cells.



Vijaya Ramesh, PhD (*Massachusetts General Hospital*) will leverage Synodos for NF2 data to test single and combination drugs in NF2-deficient meningioma models. Dr. Ramesh was one of the key investigators in the large-scale

omics and drug screening studies conducted as part of the CTF-funded Synodos for NF2 project. Through this effort, Dr. Ramesh and her team identified several interesting drug targets in their cell model for NF2-associated meningioma. The current proposal builds on the rigor and strength of these published and unpublished discoveries, and will further test some of the targets and drug combinations identified previously. Success in these studies will provide a framework to pursue new avenues in NF2 and meningioma research for clinical care.

The NF2 Accelerator Initiative Committee

NF2 Accelerator Initiative Committee is a team of individuals deeply impacted by NF2. They are a dedicated group of NF2 patients, fathers, mothers, and grandparents committed to helping the Children's Tumor Foundation drive research toward the discovery of treatments, and ultimately an end to the suffering of NF2.

Colorado Rockies Baseball Player **Ian Desmond** was honored as an NF Champion at the CTF 2019 National Gala, and serves as the Honorary Chair of this initiative. In 2012, Ian befriended South Carolina native Ethan Brown, who had been diagnosed with NF2.

Ian Desmond,
Honorary Chair

RB Harrison,
Co-Chair

John Morris,
Co-Chair

**Nicola Kean
Brainin**

Tracy Galloway

Edith Garrett

Carol Harrison

Matthew Hay

Beth Hennessey

Becky Irvine

Lara Levine

Roland Thoms



"Back in 2012, I connected with Ethan Brown, who lives with NF2. I wanted to help in any way I could. I know that working with CTF's NF2 Accelerator Initiative is my opportunity to make a difference."

— **Ian Desmond**, Colorado Rockies Baseball Player and NF Champion



"NF2 doesn't get a lot of attention despite it being relatively prevalent. The NF2 Accelerator Initiative is important because it shines a light on the work that CTF is doing for NF2 research, treatment, and advancement."

— **Matt Hay**, who lives with NF2



"Having a child with NF2 has opened my eyes and those of my family to the difficulty of attacking rare diseases. My hope is that we can find a way to slow the progression and ultimately eradicate NF2."

— **John Morris**, whose youngest son lives with NF2



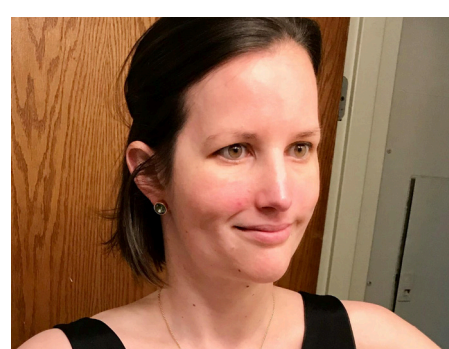
"I believe much better treatments for NF2 are within our grasp TODAY. To reach that goal, it will take a rock-solid belief, within each of us affected either directly or indirectly, that better options are truly attainable. If you have NF2, or have a family member or friend with NF2, you are needed. You are part of the solution."

— **Tracy Tulloh Galloway**, mother to **McKinnon**, who lives with NF2



"We, like any parents, only want the best for our children and when something is wrong we try and fix it. Brian has NF2, so we are trying to fix it. It is that simple. We want to 'fix' it, for Brian, so NF2 is a distant memory."

— **RB Harrison**, father to **Brian**, who lives with NF2



"Research has already had a positive impact on my quality of life, but there is a need for more. Initiatives like this give me great hope for the future, for myself and others affected by NF2."

— **Edith Garrett**, who lives with NF2

New Partnership: Healx



The Children’s Tumor Foundation is very excited to announce our global partnership with Healx, a leading technology company that will progress new AI (artificial intelligence)-derived therapies for neurofibromatosis. Healx’s primary mission is to advance new treatments for rare disease patients. It will combine its AI technology and drug discovery expertise with the disease data, networks, and patient insights of the Children’s Tumor Foundation’s R&D enabling platform in order to predict and progress new therapies for NF. Leading this effort is Simone Manso who joins Healx as Head of NF Strategic Partnerships. Simone also serves as a member of CTF’s Board of Directors and is the Chairman of CTF Europe. With this news from Healx, combined with the recent announcement from the FDA and AstraZeneca, we expect pharma and biotech interest will continue to grow, leading to more therapies for all forms of NF.

“Healx has the tech and pharmacology expertise, along with the ability to quickly move treatments towards patients, whilst CTF brings the strong NF know-how and patient, clinical and academic networks. Most importantly, both teams have a shared passion for striving to improve the quality of life for NF patients. I can’t think of a better partnership and I am honoured to lead this effort, which is personally, very close to my heart. This is where the magic can happen!”



- Simone Manso,
Head of Neurofibromatosis Strategic Partnerships at Healx

Good News for NF Patients with Low Grade Glioma (LGG)

Investments in LGG research to transform patient care: congratulations to Gilbert Family Foundation for sponsoring first-rate consensus workshop and gratitude to Synodos LGG donors

A paper published in the academic journal *Neuro-Oncology* by NF experts has demonstrated an increased understanding of low grade gliomas (LGG) occurring in children and adults with NF1. While the biology of LGG has become better known over the past decade, the complexities of these tumors have inhibited practical application of this knowledge to NF1-related LGGs, which can potentially impact close to a third of NF1 patients. According to Dr. Roger Packer, the Gilbert Family Foundation consensus conference held last year with NF1 and LGG experts was aimed at pulling together NF and low grade glioma experts to assess whether new therapeutic strategies could be developed for patients with LGG.

In response to the timing of the meeting, Dr. Packer said that, “the LGG Synodos teams, funded by CTF, had collaborated to analyze for the first time in NF history a large enough number of specimens to draw some important conclusions which probably will have implications in how LGG patients will be treated going forward.”

We would like to thank all the donors to the Synodos for LGG project, with special thanks to the lead funders Jim Bob & Laurée Moffett, Flashes of Hope, and CureNFwithJack. They believed in our audacious global collaborative projects and stepped up to fund this effort.

And, thanks to the Synodos teams who relentlessly work together to generate the data that will help NF patients, and who have made all data openly available on the CTF-funded NF Data Portal.

NF Tissue Biobank Moves to Indiana University Biorepository

The Children’s Tumor Foundation and the Developmental and HyperActive Ras Tumor Specialized Programs of Research Excellence (DHART SPORE) Biorepository at Indiana University have agreed to merge their NF tissue collections. The arrangement is a win-win, with CTF gaining an online inventory and a sustainable home for its tissue collection, and Indiana University expanding its collection of curated NF-specific tissue.

The CTF biobank began its collection in 2013 with surgically-removed cutaneous neurofibroma. In 2014, strong interest from the NF community led to the establishment of a post-mortem body donation program to bank tissue from patients with NF1, NF2, or schwannomatosis. This was accomplished in

collaboration with the National Disease Research Interchange (NDRI), providers of a nationwide tissue recovery service.

As CTF’s collection grew, it became clear that a full-time biobank manager was needed to run the project. CTF began looking for a partner that could provide this and found that partner in Indiana’s DHART SPORE. Under the new agreement, CTF will continue facilitating patient requests to donate tissue, while DHART SPORE will provide biorepository services. CTF will continue to have a voice in determining tissue usage.

This new partnership is a fantastic move forward, allowing researchers and patients to work together to end NF.

2020 NF CONFERENCE Goes Virtual

In light of the global public health crisis related to the COVID-19 pandemic and, most importantly, in the interest of the health and safety of the entire NF community, CTF, along with its Board of Directors and this year's planning committee, made the decision to cancel this year's NF Conference which was to have taken place at the Loews Hotel in Philadelphia* from June 13 – 16.

While an in-person meeting is not possible given the current circumstances, there is still vital and timely information to share with the community. We will therefore be hosting a two-day, scaled down meeting in virtual format. This two-day virtual conference will be held **June 15-16, 2020**.

The meeting will kick off on Monday, June 15 with opening remarks by Dr. Francis Collins, Director of the National Institutes of Health. Throughout the two days, platform and poster presentations will be included in which the latest in NF research will be shared. In order to accommodate any late-breaking research, the abstract submission date has been extended to May 11, 2020.



Further details regarding the meeting and registration will be posted to **ctf.org/nfconference** as they become available.

**We wish to thank the Loews Hotel in Philadelphia for working with CTF to postpone our stay with them until June 2022.*

Re-Designed NF Registry to Open in May

Since 2012, the Children's Tumor Foundation's patient-driven Registry has served as a place for NF Heroes everywhere in the world to help advance knowledge of how NF affects people over their lifetimes. The Registry also emails participants about studies of possible interest, based on the symptoms they have reported. As of 2020, the NF Registry has contacted patients about more than 40 clinical studies and grown to over 9,700 members.

Interest in this resource is growing even stronger as treatments advance. With this in mind, CTF decided to invest in a new platform called OpenApp that will make participation easier while expanding the registry's functions.

FOR REGISTRANTS:

WHAT IS STAYING THE SAME?

- The website will remain **nregistry.org**
- Information you previously entered will

be transferred to the new system

- With your consent, the Registry will continue to notify you of clinical trials or studies that match with your symptoms
- With your consent, de-identified information will be available to qualified researchers to help speed up treatment development
- The Registry will provide a secure, privacy-protected system for accumulating patient-entered data about NF symptoms and experiences.

WHAT WILL BE DIFFERENT?

- Your email address will be your new username (your password is the same)
- We will ask you to read the new patient consent material and agree to participating in the new platform
- Your user experience will be enhanced by upgraded system speed and streamlined surveys.

Questions? Contact us by email at **nregistry@ctf.org**

NF Clinic Network Expands to 63 Clinics

The CTF Clinical Care Advisory Board has recently accepted six new NF clinics into the NF Clinic Network (NFCN) in various areas of the country. All newly approved clinics provide adult care, and a few see both children and adults. There are now 63 clinics in the NFCN.

New clinics include:

- Swedish Medical Center in Seattle, Washington
- Froedtert and Medical College of Wisconsin in Milwaukee, Wisconsin
- UF Health Neuromedicine Hospital in Gainesville, Florida
- University of TX/MD Anderson Cancer Center in Houston, Texas
- Wake Forest School of Medicine in Winston Salem, North Carolina
- Randall Children's Hospital at Legacy Emanuel in Portland, Oregon

For more information go to **ctf.org/doctor**, where each clinic has a link to access specific details, including type of NF seen, number of patients, areas of specialty, and any involvement in NF research.

MAY is NF Awareness Month!

Visit ctf.org/nfawareness to learn more ways YOU can **Make NF Visible!**



WEAR

our exclusive CTF blue and green gear all month, especially on May 17 & 22



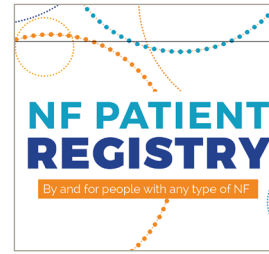
DONATE

to fund the cutting-edge research that will end NF



CHANGE

your profile picture to one that celebrates NF Awareness



JOIN

the NF Registry if you or your child has NF



TAG

your photo(s) on social media with #EndNF



LIKE

Children's Tumor Foundation on social media



SHARE

SHARE exclusive photo series, Make NF Visible



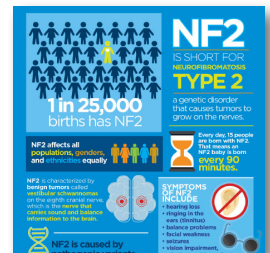
PARTICIPATE

in our webinars and our Home Is Where the Heart Is Zoomathon on May 17



WATCH

our NF Awareness Month videos on our YouTube channel



EDUCATE

using informative fact sheets and brochures



SHINE A LIGHT

Home is where the heart is, so let's turn our attention to our families and homes to Shine a Light on NF this year. You can light up your home with blue and green Christmas lights, leave awareness messages in chalk on your sidewalk, or change your porch lights to blue and green to spread awareness of NF.

A number of landmarks and buildings around the world are still Shining a Light on NF. Visit ctf.org/shinealight for the list of participating locations.

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



NF is a rare genetic disorder.
How do you Make NF Visible?

Enter the 2020 Children's Tumor Foundation NF Awareness Month "Make NF Visible" photo contest! Email media@ctf.org and submit your entry. The photo must include CTF-branded gear. Contest ends May 31, 2020.



Make NF Visible

The theme for this year's NF Awareness Month campaign, Make NF Visible, creates a space for us to connect everything we do at the Foundation: the external things the community is doing to raise the profile of this rare disease, and the internal struggle patients experience living with a genetic disorder that manifests differently in each NF patient.

We partnered with award-winning photographer and NF Dad Craig Warga for a new photo series, MAKE NF VISIBLE, that looks at the different ways NF can affect a person's life, even when no one else can see. We paired people with NF who have manifestations that can be seen with those whose affectations can't be seen, as a way to highlight the visible and invisible ways NF makes itself palpable in a person's life.

View the entire collection and learn more about each of the NF Heroes in the photographs at: ctf.org/make-nf-visible



Around the COUNTRY

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

Two Counties, One Cause



George's daughter Brielle with NF National Ambassador Brianna Worden

"We created an event called Two Counties One Cause, a basketball tournament here in New York between Rockland and Westchester County teams, to give back to the Children's Tumor Foundation. As a father of a child with NF1, you feel helpless sometimes and it's not a great feeling. With the help of some special individuals and community support, our event raised more than \$28,000. We have been so lucky, and it's humbling what people will do for others. This event really allows you to see the best in people."

— **GEORGE GAINE**, event organizer and father to NF Hero Brielle

METAFORMERS' METACONFERENCE VOLUNTEER EVENT

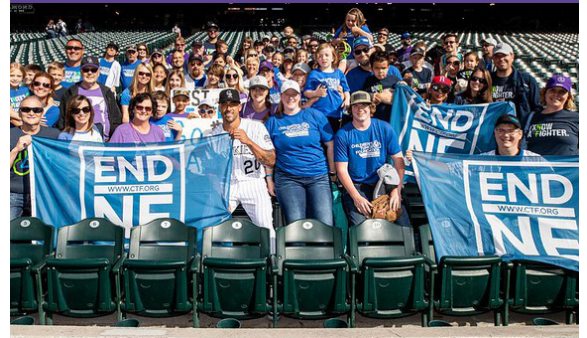
Each year, Metaformers, a Virginia-based IT consulting company, plans a volunteer activity at their annual conference. This year, CTF volunteer Lisa Gutierrez was asked to plan the year's volunteer activity, and she used the event to spread awareness about NF. Attendees learned about neurofibromatosis and the Children's Tumor Foundation through a 45-minute presentation, then helped stuff activity bags with games, puzzles, comics, fidgets, CTF swag, and personally decorated cards of encouragement, to be distributed to NF patients at clinics across the country. The event was a tremendous success, and our sincere gratitude goes out to Lisa and all of her colleagues!



End NF with Ian Desmond

Colorado Rockies Baseball Center-fielder Ian Desmond is an on-going CTF supporter, donor, and friend to the Children's Tumor Foundation. He is a champion of the NF cause: donating and raising funds during NF Awareness Month and taking the time to meet up with patients and families during Rockies games across the country. Ian's support is a result of a friendship that he developed with NF2 hero Ethan Brown of South Carolina, and he is now the Honorary Chair of the NF2 Accelerator Initiative.

In 2019, Ian asked if we would help organize meet-and-greets at every away game on the Rockies schedule so that he could build up the NF community and share his personal story. In a true "team" effort, there were 18 group events held across the country! We extend our utmost thanks to Ian and his family for this ongoing, community-building support. Please check ctf.org/iandesmond for updates about End NF With Ian Desmond throughout the year.



DINNER BETWEEN FRIENDS

The first Dinner Between Friends was hosted by Kathy & Tony Folk, and brought together old friends and new ones to share a home-cooked meal while raising awareness and funds for CTF. Actor and producer Jonathan Sadowski came to help cook, and served his world-class pork tenderloin. The evening raised over \$1,000 for NF research.



This year, Cupid's Charity hosted Undie Runs in 38 cities with nearly 9,000 people participating. These fun runs raised awareness and, more importantly, \$2 million!

Cupid's works with volunteers to produce these events. Some of these volunteer-leads have close personal connections to NF, others do not and are just incredibly passionate people who want to help support a great cause. That's one of the unique aspects of these events, they bring together participants, volunteers, and fundraisers with a connection as well as thousands of people who have never heard of NF.

Cupid's Charity has been a proud partner of CTF for a decade. This year marked the 10th anniversary of the first Cupid's Undie Run which took place in Washington, DC. Since its inception, Cupid's has raised more than \$10 million to support CTF's research efforts and introduced tens of thousands of people to NF and our shared goal of ending NF.



COCKTAILS FOR A CURE LONG ISLAND

January's Cocktails for a Cure Long Island event was a beautiful evening at the Milleridge Cottage that included a delicious buffet, silent auction, raffle, and a live auction of NF Hero artwork created by Julia Perfetti, Charlotte Spoto, and Charlie Romano. The event raised more than \$100,000 for NF research!

Special thanks to the wonderful host committee for this annual benefit: Debbie Acker, Meg Blank, Pam Blank, Stacey Decillis, Angela Fox, Anita Gribben, Kristin Kalendarian, Jodi Markowitz, Erika Millet, Laura Perfetti, Marietta Perfetti, Kim Riso, Victoria Romano, Danielle Schmidt, and Cristina Spoto.

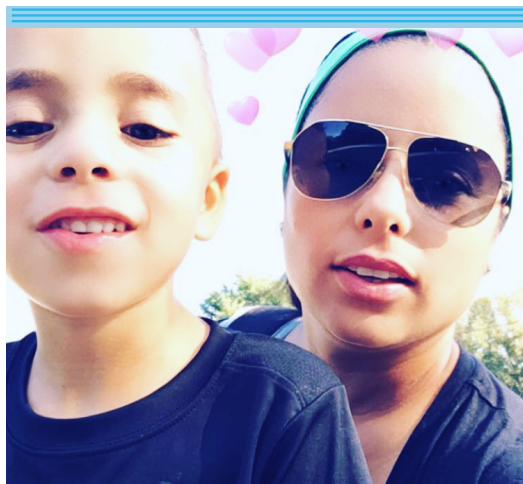


Laura Perfetti, Brianna Worden, and Anita Gribben at Cocktails for a Cure Long Island.

NF Collective Summit

The Children's Tumor Foundation welcomed the NF Collective to our New York office February 17-18. Initiated in 2015 by leader Tracy Wirtanen, the NF Collective is a group of seven non-profit NF-support organizations from around the country, dedicated to working together on projects to improve the lives of individuals with NF. David Viskochil, MD, PhD, NF clinic director from the University of Utah, participates as the medical and clinical liaison. The initial collective project, completed last year, was the development of the NF Collective website to assist families in finding an NF provider. This year, the summit explored new projects, and the groups decided on the goal of improving the transition process from pediatric to adult care. Our first steps are to assess the current state of clinic transition programs and begin to compile transition resources for families with NF. Learn more at nfcollective.org.





“ Every step we take on the walk is a step forward to find a cure! ”

— VANESSA DANGOIA, 2020 Shine a Light Walk New England Team Captain



“ I walk because I want everyone to know what NF is. I don't want anyone else to walk out of an appointment and be lost and confused like I was. I want to educate and spread awareness, so that one day we will have a walk to celebrate a cure for NF. ”

—NAOMI CUKA, 2020 Shine a Light Walk South Dakota Organizer

The **2020 Shine a Light Walk** campaign got off to a strong start with 32 Walks on the calendar, two new Walks launched in the Carolinas and South Dakota, and a significant increase in fundraising year over year.

Unfortunately, the COVID-19 pandemic forced us to switch gears and postpone our spring Walks until the fall. Despite the disruption that social distancing has brought to all of our daily lives, however, we assure you that one thing remains unchanged: our goal to end NF. The Shine a Light NF Walks play a critical role in funding CTF's mission and bringing NF families together each year in a spirit of community and compassion. We need your support now more than ever! We will continue to actively work with Walk organizers, team captains, and participants throughout the summer and look forward to partnering together during this challenging time. Please see our updated Walk schedule below. In this milestone year that marks the first FDA approval of a treatment for NF, we can't wait for the day we can gather together and celebrate at a Walk near you...

Visit shinealightwalk.org and register today!

“ We walk for a cure but we also walk for community. NF is a long journey with ups and downs and there is a lot of comfort in going through it with others. It helps to feel that other people are behind you. We walk every year so we don't have to walk alone. It's great to see the NF community in North Carolina come together, and we are happy to see familiar faces and new faces every year. ”

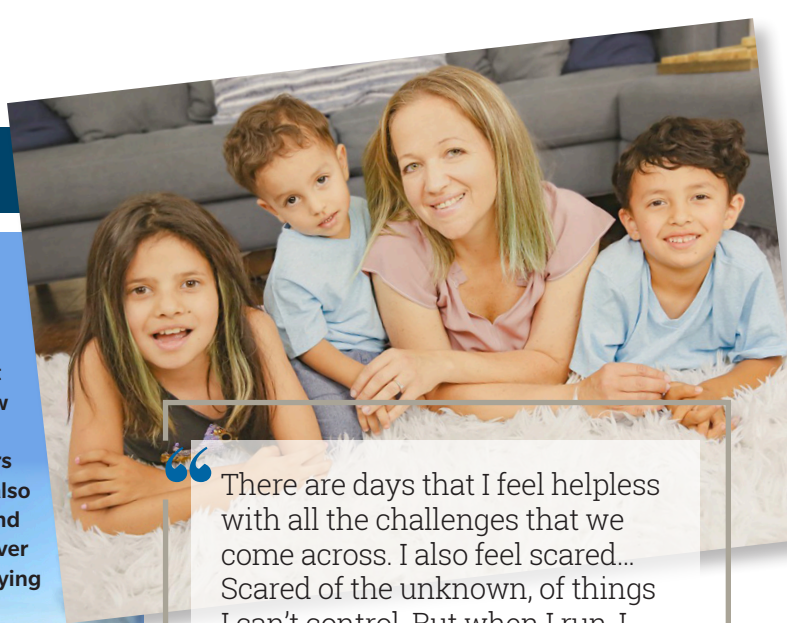
—DR. SURESH NAGAPPAN, 2020 Shine a Light Walk Kernersville Team Captain



UPCOMING SHINE A LIGHT WALKS

Please go to shinealightwalk.org to confirm upcoming event dates.

7/26/2020	Michigan	shinealightwalk.org/michigan2020
8/16/2020	Seattle	shinealightwalk.org/seattle2020
8/22/2020	Bay Area	shinealightwalk.org/bayarea2020
8/29/2020	Iowa	shinealightwalk.org/iowa2020



Little Heroes 5K

On Sunday, February 23, the Little Heroes of North Georgia committee hosted its 8th Annual Little Heroes 5K, raising \$35,000 through the support of community and business sponsors. As a part of their efforts to attract new audiences, this year they introduced a 5K Weight Vest Division, drawing area CrossFit athletes to run the 5K in 20lb vests! Led by longtime volunteers Carolanne Owenby and Tara Rogers, this year-round volunteer committee also hosts an annual “Crossfit for a Cure” event, which this May will be virtual, and will expand their annual “Rocking For Research” concert event in the fall. Over the last 8 years, their efforts have raised over \$500,000 for NF research, rallying around NF Hero Robert Owenby, who lives with NF1.



“There are days that I feel helpless with all the challenges that we come across. I also feel scared... Scared of the unknown, of things I can’t control. But when I run, I feel like I can control THIS. This very moment. I feel like, I got it. I am strong enough to keep fighting and won’t give up... I’m so happy to be able to raise money and bring awareness as a member of the NF Endurance Team. I have met many medical professionals who have never even heard of NF, and to be able to educate one person at a time gives me purpose.”

—SASHA DREBSKAYA, NF Hero and NF Endurance team member, who runs for her three kids, all of whom also live with NF

NF ENDURANCE EVENTS

as of May 1, 2020. For the latest event information, go to nfendurance.org

DATE	EVENT	URL: Go to: join.ctf.org/ _____
TBD	Five Boro Bike Tour	fiveborobiketour
TBD	RnR Atlantic City	rocknroll
TBD	Colfax	colfax
TBD	RnR San Diego	rocknroll
TBD	RnR Seattle	rocknroll
July 18-19	RnR Chicago	rocknroll
Aug. 16	Tour of Napa Valley	napa
Sept. 5-6	RnR Virginia Beach	rocknroll
Sept. 19-20	RnR Philadelphia	rocknroll
Sept. 19-20	RnR Montreal	rocknroll
Sept. 27	Berlin Marathon	berlin
Oct. 3-4	RnR San Jose	rocknroll
Oct. 10-11	Flying Pig Marathon	flyingpig
Oct. 11	Chicago Marathon	chicagomarathon
Oct. 17-18	RnR Denver	rocknroll
Nov. 1	NYC Marathon	nycmarthon
Nov. 7	Indy Monumental	indy
Nov. 7-8	RnR Savannah	rocknroll
Nov. 14-15	RnR Las Vegas	rocknroll
Dec. 5-6	RnR San Antonio	rocknroll
All year	Rock ‘n’ Roll Series	rocknroll
All year	Choose Your Own Challenge	cyoc
All year	Spartan Races	spartan

CHOOSE YOUR OWN CHALLENGE: Emma’s Hiking Challenge for CTF

To commemorate a milestone birthday, Emma Coltoff is hiking 250 miles, starting on her birthday, January 31, and hiking through May 31st, the end of NF Awareness month. Emma has previously participated in NF Walks and Cupid’s Undie Run, but hiking is Emma’s passion, so CTF’s “Choose Your Own Challenge” option was perfect for her! Over the course of four months, she will log miles during evening and weekend hikes. She is journaling about her 250-mile hike challenge on her fundraising page and welcomes family, friends, and co-workers to join her for some of the miles. Emma is hiking for two NF Heroes: in honor of her sister Lily, and in memory of their father Joel.



stories

OF NF

Johanna Podio, NF1

Johanna was diagnosed with NF1 when she was three years old. She has always had issues with her reflexes and has dealt with pain in her back and joints all through childhood. She suffered severe migraines as well.

Johanna started dancing when she was six years

old as a form of physical therapy. She no longer competes due to the pain in her back becoming too intense, but she still dances on pointe in ballet, contemporary ballet, and tap. She plays golf as well.

In addition to the pain, Johanna also has learning issues and has always tested low in school assessments. She works hard on her schooling and just finished her high school senior year early, in the top 10 of her class. Johanna loves to write and has had two stories published in a book. She plans on attending college and dreams of studying journalism and attending film school.

She is currently in a back brace to help give her support from the pain. Through all the MRI scans and doctor visits she always maintains a positive outlook and attitude. She never gives up and never lets her condition dictate how she participates in her schooling, sports, and life.

Johanna has always approached her NF with determination and a positive attitude. We as a family have always approached each test, doctor's visit, and treatment on a day by day basis. Johanna is always trying to approach her NF as a learning experience instead of a negative one. She is our hero because of her courage and positive attitude. She never complains about speech therapy, daily strengthening exercises, or her constant tutoring that she goes to help with her memory. She has grown into such a beautiful strong courageous young lady.

—Submitted by Lisa,
Johanna's mom



Michelle Smith, schwannomatosis

When I was 49 years old, due to unmerciful pain in my back, I had an MRI that revealed one tumor. I was passed along from one doctor and one facility to another, hearing the same thing from each: "I have never seen anything like this before and it's out of my wheelhouse."

I went several years being passed around; I tried pain management therapies and acupuncture... it felt like I tried everything. By then I had three tumors and heart-stopping pain. The tumors were growing. My primary care physician decided that we had to find a surgeon to look at this and found a neurosurgeon that specialized in nerve tumors at Stanford Cancer Center. I left home not knowing when I would return. I had those three tumors removed and four months later returned home free of tumors.

Two months later, a new tumor appeared. I ultimately ended up at MD Anderson in Houston where they have an NF Clinic, to find out why I was continuing to grow tumors. I was diagnosed there with schwannomatosis. I have multiple tumors now. I recently had a spinal cord stimulator implanted as I was unable to walk. It put me back on my feet and off to the races again!

NF changed my entire world. Making plans for even tomorrow can be a challenge as I never know how bad my pain will be or when I will be needing surgery. On the positive side, it has made me appreciate and savor all the moments I have and live for each day. I no longer say "One day I want to..." - I do it now.

I am a Real Estate Broker in Arizona and California. I reside in Arizona and spend as much time in San Francisco as possible with my children and grandchildren. I love to travel abroad and experience other cultures. I am currently learning to speak my heritage language, Swedish, for my upcoming trip.

I became a vegetarian and work out with a trainer 4 days a week to make my body as strong as I can for the next surgery and for recovery. I have become much more conscious of what goes in and on my body.

I hope to show the children, and their parents, struggling with this terrible condition, that a long adventurous life can still be had. I have learned to live with the limited knowledge of this disorder, the lack of a cure, and the uncertainty of what tomorrow brings, and look forward to each day knowing that I will rise to each challenge with a smile on my face.



Michelle,
pictured with her
granddaughter



Extraordinary Spirit / **STEPHANIE JARAMILLO**

Stephanie Jaramillo is a fighter, to say the least! For two years in a row, she joined a team of NF patients, advocates, and CTF staff who took Washington, DC by storm for Rare

Disease Week to raise awareness for neurofibromatosis and advocate for continued governmental investment in NF research. She has also obtained yearly proclamations from the city of Denver declaring May as NF Awareness Month.

Stephanie has been on the planning committee of the Denver NF Walk for years, and in 2019, Stephanie became the lead organizer of the Shine A Light NF Walk in Denver. The event included 300 participants, and had a record-breaking year for fundraising, thanks to the leadership of Stephanie and her committee of volunteers.

Relentless fundraising and awareness efforts for the Children's Tumor Foundation aren't all that Stephanie does. In addition to her role as a mother, advocate, and volunteer, Stephanie works as a mental health and substance abuse therapist. Her fierce pursuit of the proper diag-

nosis for her son Caiden, followed by years of advocacy for him, speaks to her ability to approach any problem or challenge with incredible bravery.

Stephanie spoke of her journey: "It was suspected at birth that Caiden might have NF, but back then there wasn't genetic testing, so it was a clinical diagnosis but he didn't meet enough criteria. It took us seven years to actually get an NF diagnosis, which was a very, very frustrating process. Lots of different words were thrown at me, like leukemia, and other things. And then it turns out it was NF after all, the very thing they suggested from the beginning. For me, finally having the diagnosis was such a relief. I know other people have a different experience, but for me it was like, 'Oh, thank goodness we finally know what we're up against.'"

When Caiden was age 7, he had an MRI because he was suffering from migraines. That scan revealed that he had an optic pathway glioma, and confirmed his diagnosis of NF1. Even before Caiden's definitive diagnosis, Stephanie had already started fundraising for

the Children's Tumor Foundation. After news of the diagnosis, she hit the ground running hard and amplified her fundraising and advocacy efforts.

Thankfully, Stephanie had a wonderful and supportive community in Denver, and was welcomed into the NF community with open arms. "This was huge for me. I immediately connected with Shelly Pesta, whose son Jeremy is exactly 10 years older than Caiden, so Shelly became a mentor for me – both as a fundraiser and as an NF mom, she really took me under her wing. I feel like successful fundraising is the consequence of having a good connection."

Caiden will be 16 years old this May, and is doing very well. He has since developed a second NF-related brain tumor on his prefrontal cortex, but thankfully both tumors are stable. Stephanie said, "As a mom, I'm thrilled that his health is good. He also has autism and developmental disabilities, and is in a moderate intellectual disability range. But I'm happy to say that we got him reading, so he's officially literate. Which is just huge."

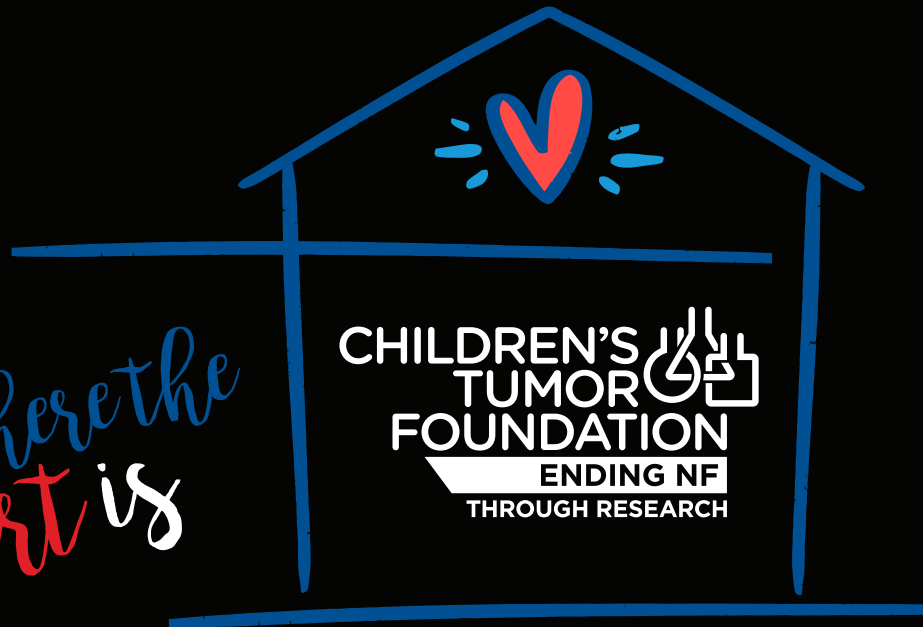
One of Stephanie's challenges has included fighting for Caiden's rights in school. Advocating in yearly IEP meetings, and ensuring that he is getting the services he needs takes focus and fortitude. Additionally, she uncovered some disturbing mistreatment of Caiden in his school, and fought to have him removed from that setting, and for changes in their local school system.

"That situation forced me to really find my voice, which is funny because prior to that, I was working as a mental health therapist in jails. You'd think I would have more of a hardened personality, but that just wasn't me. It definitely pushed me. I've never felt so motivated to fight!"

Stephanie Jaramillo's personal experience as well as her professional background have made her a courageous leader and a nurturer of others. She is a shining example of the bond that is so powerful in the NF community, in which we draw strength from one another.

"The most important part of my involvement with CTF is that I was very well supported on my journey. Now that's what I'm trying to do for others. I want to be that person that helps in any way that I can."

Home
is where the
Heart is



A ZOOMATHON EVENT
to benefit
the Children's Tumor Foundation
and to Make NF Visible



May 17, 2020
World NF Day
7PM-9PM ET

On May 17th (World NF Awareness Day) we're coming together to make sure the world knows about neurofibromatosis! Tune in at 7PM ET, when we'll be joined by well-known actors, musicians, athletes, comedians, chefs, magicians, celebrities, and NF Heroes, all combining forces for this important cause: **TO MAKE NF VISIBLE!**

Hosted by actor/producer [Jonathan Sadowski](#), this Zoomathon event to benefit the Children's Tumor Foundation will be live streamed on Zoom, Facebook and Youtube.

To learn more and see the full list of stars, visit:

ctf.org/heart

streaming on:

zoom



#EndNF

Officially launched in November of 2018, CTF Europe had its first full year of activities in 2019. The overall purpose of CTF Europe is to ensure that the NF research and development community benefits from European funding, by establishing unique public-private partnerships in Europe, such as the Innovative Medicine Initiative (IMI), and align the efforts undertaken in the US with those in Europe.

To accomplish these goals, CTF has been liaising with key European leaders to raise awareness of neurofibromatosis, and drawing attention to the unique opportunity that NF can offer to investors as a prototype for rare disease. The CTF Europe strategy has included participation as work package leader in a number of projects highlighted below.

European Project Highlights

IMI – The Innovative Medicines Initiative is the world’s biggest public-private partnership in the life sciences sector, and serves as a partner between the EU Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA). The IMI aims to speed up the development of innovative medicines, particularly in areas where there is an unmet medical or social need, by facilitating collaboration between key players involved in health research (such as universities, research centers, pharma, etc.). CTF is participating in two IMI projects:

1. EU PEARL: INNOVATIVE CLINICAL TRIALS

The EU “Patient-centric clinical trial platform” (EU PEARL) study is focused on creating a framework and methodology that will transform clinical trials into a cross-company collaborative, multi-compound platform focused on patients. NF is one of four diseases involved in the study as a prototype for rare diseases, along with tuberculosis, non-alcoholic steatohepatitis (NASH), and Major Depression Disorder.

2. PARADIGM

The PARADIGM (Patients Active in Research and Dialogues for an Improved Generation of Medicines) project aims to provide a framework for structured, effective, meaningful, and ethical patient engagement, and demonstrates a ‘return on engagement’ for all stakeholders.

The long-term action plan is to build an NF funding landscape in Europe that is complementary to the one in the US, by leveraging unique opportunities exclusive to Europe. These European opportunities include:

- the universal health care system, which makes it easier to do natural history studies and population studies,
- unique public-private partnerships, such as the IMI and EFPIA,
- advocating for European funds to be directed towards NF research,
- expanding global data sharing efforts,
- raising new money for NF research, without competing with current European patient associations.

NF knows no boundaries, and neither does our effort to end NF! To learn more about CTF Europe, visit: ctfeurope.org

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 funding and driving innovative research that will result in 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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NF Forum 2020: Three Meetings

In response to requests from the NF community to offer programming targeted to the unique needs of each disease group, CTF will host three NF patient and family Forums, specific to each type of NF.

**NF Forum:
For Patients and Families
Living with NF1**
2020 Virtual Meeting
[check ctf.org/nfforum](http://check.ctf.org/nfforum)
for scheduling

**NF Forum:
The NF2 Gathering**
Oct 16-18, 2020
Columbus, Ohio*

**Third Annual UCLA
NF2 and Schwannomatosis
Symposium**
November 5-6, 2020
Los Angeles, California*

*as of May 5th. Please check ctf.org/nfforum for scheduling updates and registration.

**CHILDREN'S
TUMOR
FOUNDATION**
ENDING NF
THROUGH RESEARCH

370 Lexington Ave., Ste. 2100
New York, NY 10017

**This is our new mailing
address, please update
your records.**

ON THE COVERS

Cover images are from Craig Warga's
Make NF Visible portrait series.
ctf.org/makenfvisible

Front Cover

From left: Jackson Decillis, Jane Constable,
and Alex Owens

Back Cover

Standing, from left: Owen Frenia, Alexandra Mora,
Ken Rudd, Julia Perfetti, Eric Rogers,
Robert Emolo, Aiden Warga
Sitting, from left: Sandy Frenia,
Daniel McAvoy, McKinnon Galloway
Floor, from left: El Evans, Amaya Rottloff



Special thanks to the NF
Heroes who participated
in the Make NF Visible
photo series:

- Laura Barbieri
- Jane Constable
- Jackson Decillis
- Alwyn Dias
- Robert Emolo
- El Evans
- Aidan Fraser
- Owen Frenia
- Sandy Frenia
- McKinnon Galloway
- Yaniry Lora
- Daniel McAvoy
- Alexandra Mora
- Altana Mukabenov
- Alex Owens
- Julia Perfetti
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- Ken Rudd
- Aiden Warga
- Brianna Worden

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