

# NF NEWS

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION  
WINTER 2020

## INSIDE:

- 1 DDI-RR Awardee Announcement
- 4 Virtual Celebrations to End NF
- 6 Year End Giving
- 12 Extraordinary Spirit

## Virtual Celebrations, Benefits, Ballrooms, and Bashes to End NF

On Monday, November 16, 2020, the neurofibromatosis patient community, joined by leading philanthropists, medical professionals, civic leaders, and businesses, gathered virtually for the first-ever "National Celebration Concert to End NF," featuring performances by award-winning singer-songwriter Emmylou Harris and multi-platinum musician Gavin DeGraw. This livestreamed event united participants in a celebration of NF research advancements, sharing inspirational patient stories of courage, and honoring those who have stood out in support of the Foundation's longstanding commitment to driving and funding the best and most promising NF research. Serving as masters of ceremonies were actor and producer Jonathan Sadowski, NBC Host and Correspondent Raina Seitel, and football legend Darrell Green.

*Emmylou Harris, 14-time Grammy Award winner and Billboard Century Award recipient starred in CTF's National Celebration Concert to End NF, which featured exclusive performances by Harris and well-known musician Gavin DeGraw.*

PHOTO BY KAT VILLACORTA

# FROM the President

Annette Bakker, PhD



As we approach the end of the year 2020, the global pandemic continues to keep us isolated at home, but it has also fueled togetherness within the neurofibromatosis (NF) community. I want you to know that I understand the incredible highs and difficult lows that we have been through this year. On behalf of myself, the CTF staff, and our Board of Directors, thank you for your dedication to CTF and our vision: ending NF.

While we were unable to hold our annual Gala in New York City, our Virtual National Celebration Concert made it possible for families around the world to join us for our biggest fundraising event of the year. It brought me so much joy to honor young Jack Burke with the Humanitarian Award. Jack and his family are behind CureNFwithJack, a partner organization helping us fund research

for treatments that Jack and so many others still need. We awarded AstraZeneca with a Scientific Innovation Award, named Jonathan Sadowski as the 2020 CTF Champion, and presented Lilly Ann Brooks as our 2021 National Ambassador.

I continue to be profoundly grateful to our many volunteers and donors who have hosted so many wonderful and varied virtual events, including our partners Dan and Jennifer Gilbert, who also pivoted the NF Forward's annual beNeFit to a virtual experience.

I am especially grateful for the generosity of two parents and grandparents of NF patients, Frank and Shelley Haughton, who have offered to match all donations through December 31 up to an astounding \$1 million. This is more than a magnanimous gesture - it is a call to action.

Lastly - thank you for uniting in support of NF patients in so many ways—through virtual fundraising, online volunteering, Zoom planning, and remote donating—together but apart, we are changing the future of NF for patients, and I thank you.

Annette Bakker, PhD  
President

## MESSAGE FROM THE PRESIDENT

### CTF and COVID-19

The COVID crisis around the world remains serious, but glimmers of hope are appearing. Please continue to follow CDC guidelines regarding self-care and prevention, and abide by guidelines established in your area.

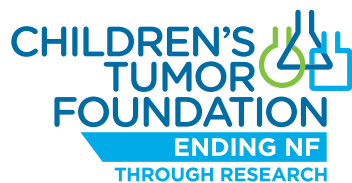
The CTF headquarters in New York remains closed, but small numbers of staff are periodically visiting the office to take care of essential business. We remain vigilant and are taking all precautions and socially distancing ourselves.

Financially, this pandemic has created hardships for businesses, families, and individuals, and nonprofit organizations like ours are no exception. We know that NF patients and families have been especially burdened by this difficult time, and we are doing everything we can to help.

Thanks to our dedicated family of donors, CTF's financial commitments to NF research are secure and unwavering. To ensure that your donations are received and processed efficiently, we have engaged a secure location, to which all donations will be received for many years to come.

**Send Donations To:**  
**Children's Tumor Foundation**  
**Mail Code: 6895**  
**P.O. Box 7247**  
**Philadelphia, PA 19170 - 0001**

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## 2020 DRUG DISCOVERY INITIATIVE REGISTERED REPORTS (DDI-RR) AWARDEES

Through a collaboration with top scientific journal *PLOS ONE*, in a process known as “Registered Reports,” awardees are offered financial support from CTF and in-principle acceptance for publication by the journal. This model allows for more rigorous, reproducible, and transparent science, guaranteeing its awardees publication, regardless of study outcome.

### ANDREA RASOLA, PHD

University of Padua



#### ***TRAPping Neurofibromas: Inhibition of the Mitochondrial Chaperone TRAP1 as an Anti-neoplastic Strategy for NF1-associated Tumors***

The aim of this project is to investigate whether TRAP1 inhibitors can inhibit the growth of neurofibroma cells, both benign and malignant, in animal models. Moreover, they will be tested on a mouse model that is genetically prone to the formation of malignant NF1-related tumors, in order to study whether TRAP1-targeting molecules can cause the regression of these malignancies.

### LEI XU, MD, PHD

Massachusetts General Hospital



#### ***Targeting the NRG-1/ErbB Signaling Axes for the Treatment of Schwannomatosis and Associated Pain***

The project proposes to determine if schwannomatosis tumor cells, by expressing elevated levels of NRG-1, activate tumor-associated macrophages to produce inflammatory cytokines and induce pain response. The successful completion of this study will shed light on the mechanisms of schwannomatosis-induced pain and provide valuable information for the development of novel, efficacious therapies to treat this debilitating pain.

### D. WADE CLAPP, MD

Indiana University



#### ***Experimental Therapeutic Evaluation of PSC5-6 using a Pre-clinical Mouse Model of Neurofibromatosis Type 1***

In this study, the researchers will test whether the RAS inhibitor PSC5-6 (a drug candidate) can halt and/or prevent the progression of plexiform neurofibromas in a genetically engineered mouse model of NF1. The proposed experiments will generate preclinical data needed to advance PSC5-6 toward a clinical trial in human NF1 patients with plexiform neurofibroma who do not respond to currently available drug therapies.

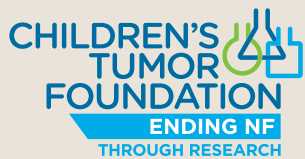
### JEREMIE VITTE, PHD

University of California, Los Angeles



#### ***Exploiting Macropinocytosis for Therapeutic Delivery to NF2-Deficient Schwannoma Cells***

The goal of this proposal is to demonstrate that macropinocytosis, a mechanism by which cells access nutrients and other survival factors from external sources, is a specific mechanism in NF2-deficient tumors. The project will validate results obtained on cells in an NF2 mouse model.



## CTF and PLOS ONE Release First Publication from this Funder-Publisher Partnership

The Children's Tumor Foundation and *PLOS ONE*, a leading peer-reviewed scientific journal, released the first output of the Drug Discovery Initiative Registered Reports (DDI-RR) Award, which was launched in 2017. The Registered Reports model, first piloted by CTF and *PLOS ONE*, ensures that all valid research – both successes and failures in the lab and clinics – are made public.

The publication, "Evaluating modified diets and dietary supplement therapies for reducing muscle lipid accumulation and improving muscle function in neurofibromatosis type 1 (NF1)," by Dr. Aaron Schindeler, PhD, associate professor at the University of Sydney, reports findings on L-Carnitine as an effective dietary supplement for reducing muscle lipid accumulation and potentially addresses muscle weakness and fatigue often observed in NF1 patients. The results of the study led to the opening of an NF1 clinical trial.

The funder-publisher partnership around the DDI-RR program allows researchers to preregister their study, obtain an in-principle acceptance (IPA) to publication in the journal *PLOS ONE*, and obtain funding from the Children's Tumor Foundation to conduct their proposed experiments. Both CTF and *PLOS ONE* maintain a separate and independent review process to align proposed research with both the funder mission as well as to safeguard soundness, accuracy, and scientific rigor. Through this model, before any experiments start, researchers have the opportunity to address reviewer remarks and submit revisions of their protocol until it is ready for publication.

The innovation of this funding model creates multiple benefits for all participants. Researchers are able to make adjustments to their protocols before they start any lab experiment, funders are ensured that the proposed research is high quality, and the publisher secures a manuscript that has robust reproducibility in line with the mission and ethos of the journal. In addition, the published manuscript links to the original registered protocol deposited on the Open Science Framework portal for full transparency and traceability.

"We are very proud to see the first manuscript of this award program out. The transparency and the quality of the protocol adds to the soundness of the research, independent from the nature of the outcome," said Salvatore La Rosa, PhD, CTF Chief Scientific Officer. "Positive or negative results are equally valuable when a robust protocol is applied, and this model allows for either to emerge."

To read more, and find a link to this publication, go to: [ctf.org/plosonepub](https://ctf.org/plosonepub)

## Thanks to the CTF Clinical Care Advisory Board

The Children's Tumor Foundation would like to thank the previous and current members of our Clinical Care Advisory Board (CCAB). The CCAB was established by CTF to improve the clinical care of patients with all forms of NF. In 2007, the CCAB recommended that CTF establish an NF Clinic Network (NFCN) to improve access to specialized care. Since that time, over 60 clinics across the U.S. have been certified by the CCAB.

In 2020, the CCAB launched a study of physician adherence to NF clinical care guidelines and published a research article for physicians on prescribing MEK inhibitors and managing their toxicities, and also created a patient information sheet, both of which can be found at [ctf.org/mek](https://ctf.org/mek). Looking toward 2021, the CCAB will focus on transition to adult care and explore the use of online case conferencing for physician education and discussions about complex cases. Ongoing CCAB projects include reviewing NF Clinic Network membership, organizing a Clinical Care Symposium, reviewing applications for CTF Clinical research Awards, and developing and reviewing patient educational resources.

CTF appreciates the time and commitment of our CCAB members and their ongoing dedication.

### CURRENT CCAB MEMBERS

#### Clinicians

- Scott Plotkin, MD, PhD (Chair)
- Oliver Adunka, MD
- Jaishri Blakeley, MD
- Gary Brenner, MD, PhD
- Jan Friedman, MD, PhD
- Bonnie Klein-Tasman, PhD
- Laura Klesse, MD, PhD
- Jennifer Janusz, PsyD, ABPP-Cn
- Justin Jordan, MD, MPH
- Tena Rosser, MD
- Elizabeth Schorry, MD (Emeritus)
- Pamela Trapane, MD
- Nicole Ulrich, MD, PhD
- David Viskochil, MD, PhD (Chair, Emeritus)
- Kaleb Yohay, MD

#### Patient Representatives

- Alwyn Dias (NF1 patient representative)
- Reema Bogin (NF2 patient representative)
- Michele Holbrook (SWN patient representative)

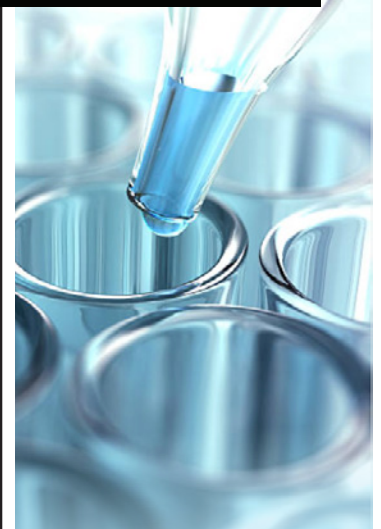
## CTF Co-Sponsors a Virtual European NF Meeting

The Children's Tumor Foundation is pleased to be a co-sponsor at the Virtual European NF Meeting which will be hosted from Rotterdam, the Netherlands, December 10-12, 2020.

Bringing together the many varied disciplines involved in NF research and care, the European NF meeting offers a forum for advancing basic, translational, and clinical research in NF and related fields, with one purpose: to improve the quality of life of NF patients. The meeting will be organized by the Erasmus MC National NF1 Expertise (ENCORE) and the patient organization for neurofibromatosis in the Netherlands (NFVN).



## NF CONFERENCE:



## Save the Dates

2021 NF Conference:  
**June 12-15**  
2022 NF Conference:  
**June 18-21**

*Dates may change pending COVID guidelines.*

The 2020 Virtual NF Conference presented the best and latest NF research and clinical care practices within a compressed two-day format. The 30th anniversary of the discovery of the NF1 gene was celebrated, as well as the first-ever FDA approval of a treatment for NF1, Koselugo (selumetinib). Additionally, D. Wade Clapp, MD, of the Indiana University School of Medicine was presented with the 2020 Friedrich von Recklinghausen Award for his commitment to NF research.

To learn more about the NF Conference, or to watch the 2020 keynote address from Francis S. Collins, MD, PhD, Director of the National Institutes of Health, go to:  
**[ctf.org/nfconference](http://ctf.org/nfconference)**

## Watch the NF Forum Sessions Online

The 2020 Virtual NF Forum meetings were designed to be relevant, provide important NF research updates, answer questions, and offer support to NF patients, families, and caregivers. The 2020 sessions from the NF Forum are now available to view at: **[ctf.org/forum](http://ctf.org/forum)**

**SAVE THE DATE**  
**2021 NF Forum**  
**June 11-12, 2021**  
*pending COVID guidelines*



### NF2 Education and Research Updates

*Co-hosted by CTF and The Ohio State University, this discussion covers NF2 clinical trials, gene therapy, and the NF2 Accelerator.*



### Poster Session

*An interactive Q&A with the creators of some of the most exciting posters from this year's virtual NF Conference.*



### Case Conference

*A panel of expert clinicians discuss two unique medical cases that address various medical complications seen in NF1.*



### Clinical Research

*Hear about where we have been and where we are going in NF1 research; will also discuss results of recent trials.*



### The Impact of NF on Relationships, Learning, and School

*Discussion of how NF1 impacts school (IEPs, learning disabilities, social-emotional issues).*

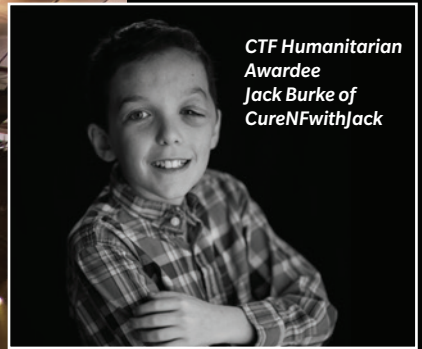
# Going Virtual

## TO END NF

Emmylou Harris, 14-time Grammy Award winner and Billboard Century Award recipient starred in CTF's National Celebration Concert to End NF, which featured exclusive performances by Harris and popular musician Gavin DeGraw.



PHOTO BY KAT VILLACORTA



CTF Humanitarian Awardee  
Jack Burke of  
CureNFwithJack



CTF 2021  
National  
Ambassador  
Lilly Ann  
Brooks

### THE NATIONAL CELEBRATION CONCERT TO END NF

The star-studded National Celebration Concert to End NF was the culmination of a “Year of Firsts” for the Foundation. An evening of inspiration and celebration, the Foundation presented this year’s National Humanitarian Award to **Jack Burke**. Jack and his family have raised millions of dollars to support the mission of CTF through their foundation, CureNFwithJack, and through their participation in the annual Cupid’s Undie Run. While still a teenager, Jack is also an ardent public speaker, influencing both corporate executives and perfect strangers alike to invest in our collective mission to end NF.

The Children’s Tumor Foundation was proud to honor **AstraZeneca** with the Scientific Innovation Award for its commitment to innovative research, improving patient outcomes, and bringing new treatments to the forefront for those living with NF. AstraZeneca is a global, science-led bio-pharmaceutical company that focuses on the discovery, development, and commercialization of prescription medicines.

The Foundation also introduced the 2021 National Ambassador, an award bestowed upon a young adult living with NF to recognize their courage living with the disorder and their personal efforts to further the Foundation’s goals. The 2021 NF Ambassador is **Lilly Ann Brooks**, a college student living with NF1. Lilly Ann was diagnosed with NF when she was 18 months old and has tumors on her spine, neck, chest, and upper right arm. She suffers from severe scoliosis because of neurofibromatosis. But that has never stopped Lilly Ann, who is now a sophomore at the University of Alabama. To congratulate Lilly Ann, Broadway star Denée Benton beautifully sang “The Spark of Creation” from the musical, *Children of Eden*.

Last year’s recipient of the CTF Champion Award, Ian Desmond of the Colorado Rockies, presented the award this year to passionate CTF crusader and friend **Jonathan Sadowski**. Since first becoming involved with CTF in 2015 when he hosted the Foundation’s annual LA Fashion

Show for NF patients and families, Jonathan’s exuberance and charm has brought awareness of NF to new audiences in both the entertainment industry and beyond.

Generous CTF donors Frank and Shelley Haughton made a matching gift announcement that propelled the evening’s fundraising goals. We are profoundly grateful to the Haughtons and thrilled to share that all donations made to CTF through December 31 will be matched up to \$1 million.

Special thanks to the event co-chairs, Erica Hartman-Horvitz, Shelley Haughton, and Liz Rodbell for a wonderful evening. Those who were unable to join the livestream may go to [ctf.org/celebration](https://www.ctf.org/celebration) to view this elegant event, and learn of the total funds raised, which at the time this newsletter went to press had already reached \$2 million.

### VIRTUAL BENEFIT VIII

Over the past seven years, **Jennifer and Dan Gilbert** have hosted the beNeFit, which has raised over \$30 million to end NF, with funds benefiting NF Forward and the Children’s Tumor Foundation. Together, thousands of amazing supporters have broken all fundraising records to advance research toward a cure for this devastating disorder. This extraordinary outpouring has provided hope to the 2.5 million kids and adults who battle this relentless beast every day.

Usually taking place at Detroit’s TCF Center (formerly the Cobo Center), the 2020 beNeFit VIII was a virtual “Light Up The Night” online viewing experience on November 21, 2020. The evening included entertainment and live and silent auctions, and culminated in a presentation of the annual Strength and Honor Award which was given to NF Hero **Maddox Gibson**. This newsletter was sent to print



Actor and  
Producer  
Jonathan  
Sadowski was  
presented  
with the CTF  
Champion  
award

From Left to Right: Star Dr. Greg Sharp, Star Instructor Allison Stodola-Wilson, Star Instructor Stephen K. Stone, Star Elicia Dover, Star Anne Imanuel Preston, Star Instructor Brian Earles, Star Christina Lecuyer, Star Instructor Anthony B. Bryant, photo by David Lewis.



Halloween Bash co-chairs Leslie and Richard Kates at the virtual event



TO MAKE A DONATION:  
Text BASHNF to 41444  
Visit [ctf.org/halloweenbash](http://ctf.org/halloweenbash)  
Call 800-323-7938  
Send a check to Children's Tumor Foundation  
Attn: Halloween Bash  
370 Lexington Ave.  
Ste. 2100  
New York, NY 10017



Halloween Bash co-chair Roland Thoms and his daughter Camille

# BENEFIT VIII

LIGHT UP THE NIGHT TO END NF

before the beNeFit VIII had transpired. Please go to [ctf.org/news](http://ctf.org/news) to read more about this luminescent evening and its fundraising total.

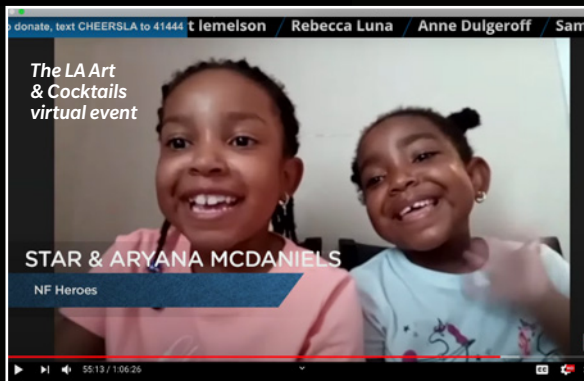
## DANCING WITH OUR STARS

On September 10, the annual Dancing with Our Stars Gala went virtual for the first time in 13 years with its ballroom competition. Vying for the coveted Mirror Ball Trophy were local celebrities including Shane Broadway, Vice President for University Relations, ASU System; Elicia Dover, KATV News Anchor; Christina Lecuyer, Confidence and Success Coach and Former Professional Golfer; Anne Imanuel Preston, TV News Anchor; and Dr. Greg Sharp, Chief Medical Officer at Arkansas Children's Hospital.

This year's event allowed individuals from across the country to attend and experience the evening. Anne Imanuel Preston was the winner of the Mirror Ball Trophy for the highest fundraiser, and Dr. Greg Sharp won the trophy for Best Performance. This beautiful evening raised more than \$150,000 to further the mission of the Children's Tumor Foundation. To view the live recording of this event, go to: [ctf.org/dwos2020](http://ctf.org/dwos2020)

## HALLOWEEN BASH

The Virtual Halloween Bash was held on Saturday, October 24, and was viewed by hundreds of people across the country and hosted by a trifecta of television and stage actors: Jonathan Sadowski, Michael B. Silver, and James Snyder. The evening featured touching mission



stories from NF Heroes, a variety of musical acts, cameos from celebrities, and wonderful spooky drinks from our own Junior Board member Zach Gratton. Co-chairs of the event were Mady and Bruce Donoff, Leslie and Richard Kates, Roland and Nicole Thoms, McKinnon Galloway, CTF Junior Board Chair, and Rose Match Suna, CTF Junior Board Vice Chair.

Roland Thom's daughter Camille brought everyone to tears with a heartfelt poem, and the festive event raised an incredible \$212,000 for NF research and can be viewed online at: [ctf.org/halloweenbash](http://ctf.org/halloweenbash)

## LA ART AND COCKTAILS

LA Art & Cocktails for a Cure was held on September 26 and combined the annual Kid's Fashion for NF and Los Angeles Cocktails for a Cure events into one virtual experience that raised more than \$14,000 toward the mission of the Foundation. Thanks to the NF Heroes who shared their artwork and stories: Teddy Chiaratti, Manny Flores, Marco Flores, Mya Jemente, Jerimiah Llamas, Aryana McDaniels, Star McDaniels, Leona Paxton, Ryder Savage, Maddox Steinert, and Grace Wallof. To view the live recording of this event, go to: [ctf.org/cocktailsla2020](http://ctf.org/cocktailsla2020)

The Children's Tumor Foundation extends our sincere gratitude to the organizers, volunteers, attendees, and donors who showed up to watch these opportunities online and supported our cause with the commitment that we know and love from our heroic NF community.

Your donation today will be **MATCHED dollar for dollar** up to \$1 million!

Dear Friends,

In April of this year, NF patients and families received the news of a lifetime — the United States Food and Drug Administration (FDA) announced the approval of Koselugo (selumetinib). **Finally, for the first time ever, there is an FDA-approved drug treatment for patients living with NF.**

This moment is a shining light in what has at times felt like overwhelming darkness. And the first spark of this moment was ignited by early-stage discoveries from Children’s Tumor Foundation-funded researchers, who proved that MEK inhibitor drugs have the potential to affect the size of NF tumors. Researchers took that potential and made it a reality: **more than 70% of NF patients taking selumetinib in a clinical trial had shrinkage of 20 to 60% in the size of their tumors.**

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



Your support of the Children’s Tumor Foundation has helped patients like **Lily, who lives with NF1**, pictured to the left. Now four-and-a-half years old, young Lily’s parents first met her when she was six months old in China. Her father Patrick was working for a nonprofit that connected doctors in the U.S. with sick orphans and underserved kids overseas. When her caregivers reached out to Patrick’s organization for help, the news was that Lily had a tumor that was growing really fast, **and no one knew how to help her.**

Patrick and his wife Lauren fell in love with Lily, and soon adopted her. **They charged ahead searching for answers, looking for a treatment that might stop her tumor from so dangerously growing.** More than a year and several surgeries later, Lily has now started taking Koselugo (selumetinib), and her parents and her doctors are looking forward to the promise that this new FDA-approved treatment might have in store for this sweet young girl.

I am so excited for Lily, and I long to hear that her success on Koselugo equals, even surpasses, that of the NF Heroes who participated in the selumetinib clinical trial that we have followed through the years. Success stories like Philip, and Jane, and Paige, and Cooper, and Aidan, and Lilly Ann, and Travis, and . . .

**The list goes on and on. But it doesn’t go far enough.**

Koselugo (selumetinib) is approved only for NF1 patients with inoperable plexiform neurofibroma tumors. It is an incredible first step. But the devastating effects of NF go far beyond this type of NF, and far beyond this one type of NF tumor. There is still no approved treatment option for NF patients with 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.**

**I have good news: more treatments are on the horizon! But we urgently need your help to bring them to FDA approval.**

I want to see an approved treatment for patients like seven-year-old **Cataleya, who lives with NF1**. At just two-years-old, Cataleya was diagnosed with bilateral optic gliomas that caused irreversible vision loss.





There is new hope for Cataleya because researchers believe that there are drug options that might work for optic glioma tumors the way they do for plexiform neurofibromas. Cataleya just joined an exciting clinical trial for patients with optic gliomas, and her family hopes that it will preserve what sight she has left.

**But we also need options for people with NF2, like 26-year-old Ethan Brown.** At age 16, Ethan received his NF2 diagnosis. Tumors formed inside and outside his body, on his brain stem, his spine, and hands. **The tumors that compressed his brain stem required three brain surgeries.** He now needs a wheelchair, has slurred speech, and has difficulty swallowing.

For patients like Ethan, the CTF-spearheaded **NF2 Accelerator Initiative** is advancing research toward treatments for NF2. One of the many promising projects funded by this initiative is an FDA-approved clinical trial for a drug called Brigatinib, specifically for patients with NF2. This potential treatment is a direct result of CTF's Synodos for NF2 research consortium, which made the research discovery that led to this breakthrough.

**Your donation at [www.ctf.org/donate](http://www.ctf.org/donate) directly funded this research discovery - and we need more breakthroughs like this for people like Michele Holbrook who was diagnosed with schwannomatosis,** at the age of 25 after her son was born. Now 54, Michele has lived with this condition for over half her life, and has become an advocate for the Children's Tumor Foundation.



Cataleya, who lives with NF1



Ethan Brown, who lives with NF2, along with his friend and NF2 Champion, Ian Desmond of the Colorado Rockies Baseball Team.

Thanks to your continued help, CTF's Synodos for Schwannomatosis is focused specifically on developing treatments for the pain of schwannomatosis. There is also a first-ever clinical trial for schwannomatosis pain that is recruiting patients now!

**In fact, because of your support, 68 potential drugs for all types of NF are in the pipeline. But unless we continue to fund this progress, those living with NF today will never see those drugs reach FDA approval.**

There is so much more work to be done — and we need your help now more than ever.

**Please don't wait - two generous CTF donors have have generously agreed to MATCH YOUR DONATIONS THROUGH DECEMBER 31 up to \$1 MILLION!**

Donate today to help us meet this

million-dollar match and double your impact for Lily, Cataleya, Ethan, Michele, and millions of others living with NF.

Sincerely,

Annette Bakker, PhD, CTF President

**P.S. Please don't wait. Donate today by returning the attached envelope.**



Michele, who lives with schwannomatosis

**IMPORTANT NOTE:** CTF has a new address specifically for donations:  
Mail Code: 6895, P.O. Box 7247, Philadelphia, PA 19170 - 0001

# stories

OF NF

## Lindsey Marson

I was diagnosed with NF1 when I was about two years old. I always try to preach positivity. Always! I say positivity is the best medicine above all. So, with that mindset, I have not let NF get in the way of life, though that doesn't mean I haven't had bad days or experiences.

Let's be real - NF sucks. No one wants to be born with any type of anything out of the ordinary. I have pseudarthrosis of the tibia, which sometimes comes along with NF1. I explain it to people like this: your bone in your leg is as strong as a tree trunk. Mine? About as strong as a stick.

My tibia is extremely fragile and can break really easily. I have broken my right leg many times in my 25 years of life and have had too many surgeries to count. I wear a KAFO (Knee Ankle Foot Orthosis) leg brace specially made for me.

That's just one side of NF - the tumors are a new ball game. I've had many removed and most recently I had the biggest one removed from my thigh. That scar is my favorite part about myself. I LOVE IT. You have to embrace your scars, tumors, leg braces—embrace it!

True story, I got my name, Lindsey, because my mom loves Lindsay Wagner – AKA “The Bionic Woman.” Funny how I am legitimately the bionic woman with my leg brace. Like I said, positivity is the absolute best medicine.



Lindsey, who lives with NF1



Desmond, who lives with NF2

## Desmond Parten

Desmond has the most contagious personality. He's a mature, hilarious, sweet, polite, and intelligent little boy. Des was born in Italy in 2011, while I was stationed there with the Air Force. He was pretty average growing up, nothing major, no illnesses, a little slow on speech but we sort of thought the language barrier in Italy had something to do with that.

When we arrived back in the U.S., I had Des evaluated for pre-school and they enrolled him in speech therapy. He wasn't severely behind but needed a little help. At the same time, I asked them to check out his walking because I noticed it seemed a little off.

When he was in first grade, a physical therapist noticed Des running at recess and said it looked like he had foot drop. We got an appointment at Boys Town National Research Hospital, where the neurologist said the nerve in his leg was dead, to pop a brace on him, and move on with physical therapy. We then waited another 6 months to be seen at Children's Hospital Neurology for a second opinion, where an MRI was scheduled so we could check out his brain.

I wish I could go back to this time, before my whole world got flipped upside down. It was a Monday evening, and Desmond's neurologist called and said that his test results revealed what she thought to be NF2. The MRIs showed a mass in Des' right ear, his brain stem, a bunch on his spine, and something on his right kidney.

It's hard to not think of what road is ahead for this little boy. I'm thankful for the knowledge of his diagnosis, but selfishly I wish I could go back to before, when I didn't worry about Desmond's future.

In October 2019, we finally got to meet with a great NF specialist in St. Louis. We also had an appointment with a nerve specialist to try to pinpoint Desmond's drop foot, who found the tumor and scheduled a surgery a few weeks later.

Eventually the casts came off, and we finally saw movement. The surgery was a success! Des still has some physical therapy to work through but he is brace-free, running, riding bikes, doing things we were told were not possible. With NF you never really know what is waiting for you around the corner, but we are walking towards the next turn now brace-free, which is a miracle in itself.

-Samantha Parten, Desmond's mother



During October, National Bullying Prevention Month, a variety of livestream events led to thousands of dollars raised through virtual community fundraising. Connect2Fight allows fundraisers to be creative with how they choose to raise funds through livestreaming. Participants ranged from NF Heroes and their families to previously unaffected content creators who were open to a charity partnership. We got off to a great start in 2020 through CTF's newest fundraising opportunity, and we know we can grow this program exponentially, with your help!

You too can start a livestream charity event and Connect2Fight. To find out more, please visit [ctf.org/connect2fight](https://ctf.org/connect2fight), or connect with us on Streamlabs, Discord, or Tiltify. You can also email [livestream@ctf.org](mailto:livestream@ctf.org) to share your ideas or plans to stream.

## Livestream Music and Art

NF2 Hero **Sebastian Mogan** of the Rhythm Bullies, livestreamed an acoustic guitar performance through Facebook Live on October 15 from Nashville, Tennessee. His performance was inspiring, and he raised funds for NF research through



his passion for music! Additionally, **Rachel Mindrup**, mom to NF Hero Henry, walked viewers through her virtual opening at Creighton University's Lied Art Gallery, featuring a selection from her "Many Faces of NF" collection of NF Hero portraits. She

received donations while sharing the stories behind her paintings, and talking about her own family's NF journey. Read more about Rachel Mindrup and her artwork in our Extraordinary Spirit feature on page 12.



### CONNECT2FIGHT ATTRACTS NEW COMMUNITIES

Connect2Fight also invites influencers and content creators from outside our NF community, who are looking to grow their philanthropic involvement, like **Antoine Bandele**. Antoine is the creator of a successful YouTube channel, and when approached by an NF Hero and fan to host a fundraiser for the Children's Tumor Foundation, he jumped into action. Antoine held the charity stream fundraiser over the month of September and into October. Each week on Friday evening, he had a different NF Hero help him open the stream to share their story with his virtual community of over 241K subscribers. Antoine's charity streams have had over 15,000 views to date, and with his community, he has raised almost \$5,000 toward NF research!



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.

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



“Being part of the NF Registry allows me to join the battle in eliminating the suffering that is caused by having NF. It's a personal choice that I have made to join CTF in ending NF.”

—ALWYN DIAS, WHO LIVES WITH NF1

## END NF Challenge

This was a year of canceled events and postponed races, but CTF's NF Endurance Team rose to the challenge - the END NF Challenge! Between our June Running Month challenge and the Fall Series, the virtual END NF Challenge became an opportunity for the global NF Endurance community to go the extra mile to end NF, by raising funds and awareness, connecting with one another in solidarity, and engaging our communities to join us in the mission to end NF.

From June to November, hundreds of END NF Challenge participants committed to working together to cover 3,000 miles (in June) and log 2,500,000 total minutes of activity (in the fall), in honor of our NF Heroes and families. By sharing miles and activity logged, and posting photos and videos on social media, the community encouraged and supported one another throughout the Challenge.

As we eagerly await the return to in-person racing and events in 2021, NF Endurance continues to grow our virtual community, both through END NF Challenge and Choose Your Own Challenge. No matter where you are or how you participate, you can be a part of our NF Endurance movement. Learn more at: [nfendurance.org](http://nfendurance.org)



## Team Nico & Nico-Palooza

Emily and Nicholas Tseffos' son Nico was diagnosed with NF1 at six months old, after his pediatrician and parents noticed a number of café au lait spots on his torso. He is now a healthy, happy, and hilarious three-year-old who loves trucks and dancing, but his parents couldn't stand by without doing something to create a brighter future for their son. Beginning in 2017, they formed Team Nico, and invited family and friends to walk and run with them at the Rock 'n' Roll Nashville Marathon, Half & 5K each April. Through 2019, their fundraising efforts in Nashville raised more than \$22,000.

After moving to Wisconsin last year, they decided to bring Team Nico to the Fox Cities Marathon and Half, scheduled for September 19, 2020. Due to COVID-19, the race was cancelled—but that didn't stop Team Nico. Instead, Emily and Nicholas



turned it into an opportunity through the NF Endurance Choose Your Own Challenge option. They challenged their family and friends to create their own race for the same date—a 5K, a bike ride, a half-marathon, a triathlon, a relay run—and called it Nico-Palooza. Their race week included a virtual Yoga Kick-Off, a virtual pre-race Happy Hour & Team Pasta Dinner on Zoom the night before, and then Nico-Palooza began bright and early on September 19.

Team members across three states rallied to walk, run, cycle, and paddle in honor of Nico and shared photos and videos of their race efforts on Instagram, with Emily and Nicholas running as a two-person team. Their incredible efforts and that of their team inspired so many, resulting in over \$32,000 raised for Nico-Palooza in 2020.

We are so grateful to Emily and Nicholas Tseffos for their ongoing commitment to end NF, and we congratulate Team Nico for coming together in support of Nico and all NF Heroes.

### CUPID'S CHARITIES

#### Trick or Treatment

Always ready to find fun ways to end NF, our partners at Cupid's Charities hosted a vote-by-dollar online costume contest for PETS! This month-long CUTENESS face-off culminated in a live costume contest, with 100% of net proceeds benefiting the Children's Tumor Foundation. Thank you to Cupid's and all the furry friends who raised nearly \$30,000 for the fight to end NF.



# SHINE A LIGHT **NF** WALK

Each year the Shine a Light Walk community continues to grow, engaging people across the country and sparking friendships among NF families and friends. The 2020 Walk season was no different in that regard, because the same passion, connection, and camaraderie was realized virtually online. Thank you to all who volunteered, shared a video of your NF story, or donated online. Over 31 Walks took place in our new virtual format, engaging over 3,000 participants and raising more than \$1 million to fund NF research and patient programs. Help us keep this momentum going, and extend your support at: [shinealightwalk.org](http://shinealightwalk.org)



## New Jersey Shine a Light NF Walk

As the 2020 Shine a Light NF Walk season took off, the New Jersey community looked forward to once again marching along the Seaside Heights Boardwalk, looking like a sea of blue and green. Due to worldwide health and safety concerns, the community unfortunately could not gather together at the shore this year, but instead came together virtually to celebrate their NF Heroes. On October 3, some local families walked in the morning and early afternoon enjoying the beautiful sunshine, while others took to the outdoors underneath the night sky, truly “shining a light” on NF! New Jersey has banded together and is determined to reach their \$50,000 goal by the end of the year, which they are so very close to achieving. They are also excited and hopeful to gather together again on the Jersey Shore for Walk Day 2021 to introduce new families to the NF community and CTF staff.

## The Carolinas Shine a Light NF Walk

The Carolinas had their first-ever walk this year, and this community came together in a big way. Ten new teams and over 100 participants registered for this inaugural walk held on October 11. Rain couldn't stop teams from all over South and North Carolina from walking, while family and friends from outside these states also joined in. We discovered new friendships, new support systems, and a new CTF community that is Shining a Light on NF in the Carolinas!



## Chicagoland Shine a Light NF Walk

This year's Chicagoland Walk took the virtual format to a whole new level. The pandemic did not allow the teams to gather together, but each celebrated as loudly as they could by sharing over 80 pictures and videos. Team Dana, Noelle's Wayfinders, and Aubri's Avengers had friends and neighbors walk all over the country, while Team Levi celebrated in their pasture, the Mighty Meeks had a car parade, and Addison's Unicorn Squad had ambulances and fire trucks join in the fun. Everyone missed the famous raffle, but as these mighty teams do, they raised more than they did last year, and we couldn't be more grateful!



# Extraordinary Spirit /

## RACHEL MINDRUP

Rachel Mindrup is more than a professional artist and art educator – she is an extraordinary spirit. Rachel is the creator of *The Many Faces of NF*, a beautiful portrait series of paintings featuring individuals who live with all types of NF. This fall, her art exhibition “Portrait of a Disorder: Neurofibromatosis” was held at Creighton University in Omaha, Nebraska, and Rachel joined our Connect2Fight program at the exhibition’s opening for a livestream talk about her art. We spoke with Rachel to learn more about the origins of her series of paintings, and her extraordinary spirit.



anything that seemed like me. I mean, I would have heart palpitations if you told me to go organize a Shine A Light on NF Walk. (I’m so glad that there are people who can do that!)

You might be familiar with Reggie Bibbs, who has his Just Ask Foundation? I thought, “Well, here’s this amazing guy, and he’s raising awareness, but I’m not doing anything.” So, really just as a thank you, I painted his portrait. It was just a watercolor, nothing grandiose - but he used it as his profile picture on Facebook. From there it grew – soon I painted a portrait of Reggie’s friend Maurice, who also used it as his Facebook profile picture. Not too long after that, April Anderson sent me a message, and I did her daughter Dakota’s portrait just before Dakota had chemotherapy.

Once I painted Dakota’s painting - that was when it took off. April shared the portrait on Facebook, and suddenly people around the country connected with me due to her network of NF parents. For about nine months after that I was doing watercolor portraits of people living with NF for donations, and they were using them as profile pictures. Finally, somebody suggested that I should make a Facebook page so people could view them as a collection and so in the fall of 2011 I did just that.

After that, I thought about how I could be more intentional with the project. Rather than



Artist Rachel Mindrup with NF Hero Ashok, one of Rachel’s Many Faces of NF subjects, and the recipient of a GoFundMe campaign that Rachel created to cover his medical expenses relating to surgery.

“I will just keep painting and sharing these stories until one day this medical mystery is solved and cured.”

—RACHEL MINDRUP

watercolors, I wondered if I should switch media. Oil is the chosen and approved method to solidify legacy, which isn’t to say it is the best, it just happens to have an archival history that shows it can last hundreds of years. Federal judges, wealthy benefactors and the President of the United State always solidify their legacy in oil paint mainly for that reason. Since I started with Reggie and his watercolor, I did his oil portrait first. I went through a series of paintings with Reggie, trying to figure out my approach. The first couple of paintings I did of him, I had him looking at the viewer confrontationally, like, “This is NF - look at me!”

The lesson I learned is that the unaffected population is not interested in confrontational gazes and simply won’t look at those images. Only people who knew me and knew about NF thought they were empowering. So, unfortunately, the very population I was interested in, the people I am trying to reach simply didn’t engage with the paintings. And, if they’re not going to look at the paintings they certainly are not going to learn about NF. So, now in my oil paintings, the subjects in the paintings are not looking at the viewer, which allows the viewer a safe place to gaze, stare, question and learn. At the end of the day, my goal is to raise awareness for NF, so I’ll keep painting and sharing these stories until one day this medical mystery is solved.

Rachel’s incredible works of art can be viewed via her popular Facebook page of the same name, or on her website: [rmindrup.com](http://rmindrup.com)

## A Musical Journey to End NF

On September 5 we were flying high at the heart of it! The virtual Musical Journey to End NF featured incredible performances from internationally renowned artists and inspiring stories of NF. In collaboration with classical guitarist Sandro Norton and APNF, the NF organization in Portugal, more than \$28,000 was raised to support the Children's Tumor Foundation Europe's clinical care and research initiatives, as well as to support the Spanish and Portuguese translations of the NF Registry. The entire event is available to view at [ctfeurope.org/journey](http://ctfeurope.org/journey).



Children's Tumor Foundation Europe celebrated the second anniversary of its launch in Brussels on November 7, 2018.

For over two years, CTF Europe has been hard at work driving research, expanding knowledge, and advancing care for the over 250,000 Europeans living with neurofibromatosis.

## Children's Tumor Foundation Europe Wins Rising Star Award at BioPharm CEO Event

The Children's Tumor Foundation (CTF) Europe was recognized as a 'rising star' at the 2020 Boston CEO and Board of Director Conference, part of Biotech Week Boston. The award was announced at BioPharm America's digital event highlighting innovation in biotech/biopharma, comprised of leading decision makers in the life sciences.

Wendy Nelson, PhD, the CEO and President of Leading Biotech Boston said in presenting the award, "The Children's Tumor Foundation has been in existence in the United States for over 40 years; however CTF Europe was founded less than 2 years ago and has made incredible strides in raising visibility, forming a neurofibromatosis registry, forging partnerships, educating the community, and raising money for research."

Accepting the award was Annette Bakker, PhD, President of the Children's Tumor Foundation and Vice Chair of Children's Tumor Foundation Europe. Annette thanked the event organizers and attendees on behalf of the neurofibromatosis community, and expressed confidence that investors and biotech leaders are increasingly recognizing patient advocacy groups like CTF as R&D accelerators, enabling needed advancements in disease research that will result in effective treatments for patients.

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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"To whom much is given, much will be expected in return. We are NOT to stand by and do nothing. We are to use the gifts that God has given to us to do our part, everything we can do to help."

—Frank and Shelley Haughton  
Parents and Grandparents of NF1 Patients



Home Is Where  
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# SHOP to End NF

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