

# NF NEWS

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION  
SPRING 2021

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

## Make NF Visible

Neurofibromatosis, or NF affects more than 2.5 million people around the world. So why don't more people know about it? Because there is no one way to define NF. Just like there is no one way to define a person living with it.

Often patients with visible signs of NF struggle to be seen as more than just their NF, while patients whose NF is invisible struggle to make others understand. Make NF Visible is about seeing NF, and seeing the person living with it.

With your help, 2021 is the year that the Children's Tumor Foundation will Make NF Visible. Please join us. [makenfvisible.org](https://www.makenfvisible.org)

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*Pictured: NF Heroes Jackson DeCillis and Aidan Fraser help to Make NF Visible. Read more about Jackson and his recent surgery on page 9.*

# FROM the President

Annette Bakker, PhD



Just over a year ago, we announced that the Children's Tumor Foundation (CTF) New York office would be closing for two weeks, based on the looming COVID-19 pandemic. I think you will all agree — this has been the longest two weeks ever! Reflecting on the past year, I want to say first and foremost just how thankful I am.

I am incredibly thankful for my friends here on the CTF staff. We have come through this together, and remain a team who loves and cares for each other. From being directly affected by COVID, to adjusting to working from home, juggling lost daycare, home school, and family obligations — it hasn't been easy. I know that is true for each of you as well.

However, I am so pleased to share that CTF was recently included in *The NonProfit Times*' list of "Best Places to

Work." We collectively feel very proud of this distinction, and also know that this honor is in many ways a reflection of our deep commitment to you, our family of neurofibromatosis (NF) patients, families, advocates, clinicians, and researchers.

There is no group of people more ready to adjust and take life as it comes than the NF community. Thank you for joining us in so many virtual events, like our upcoming World NF Awareness Day Live event on May 17.

In this newsletter we celebrate NF Awareness Month through our Make NF Visible campaign, which we will carry throughout the year and beyond. For all of you living with NF every day, we see you, and we are here for you.

We also have important news about an update to the NF diagnostic criteria. This update will be rolled out throughout 2021, and will dramatically improve the accuracy of initial diagnosis and the quality of ongoing and long-term NF care.

Thank you for letting us join you in this fight! We are truly dedicated to you, and believe that together we will succeed in ending NF.

Annette Bakker, PhD  
President

## UPDATE:

### CTF President Annette Bakker Published in the International Business Times

**M**ore visibility for neurofibromatosis, reaching a global audience! In these times of uncertainty due to COVID-19, the voice of the patient has never been more important. In an article in the *International Business Times* by CTF President Annette Bakker, PhD, she outlines how the current environment has accelerated 'patient-directed care', whereby patients take charge of their care and together with doctors make decisions about the best course of action. This advancement has the potential to impact all diseases, including neurofibromatosis. Technology is enabling both diagnosis and care to take place outside of traditional settings, but hospital limitations continue to restrict access. It's imperative that lawmakers, regulators, healthcare professionals, and patients themselves work to ensure that what we've learned in this unique moment can transform health care for the better in the future. To read the full article, go to [ctf.org/businessimes](https://ctf.org/businessimes)

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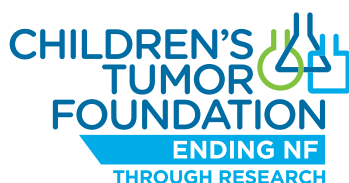
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## CTF Guides Landmark Updates to the NF Diagnostic Criteria

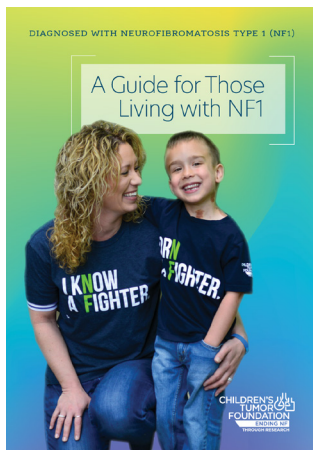
*More Accurate Diagnoses for those living with NF1, NF2, and Schwannomatosis*

The diagnostic criteria for NF1 and NF2 were established at the National Institutes of Health (NIH) consensus meeting in 1987, and the diagnostic criteria for schwannomatosis was established in 2005. Since that time, and thanks to the arduous work of so many CTF-funded researchers, there has been a tremendous increase in knowledge about these genetic disorders. In 2017, a group of NF investigators reached out to CTF to sponsor a review and revision of the NF diagnostic criteria, sparking a multi-year process that has involved more than 90 leading NF experts from around the globe.

The resulting changes in the diagnostic criteria for NF are now complete, and will become official upon release of a series of publications throughout 2021. As this newsletter is being sent to print, we are awaiting the announcement of the

publication of the new NF1 and Legius Syndrome diagnostic criteria in *Genetics in Medicine*, the official journal of the ACMG (American College of Genetics and Genomics).

This publication will be followed shortly thereafter by the new criteria for NF2 and schwannomatosis. These changes will have far-reaching impact, and will greatly improve the accuracy of diagnosis and care for patients living with NF1, Legius Syndrome, NF2, schwannomatosis, and related disorders. The Children's Tumor Foundation is preparing updated patient brochures and other important tools, including the NF Care App (see article to the right) to share this information with patients, caregivers, families, researchers, and clinicians.



CTF's new brochure for NF1 patients reflects these important updates and will be available soon in multiple languages at [ctf.org/education](http://ctf.org/education)

News, links to the publications, and new resources will be posted throughout the year at: [ctf.org/nfcriteria](http://ctf.org/nfcriteria)

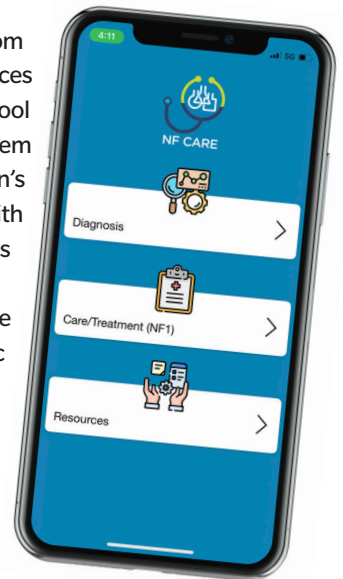
CHILDREN'S TUMOR FOUNDATION  
ENDING NF THROUGH RESEARCH

## NF1 Diagnostic Criteria Update

Learn more at:  
[ctf.org/nfcriteria](http://ctf.org/nfcriteria)

## NF Care App

The Children's Tumor Foundation NF Care App is designed to support pediatricians, family practitioners, medical students, and other healthcare providers who are not NF experts but might see patients in their practice with NF1, NF2, or schwannomatosis. The NF Care App compiles the most relevant, evidence-based clinical guidelines from multiple sources into a single tool and places them at the clinician's fingertips. With a special focus on the 2021 updates to the NF diagnostic criteria, the first rollout of the app will contain a new diagnostic tool for NF1, with updated information on NF2 and schwannomatosis to follow later this year.



The NF Care App is the result of a collaboration with Lauren and Patrick Childers of Zimmdot, LLC, who presented their concept and prototype for the app at last year's virtual Hackathon. Not only do the Childers have experience in creating apps for the medical community, but they have a deeply personal interest in creating such a tool for the NF community as their youngest daughter lives with NF1.

CTF plans to release additional apps later in 2021 that will be specifically geared toward NF patients and families, to empower them with important information and tools to take an active role in managing their care.

For more information, including links to download this free app, go to [ctf.org/nfcareapp](http://ctf.org/nfcareapp)

## CTF Research Investments Show Far Reaching Impact

The Children's Tumor Foundation was founded over forty years ago based upon its mission to fund research into all types of neurofibromatosis. CTF investments new and old continue to tremendously impact the state of NF research and clinical care around the world.

In the past 10 years alone, approximately \$38 million has been committed to CTF's various grant award programs, which investigated the broad range of manifestations present in NF1, NF2, or schwannomatosis, as well as grants that are applicable to all types of NF, such as the NF Data Portal.

Team science initiatives such as Synodos and the NF Preclinical Consortium have been hugely successful in bringing together multidisciplinary investigators from around the world to tackle research questions that cannot be answered by a

traditional single-investigator grant mechanism.

Significant successes from CTF research investments include:

- Early investments in the MEK-inhibitor selumetinib led to the first-ever FDA-approved drug for NF
- The multi-institutional, multi-investigator DHART SPORE award as well as the Department of Defense (DoD) NF clinical trials were significantly enabled by the work of the NF Preclinical Consortium
- The Sage Bionetwork NF Data Portal developed into a tremendous resource for investigators to access original datasets
- The CTF Synodos for NF2 initiative led to the identification and clinical trial launch of brigatinib, an incredibly promising drug for NF2
- The Young Investigator Award program has effectively built an NF

research pipeline over the nearly 40 years of this grant mechanism, and has seeded the NF field with many of its most dedicated researchers

- CTF has established partnerships with biotech and pharmaceutical companies, which has proven to be critical to orphan drug discovery

As we look to the future of NF research, we are informed by the successes of the past. As CTF expands globally we will increase our partnerships with biotech and pharmaceutical companies, and work to further develop orphan drugs. Opportunities for new awards will be guided by the work of our ongoing or recently concluded Synodos projects. None of this growth would be possible without the continued support of CTF's family of donors, volunteers, and fundraisers. This progress was fueled by your investments in the Children's Tumor Foundation, as will the success the future will hold for NF research.

## Optic Pathway Glioma in NF1: When to treat these tumors?

When doctors identify an optic pathway glioma (OPG) tumor in a child with NF1, the ultimate question is whether or not to recommend treatment, which is chemotherapy. Some OPGs will never go on to affect the child's vision, while others may progress and cause permanent vision loss. In the past, there has been a lack of consensus among the clinicians who treat patients with OPG, with some clinicians starting patients on chemotherapy based on MRI findings, while others mostly rely on tests of visual function. These doctors have needed more information in order to understand what factors in each patient make it more likely that the OPG will progress, and whether treatment should be recommended.

To resolve the issue, and prevent chemotherapy that might be unnecessary, the Children's Tumor Foundation together with the

Gilbert Family Foundation funded a long-term study involving 25 institutions from around the world. The study that began in 2014 is observational, meaning that the clinician follows a patient's treatment while continuing to monitor visual outcomes over the years that follow.

Reporting on the current enrollment status at a recent meeting of the NF Clinical Trials Consortium, Michael J. Fisher, MD, Director of the Neurofibromatosis Program at Children's Hospital of Philadelphia and a principal investigator of the study, said that over 160 patients have now been enrolled. Enrollment will continue until the study reaches 250 patients. He noted that the long-term natural histories created for the NF1-OPG study may also support different long-term history studies of NF1 symptoms other than OPG, such as vascular or cognitive natural histories.

# ENDING CHILDHOOD TUMORS: THE BRIDGE INITIATIVE

The BRIDGE Initiative is a collaboration that aims to convince pharmaceutical and biotech companies to release discontinued but valuable medicines. Many promising medicines, despite strong safety data, are deprioritized by pharma for non-technical reasons such as strategy, organization, or financial changes. The BRIDGE Initiative is committed to unlocking these drugs – for intended or new indications – and working to overcome the challenges within those companies.

## Who are we?

The BRIDGE Initiative is driven by three nonprofit organizations:

- Milken Institute's FasterCures, a think tank driven by the singular goal of accelerating medical research
- CureSearch for Children's Cancer, an organization focused on ending childhood cancer
- Children's Tumor Foundation, driving research, expanding knowledge, and advancing care for the NF community

## What are our challenges?

Once a medicine has been discontinued, members of the original teams have moved on to new projects. The data on these medicines may also be difficult to find.

## How will we do it?

Members from the BRIDGE Team have shown that it is possible to revitalize and spin-out a discontinued medicine that has promise for NF. We assembled two world-class advisory boards who have been instrumental in building a list of molecular targets that are relevant for either NF or pediatric cancer or both.

## What do we need?

We need more courageous pharmaceutical and biotech partners that are willing to work with us to develop frameworks that will make medicines available for patients in need. We also need patient-focused investors and donors who are willing to take a risk on these potential treatments. If you or someone you know is interested in investing in The BRIDGE, please reach out to us directly at [info@ctf.org](mailto:info@ctf.org).

## 2020 HACK FOR NF

### The Children's Tumor Foundation Hackathon

The Children's Tumor Foundation hosted its second annual Hack for NF, a six-week virtual hackathon for NF research, in the fall of 2020. This event presents an innovative way for CTF to find solutions using the data analytics and research methodologies being used by researchers every day.

The 2020 virtual event garnered over 400 experts in different disciplines, including healthcare startups, developers, solutions architects, and hackathon enthusiasts, working for six weeks to drive scientific and medical innovation and improve the lives of patients living with neurofibromatosis and other rare diseases. A final group of 150 participants submitted solutions ranging from new ways to analyze data and identify new drug targets, engaging patients via mobile devices, to data visualization apps and analytical tools for the NF Data Portal. Each winning project received a cash prize to continue developing their projects. The three winning projects were:

- **AVI: A Virtual Pet for Children with NF** - a tool that utilizes natural language

processing to help engage children in recording their NF symptoms over time

- **NF Matrix** - a comprehensive platform that integrates the needs of NF patients, providers, and researchers, and is flexible across devices
- **Self-Updating Causal Models to Accelerate Discovery in NF** - a research platform that utilizes text mining and natural language processing to build, update, and test causal models of NF

The first NF Incubator was also launched with additional funding provided by the Children's Tumor Foundation, Neurofibromatosis Therapeutic Acceleration Program, and the Gilbert Family Foundation. The projects qualifying for a total of \$22,500 in incubation funding included:

- **Veometrics**
- **Gene Network-based Drug Discovery in Plexiform Neurofibromas**
- **Neurofibromatosis (NF) Recommendations (NF Care App)**
- **AVI: A Virtual Pet for Children with NF**
- **Cutaneous Neurofibromas Drug Discovery, Copper and Zinc as New Candidates**



The solutions to really try and improve the quality of life in NF2 patients depends on input from a lot of different patients with different symptoms and different presentations of NF2.

—NF2 PATIENT COLE HARRELL, who participated as a Hackathon judge

One key component of the Hackathon this year was the partnership between patients, caregivers, and participants. Eleven patient mentors representing NF1, NF2, and schwannomatosis offered input on the proposed projects by sharing their unique and valuable perspectives as patients to help develop meaningful solutions for those living with NF.

Planning for the 2021 Hackathon has already started and dates will be announced soon.

Read more about the projects that were presented at [ctf.org/2020hackathon](https://ctf.org/2020hackathon)

## Clinical Care Advisory Board Continues Momentum at 2021 Virtual Retreat

The CTF Clinical Care Advisory Board (CCAB) is a dedicated group of 14 NF clinicians, 3 patient representatives, and CTF staff with a goal to standardize and improve NF care.

In 2021, the CCAB has embarked upon a project to increase the delivery of guideline-driven care. This “Guidelines” project completed an initial step of surveying NF clinicians on their awareness of various published guidelines for care delivery, and also ranked their level of agreement with these guidelines. In early May, to coincide with NF Awareness Month, a survey for patients will be available as part of the NF Registry. The survey asks about the care received during the person’s most recent visit to an NF care provider. Ultimately, the CCAB will compare the two surveys to see if patients report receiving the guideline-driven care that clinicians agree upon. Additionally, the CCAB will determine if an intervention is needed to create greater agreement with the published guidelines, and if so, the CCAB will implement this project. Please plan to update your NF Registry data during the first two weeks of May, and look for the patient survey to help with this important initiative to increase the quality and consistency of NF care.

## NF Collective Resource for Young Adults

The Children’s Tumor Foundation is one of seven NF organizations working collaboratively as the NF Collective, with a common goal of improving the lives of individuals with NF and their families. Earlier this year, the collective created a resource called “A Guide for NF Patients and Caregivers: Transitioning to Adult Care.” To complement this resource, the organizations hosted a webinar event on February 24 featuring several young adults with NF. Watch this inspiring group of champions discuss their challenges and successes at: [ctf.org/transitions](https://ctf.org/transitions)

## Children’s Tumor Foundation & NF2 BioSolutions Announce Patient-Focused Research

**T**he Children’s Tumor Foundation and NF2 BioSolutions have joined in an initiative to advance patient-focused research efforts for the NF2 community. The collaboration was announced in recognition of Rare Disease Day, and is focused on recruitment for two key resources, the NF Registry and the NF2 Biobank. The two organizations are working together to raise awareness of NF2 and to encourage robust participation in these two important tools, which will help increase scientific understanding of NF2, accelerate drug development of effective treatments, and lead to improved lives for NF2 patients.

Leading by collaborative example, the Children’s Tumor Foundation and NF2 BioSolutions are providing patients and caregivers safe, effective ways to share critical information about their condition with researchers, empowering them to impact the research focus of experts looking to better understand NF2.

The NF Registry, created and sponsored by the Children’s Tumor Foundation, is a patient-driven resource for accelerating research and finding treatments for all forms of NF. Patients who join the NF Registry increase understanding of NF2 by providing information about their medical condition.

The NF2 Biobank is sponsored and supported by NF2 BioSolutions in collaboration with the Children’s Brain Tumor Network at the Children’s Hospital of Philadelphia; it collects tissue samples and tumors from NF2 patients. The inspiration for this initiative arose after meeting many researchers and lab directors, where it was discovered that access to NF2 tissue is a substantial roadblock to the advancement of research. With the NF Registry and the NF2 Biobank, both patients and researchers can share and access NF2 information in a collaborative environment that increases patient power while at the same time increasing research knowledge of NF2.



Joining the NF Registry gives you access to the latest discoveries about NF1, NF2, or schwannomatosis, helping you and your family find the best possible care. Translations of the NF Registry into Spanish, French, Portuguese, and Italian are underway.

[nregistry.org](https://nregistry.org)

“ Sometimes there are good days and sometimes there are bad days, but it’s a matter of taking it one step at a time. Take the NF Registry on your journey with you. ”

— SEQUOYAH DANIEL-ROBINSON WHO LIVES WITH NF2

# Synodos for Schwannomatosis Data Release

“I've dedicated myself to doing anything I can to cure or treat these disorders, for my family, for my friends, for people I don't even know. This I view as my life mission, as long as it takes, whatever it takes. I'm in it until we end the scourge of NF.”

—RICHARD A. HORVITZ,  
Synodos for Schwannomatosis  
benefactor

A multi-year effort to better understand the landscape of schwannomatosis with the end goal of developing effective treatments, funded by the Children's Tumor Foundation Synodos initiative and led by Gelareh Zadeh, MD, PhD, and Laura Papi, MD, PhD, was recently published in *Acta Neuropathologica*. Experts from institutions spread across four different countries worked together to develop a clinically annotated schwannomatosis biobank, establish the genomic and epigenomic landscape of schwannomatosis to identify disease-driving alterations, and correlate the molecular findings with key clinical parameters.

Along with the publication, a comprehensive data resource including whole genome, whole exome, RNA sequencing, and methylation data have been made available to the research community. Visit the NF Data Portal at [nfdataportal.org](http://nfdataportal.org) to learn more about this study, and to request permission to access the largest data resource to date on schwannomatosis.

Conceived and funded by the Children's Tumor Foundation, Synodos for Schwannomatosis is a \$1 million, two-year collaborative effort of basic, translational, and clinical researchers to find solutions to the unique problems that affect schwannomatosis patients in the fastest, most efficient manner by sharing their real-time data and results.

Synodos for Schwannomatosis was funded by a generous gift from Richard A. Horvitz and Erica Hartman-Horvitz. Mr. Horvitz's long-standing involvement with the Children's Tumor Foundation demonstrates his passion and unwavering commitment to finding treatments and cures for all forms of neurofibromatosis.

## 2021 Virtual NF Forum June 25-26

We're proud to announce that our 2021 NF Patient and Family Forum will be hosted virtually on June 25 and 26, providing people all over the world living with NF the opportunity to connect and learn from NF experts. This event is for everyone living with or affected by all types of NF, with content relevant to NF1, NF2, and schwannomatosis. Learn more or register at: [nfforum.org](http://nfforum.org)



## NF CONFERENCE:



## 2021 Virtual NF Conference June 14-16

Because of the ongoing constraints of the COVID-19 pandemic, the 2021 NF Conference will be held virtually for the second consecutive year. This annual global event, spanning two-and-a-half days, will feature an international array of NF experts and others, presenting the latest in research and clinical care for NF1, NF2, and schwannomatosis. The annual NF Conference is considered to be the most important scholarly event on the NF research and clinical calendar, attracting more than 600 individuals dedicated to improving the lives of NF patients worldwide. For more information, go to: [ctf.org/nfconference](http://ctf.org/nfconference)

# MAY is NF Awareness Month!

Visit [makenfvisible.org](http://makenfvisible.org) 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



## PROCLAIM

NF Awareness Month by securing a proclamation in your city or state



## LIKE

Children's Tumor Foundation on social media, and tag your posts with #EndNF



## SHARE

our exclusive photo series, Make NF Visible



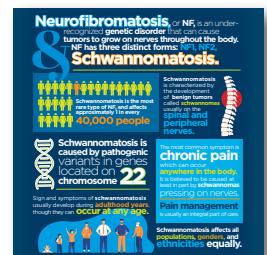
## PARTICIPATE

in our webinars and our World NF Day Live Event on May 17



## WATCH

our NF Awareness Month videos on our YouTube channel



## EDUCATE

using informative fact sheets and brochures

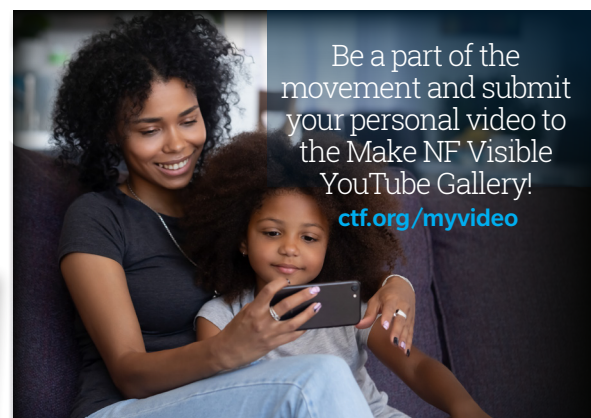


## SHINE A LIGHT

We're back, and so is Niagara Falls! Businesses around the world are slowly reopening, and many will be lighting up in blue and green to spread NF Awareness around the world. At home, you can light up your home with blue and green lights, leave awareness messages in chalk on your sidewalk, or change your porch lights to blue and green to spread awareness of NF.

Visit [ctf.org/shinealight](http://ctf.org/shinealight) for the list of participating locations.

Download your NF Awareness Month resources at: [makenfvisible.org](http://makenfvisible.org)



Be a part of the movement and submit your personal video to the Make NF Visible YouTube Gallery!

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

Simply use your smartphone, computer, or camera to record a video of yourself, then upload it on our easy form.

**In your video answer these five questions:**

1. Begin with, "My name is <name> and I have <NF type>"
2. What is something about YOUR NF people can't see?
3. What is something ABOUT YOU that NF keeps people from seeing?
4. Why is it important to Make NF Visible?
5. End your video with, "I want you to see me, and see NF."



This year the Children's Tumor Foundation launched **Make NF Visible**, a year-long campaign about how we see NF, and how we see the person living with it. **Please join this important movement by donating today at [ctf.org/NF](https://ctf.org/NF).** With your help, we can make NF known around the world, leading to improved treatments, improved care, and improved lives for people like nine-year-old Jackson (pictured here) who live with NF.

In December of 2020, Jackson underwent a harrowing surgery due to NF-related scoliosis. Jackson's yearly MRIs tracked the plexiform neurofibroma tumor in his back, and the resulting curvature of his spine. With the scans showing that his spine was already at an 85 degree curve, surgery was the only option. Jackson underwent a partial fusion of his back and his surgeons put in two growing rods.

Thankfully, Jackson's surgery was a success. His doctor now wants him to start taking Koselugo (selumetinib) because his plexiform neurofibroma is growing toward his liver. Just one year ago, the United States Food and Drug Administration (FDA) announced the approval of the MEK-inhibitor drug Koselugo (selumetinib) for inoperable plexiform neurofibromas. **This historical moment marked the first ever FDA-approved drug treatment for people living with NF.**



This treatment is a direct result of CTF-funded research that discovered MEK-inhibitor drugs have the potential to affect tumor size. Now more than 70% of NF patients taking Koselugo (selumetinib) have had shrinkage of 20 to 60% in the size of their tumors. **That pioneering research was funded by donors like YOU!**

But — Koselugo (selumetinib) is approved **only** for NF1 patients with inoperable plexiform neurofibroma tumors. It is an incredible first step. **We cannot stop until there are treatments for all forms of neurofibromatosis – NF1, NF2, and schwannomatosis.**

We want to see an approved treatment for **patients with NF2, like Sequoyah**, (pictured on pg. 6), who recently lost her father due to complications from NF2. For patients like Sequoyah, the CTF-spearheaded NF2 Accelerator Initiative is speeding research toward treatments for NF2. One of the many promising projects of this initiative is an FDA-approved clinical trial for a drug called Brigatinib for patients with NF2 — and a direct result of CTF's Synodos for NF2 research.

We need even more breakthroughs for people like **Eric Rogers who live with schwannomatosis, the most rare form of NF.** Eric has become a CTF advocate, running with the NF Endurance team, and making a difference for people living with all types of NF. Please join Eric, Sequoyah, and Jackson and donate today by returning the attached envelope, or going to [ctf.org/NF](https://ctf.org/NF).

**Your gift will help Make NF Visible.**

# SPECIAL EVENTS

A World NF Day **LIVE** Event  
to benefit the Children's Tumor Foundation

MAY 17  
8:00 PM ET

## Make **NF** Visible

HOSTED BY:

Jonathan Sadowski

James Snyder



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

### COCKTAILS FOR A CURE LONG ISLAND



Due to COVID-19, Cocktails for a Cure Long Island shifted to an "Un-event" with a Valentine-themed card that invited recipients to donate to the Foundation in lieu of an in-person event. More than \$25,000 was raised as a result of this Valentine's Day-themed mailing. Our thanks to the host committee: Meg Blank, Pam Blank, Tammy and Yaakov Cohen, Stacey Decillis, Brian Ferruggiari, Angela Fox, Anita Gribben, Kristin Kalendarian, Doreen Marangoni, Jodi Markowitz, Erika Millet, Laura and Anthony Perfetti, Marietta Perfetti, Kim Riso, Victoria Romano, Danielle Schmidt, and Cristina Spoto.

## National Virtual Poker Tournament

The first ever National Virtual Poker tournament was held in February as a coast-to-coast event which allowed people from all over the country to attend. The star-studded evening included 14 celebrities who participated and lent their names to CTF's fight to end NF. Held on the Poker4Life platform, the event used Zoom in a way that allowed the attendees to start the evening together virtually in a Zoom Toast. The players were then greeted by the evening's emcee Phil Gordon, World Poker Tour Champion and host of *Celebrity Poker Showdown*, and then CTF National Ambassador Lilly Ann Brooks delivered a meaningful message about what it is like to live with NF.

Co-Chairs Dan Altman and Michael B. Silver shared their reasons for being there; Dan's daughter Jesse is affected by NF, and Michael's nephew, Joe Jaffa, also lives with NF. Rick and Amanda Jaffa, Joe's parents, are longtime supporters and donors of CTF, and it was Amanda who got her brother Michael involved with CTF years ago through the LA Poker Tournament. Dan Altman has hosted a poker tournament in New York City for 14 years and raised over \$2.1 million for the Foundation's research initiatives on behalf of his daughter.

After the Zoom Toast, the cards flew! While over 190 players signed in to the poker platform and got ready to play at their tables online, they chatted with those they were playing against in breakout rooms via Zoom. This fun and interactive format allowed everyone to interact with each other and made the evening especially memorable.

The final table had over 40 people that stayed logged in to Zoom to watch and see who the winner would finally be. It came down to two players, actor David Costabile, most known from Showtime's *Billions*,

and Dan Wilpon, CTF Poker Committee and longtime donor. The competition was fierce, but in the end the winner overall was Dan Wilpon. What a wonderful evening for our NF community to come together across the nation in the fight to end NF!



# Connect2Fight Celebrates Rare Disease Month

Connect2Fight is CTF's new livestream and gaming platform, and is making new connections with broadcasters and content creators for charity livestreams. To celebrate Rare Disease Month in February, Connect2Fight hosted a series of *CTF Plays Among Us* charity livestream events that brought the NF community together with celebrity champions, content creators, NF Heroes, and even CTF President Annette Bakker. The seven separate February events collectively raised over \$12,000 for NF research, and spread awareness for neurofibromatosis and rare diseases as a result of more than 1,500 views between YouTube and our newly growing

Twitch channel: [twitch.tv/childrenstumorfoundation](https://www.twitch.tv/childrenstumorfoundation)

Each of these games ended differently, but one thing that was consistent was the success we had in making connections!

Through CTF's Connect2Fight program we want to end NF as fast as we can by connecting the unconnected.

If you'd like to join a future CTF-hosted event, or host your own charity livestream whenever it's convenient for you, contact the Connect2Fight team at [livestream@ctf.org](mailto:livestream@ctf.org) or visit our website at: [ctf.org/connect2fight](https://ctf.org/connect2fight)

**CONNECT 2 FIGHT**  
ctf.org

**CTF PLAYS AMONG US**  
with special guests

Nick Folk   Raina Seitel   Loony2unes

James Synder   Kevin Martin

## Download CTF's Spare Change App

One of the easiest ways to help CTF fund our mission to end NF is to give a little bit each day. Just link your bank account or credit card to the Spare Change to End NF mobile phone app and every purchase you make will be automatically rounded up to the nearest dollar and donated to the Children's Tumor Foundation. Users can set a monthly limit, a recurring giving amount, or pause your gifts at any time. To get started, go to [ctf.org/sparechange](https://ctf.org/sparechange) for more details and links to download the app via the App Store or Google Play.



SPARE  
CHANGE  
TO END NF

# stories

OF NF

## Levi Spano NF1

Levi is our fourth child, and just before he turned four months old, I noticed a large brown mark covering his left shoulder and part of his back. His left arm also looked fatter than his right arm. I brought it to the attention of Levi's pediatrician who then sent us to a dermatologist. The dermatologist sent us for genetic testing and the results came back that he had NF1. Levi was seven months old at the time of his diagnosis and I had never heard of NF before.

As soon as I received Levi's diagnosis, I brought him to the wonderful neurologist at the NYU NF Clinic and he ordered an MRI of Levi's brain, spine, and left shoulder. It was discovered that Levi has plexiform tumors on both sides of his cervical spine, actually pressing into the spinal cord, offsetting it slightly. He also has a plexiform in his left brachial plexus. We were devastated, but also relieved we caught it so early.



Levi is now 13 months old and still unable to roll over, crawl, pull himself up, or stand. He can sit but can't get in or out of the sitting position. He gets occupational and physical therapy four mornings a week, plus feeding therapy once a week. He has a lot of weakness in both arms but every day he gets a

little stronger. I have a part-time job just getting him to all these appointments.

Our family is Levi's biggest support system! I told my other kids about his condition and that we're going to get through this as a family. Levi goes into every appointment and test with a smile on his face. He wakes up from his anesthesia smiling and cooing. I'm constantly in awe of what's been thrown at him yet he gets through it with his happy demeanor. He's so tough and I'm just following his lead. People ask me how I'm not falling apart and I tell them that there's no reason to fall apart. Levi's tough and we're going to get through this. As his mother I'm going to do absolutely everything in my power to advocate for him and get him the best care possible.

– Submitted by Leah Spano, Levi's mom

## Amanda Rose NF2

After a misdiagnosis in January 2020 due to double and blurred vision, I was officially diagnosed with NF2 after a brain surgery on February 28, 2020.

Like anyone who receives a life-changing diagnosis, I went through a period of grief for several months. It's crazy how your life can seemingly change in one instant. However, after pulling myself up with tremendous help from my husband, family, and friends, I came to the realization that this diagnosis does not have to affect my daily routine.

I struggle with double vision, a symptom I was dealing with long before my diagnosis. I also have occasional hearing loss in my right ear, which comes and goes, and sounds like someone is talking to me underwater. It's still manageable, which is a true blessing. But I can still do the things I love. Sure, I have to attend more doctor's appointments than the average person, but I'm learning to cope with that, and my husband and family are so good about making them fun — going out to dinner or somewhere fun after each appointment.

After my husband and I had the time to process my NF2 diagnosis last year, we made a goal of spreading awareness about NF as much as we possibly can. In addition, we are doing our best to share the idea that a life-changing diagnosis is not necessarily a setback, but can be used as a tool to help others. My hope for my diagnosis is that if I can help even one person see their value, regardless of their diagnosis, I've succeeded.

I have learned to control the things I CAN control, because there will be a lot of things in my future related to NF2 that will be completely out of my control.

I don't plan to make any changes to my future goals. If an issue arises due to NF2, I will deal with it head on. Just five days before I was diagnosed with my brain tumors, I opened a boutique floral and gift shop. I've owned a small business for over 10 years designing and planning weddings, wedding flowers, and wedding stationery. It's truly been a dream.



# SHINE A LIGHT NF WALK

Shine a Light NF Walk has officially kicked off the 2021 season! We are planning for as many in-person walks as possible in accordance with CDC and state guidelines, with an opportunity to participate virtually as well. New incentives, new T-shirts, and renewed energy will help us reach our goal of ending NF! Go to [shinealightwalk.org](http://shinealightwalk.org) to learn more or register today!

## MYA'S NF WARRIORS, LOS ANGELES

“The walk creates such a bond that is unique because we all have something in common that is so important to us.”

## TEAM MIA, HOUSTON



“Team Mia is excited to meet other families, celebrate together and hopefully all be in the same place this year!”

## TEAM AVENJOES ASSEMBLE, CINCINNATI

“The walk celebrates the NF Heroes and brings us together to let us know we are not in this alone.”



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# NF ENDURANCE

At the Children's Tumor Foundation, we're dedicated to bettering the lives of over 2.5 million people living with NF. The CTF NF Endurance Team is a global community of individuals pushing themselves to go the extra mile to end NF. After all of the challenges that 2020 brought, the NF Endurance season presents many opportunities to unite in the fight to end NF.

**Choose Your Own Challenge!** Climb a mountain, tackle an obstacle course, take an epic hike, or run a race in your local community — the challenge is up to you.

Is premier racing more your style? Get a coveted entry into the world's most exclusive races — **Chicago, Berlin, New York City, Rock 'n' Roll Series** — as a part of the NF Endurance Team. Spots are limited this year and going fast.

Visit us at [nfendurance.org](http://nfendurance.org) and discover what your NF Endurance journey will look like this year!





## WuXi AppTec Hosts Rare Disease Day

On February 28, CTF partner WuXi AppTec, a leading global provider of research and development and manufacturing services headquartered in China, highlighted the voices and stories of brave and determined individuals in the WuXi Rare Disease Awareness Concert. Through this concert, WuXi extended support to the international rare disease community with featured musical performances by rare disease patients and volunteers, including CTF NF Heroes Brianna Worden, who lives with NF1, and the talented Lindebeck family, which includes NF2 Hero Nicholas, sister Chloe, and dad Peter. Leaders representing rare disease associations, including a special greeting from CTF President Annette Bakker, and patient advocacy groups also participated from around the world. Watch the concert at: [ctf.org/rareconcert](http://ctf.org/rareconcert)



## CTF GUEST BLOG WITH EFPIA

In a guest blog for EFPIA (European Federation of Pharmaceutical Industries and Associations), CTF President Annette Bakker writes that a key lesson from the all-out effort to develop COVID-19 vaccines has been the effectiveness of platform trials, whereby multiple drugs are tested simultaneously in order to quickly learn which work best. In Europe, CTF is part of a large public-private partnership grant called EU-PEARL that is aimed at developing platform trials for all NF manifestations. Read more about this promising innovation, including the INTUITT-NF2 multi-site platform trial (co-funded by CTF and Takeda) which is evaluating treatments for multiple tumor manifestations in NF2, at: [ctf.org/efpia](http://ctf.org/efpia)



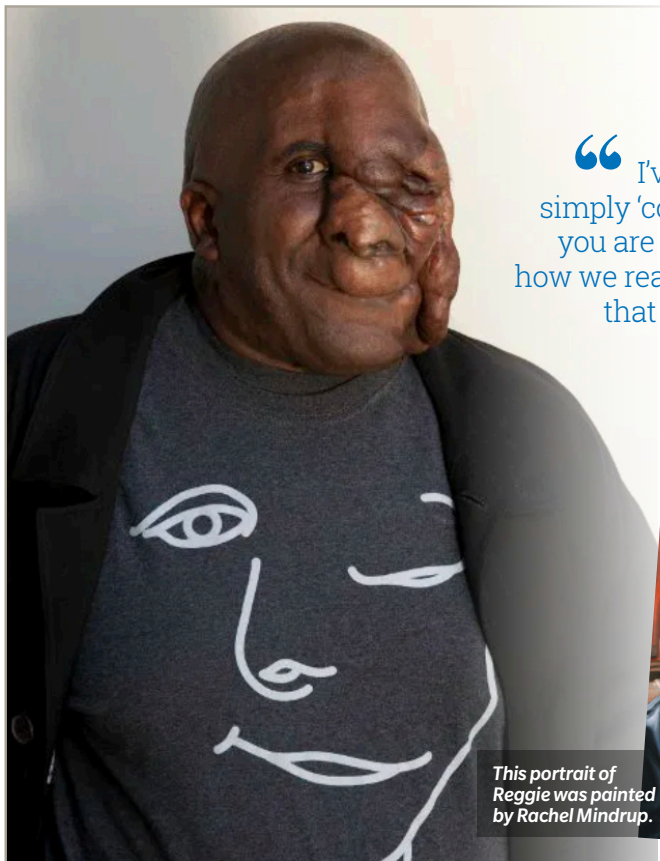
European Federation of Pharmaceutical Industries and Associations

## Broadening Our Global Reach

On Saturday, February 27, the Children's Tumor Foundation in association with the GENES Foundation hosted a day-long educational symposium for clinicians and other healthcare providers throughout Latin America, from Mexico to Peru to Brazil. The symposium featured some of the most well-known experts in the NF field, and was conducted bi-lingually, with both native English and Spanish-language speakers, with the use of simultaneous translators to ensure that the Spanish-language audience were able to capture every word. Over 500 people registered for this landmark event, which was warmly received and appreciated for the depth of information on NF care and research that was shared by high caliber speakers.

**¡BIENVENIDOS!**  
**PRIMER SEMINARIO VIRTUAL LATINOAMERICANO**  
**SÁBADO 27 FEBRERO 2021**  
**SOBRE NEUROFIBROMATOSIS**  
 En un esfuerzo conjunto entre CTF (Children's Tumor Foundation USA) y Fundación GENES Internacional, se ha logrado reunir a los mayores expertos con reconocimiento mundial en el tema.  
 PRESENTACIÓN DIRIGIDA A PROFESIONALES DE LA SALUD

We are hopeful this event will lead to more involvement with the entire Latin American NF care community.



“ I’ve always felt that life simply ‘comes at you’ whether you are ready or not... and it’s how we react to life’s challenges that I believe is a person’s measure. ”

**REGGIE BIBBS,**  
who lives with NF1



*This portrait of Reggie was painted by Rachel Mindrup.*

## Extraordinary Spirit / **REGGIE BIBBS**

**T**he Just Ask Foundation started as a simple concept. Reggie Bibbs, the founder of Just Ask, spent the first 40 years of his life in hiding because of having disfiguring tumors caused by severe neurofibromatosis. He was concerned about how his disfigurement affected people that didn’t know him. He was less concerned about how they made him feel as he was concerned about how he made them feel. He struggled to find a way to spread awareness and let people know that he, at heart, was no different than anyone else.

That’s when Reggie teamed up with Lou Congelio, founder and Chief Creative Officer of ACME Fish Advertising in Houston, Texas. Reggie approached Lou with a simple, yet ingenious idea. To design a T-shirt and business card campaign featuring the slogan “Just Ask.” The shirts and business cards were designed to make others feel comfortable approaching Reggie, giving him the opportunity and confidence to not only interact with total strangers, but to tell them about NF.

He wanted people to “Just Ask” about his

condition – and ask they did! The more Reggie put himself out there, the more positive responses he received from others. Now, rather than sitting in his house wondering what life was like, he started living it.

Reggie started attending major events all over his hometown of Houston, Texas. He attended events such as the International Festival, the Art Car Parade, and the Houston Roller Derby. And everywhere he went, he made new friends and spread the word about NF.

With the success of his “Just Ask” movement, word spread. Others with NF wanted to follow Reggie’s example. So, with help from a handful of friends, Reggie has turned his simple idea and grassroots movement into the Just Ask Foundation – an organization dedicated to spreading awareness about neurofibromatosis through the people most affected by it.

It is truly amazing what a simple T-shirt and a handful of business cards can do.

To learn more about Reggie and his amazing story, and support the work he is doing, go to [justaskfoundation.org](http://justaskfoundation.org).

NF News is the official publication of the Children’s Tumor Foundation. All issues are available on our website at [www.ctf.org](http://www.ctf.org). Please direct any questions or feedback to [info@ctf.org](mailto:info@ctf.org).

The Children’s Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to 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](http://www.ctf.org).

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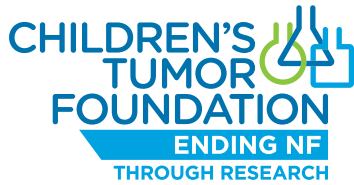
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# Best Place to Give, Best Place to Work

## Children's Tumor Foundation Receives High Recognition



Charity Navigator gives the Children's Tumor Foundation its highest rating, 4 stars, placing CTF in the **top of charities in America** for best practices and performance efficiency.



*The Nonprofit Times* designates the Children's Tumor Foundation as a 2021 Best Place to Work in its annual ranking of the **top 50 charities to work for in America**.

These achievements reflect the Foundation's commitment to being among the best investments in the nonprofit sector, both in terms of its mission and its people.

To learn more about these honors, please visit [ctf.org/news](https://ctf.org/news).