NF NEWS

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION

WINTER 2021

CHILDREN'S TUMOR FOUNDATION
ENDING NF
THROUGH RESEARCH

> "When I saw the NF1 Gene Therapy Initiative from the Children's Tumor Foundation, it aligned perfectly with my experience in genome editing technology and the pioneering AAV capsid technology being performed at our institute ... our team has made some exciting progress and we hope to continue this research to benefit the NF community."
>
> *—Samantha Ginn, PhD, of the Children's Medical Research Institute in Australia, and CTF Gene Therapy Initiative Awardee*

INSIDE:

FROM **the President**

Annette Bakker, PhD

This December marks my 10-year anniversary with the Children's Tumor Foundation, and throughout this incredible decade of my life, I have been continually inspired by the courage and perseverance of the neurofibromatosis (NF) community. You have kept up your valiant efforts to join the Children's Tumor Foundation (CTF) in the fight for treatments and a cure for these complex genetic disorders despite much change and uncertainty. I want you to know that I appreciate each of you, and we thank you for not just enduring but thriving throughout this year.

We were thrilled to hold the National Gala in person this fall, hosted simultaneously in New York City and Boston, Massachusetts. The evening's program was also made available to everyone virtually so that families around the world could join us for our biggest fundraising event of the year. I was honored to present our partners at SpringWorks Therapeutics with a Medical Innovation Award for their incredible work in the NF and rare disease space.

Leslie and Dick Kates, longtime supporters who have been a vital part of the history of this Foundation, were presented with the CTF Humanitarian Award, and the lovely Raina Seitel was named our 2021 CTF Champion. The evening ended with an inspiring presentation from our new 2022 Ambassador, Eddie Purtell. Eddie is an NF Hero who has endured a lifetime of surgeries and treatments but has proven himself a fighter, running for the NF Endurance Team throughout the years and thriving as a young professional in Denver, Colorado. Eddie is a shining example of the strength and perseverance of the entire NF community, and we are so honored to have him as our ambassador.

I continue to be profoundly grateful to our many volunteers and donors who have hosted so many excellent and varied virtual events, including our partners Dan and Jennifer Gilbert, who held NF Forward's annual beNeFit this year and broadened it to both an in-person and a virtual experience. Travis Carpenter, one of our cherished CTF NF Heroes, was also honored that evening. My utmost congratulations to Travis and his family for this well-deserved honor.

On the **Cover**

The CTF NF1 Gene Therapy Initiative is funding a research program focused on gene-based therapeutic approaches for the treatment of NF1. Two independent groups were awarded funding under this initiative, each for $240,000 for a total duration of two years. We asked one of the leaders of these groups, **Samantha Ginn, PhD**, of Children's Medical Research Institute, Australia, to tell us more about her work and how she ended up in the NF field. Read her complete response at **ctf.org/news**.

With great pleasure, we recently announced that the Children's Tumor Foundation welcomed Cupid's Charity into official CTF operations. The inspiring team at Cupid's has been a vital part of the CTF family for many years, and we are thrilled to fully bring the Cupid's program into CTF.

This newsletter recaps the events of so many CTF volunteers and NF patients, who unite with us in so many ways—through joining, fundraising, volunteering, planning, and donating. Together we are changing the future of NF! Thank you for your dedication to CTF and our vision: ending NF.

Sincerely,

Annette Bakker, PhD
President

Research NEWS

2021 Hack4Rare Winners Announced

The 2021 Hack4Rare was a global hackathon for rare diseases hosted by the Children's Tumor Foundation and MIT Hacking Medicine. The virtual event brought together healthcare startups, researchers, developers, solutions architects, and hackathon enthusiasts for five weeks from June 25 to July 30, to drive scientific and medical innovation and improve the lives of patients living with rare diseases, including: neurofibromatosis (NF), PTEN Hamartoma Tumor Syndrome, RASopathies, and Desmoid Tumors. More than 300 active participants took part in Hack4Rare from around the world.

The Hack4Rare winning projects were recently announced with first, second, and third place winners on each track to receive $1,000, $750, and $500, respectively. The winning projects of the neurofibromatosis track of the 2021 Hack4Rare include:

- **1st place: Synthetic NF1 MRI Images**

The team is creating a machine learning process that will allow computers to create synthetic Whole Body MRI (WBMRI) scans by learning from real WBMRIs. Since the problem of creating new algorithms to better characterize NF imaging is the lack of enough data, the team is trying to use computers to generate that data.

- **2nd place: LetsTalkAboutNF.com**

A curated podcast series that facilitates discussion around the shared yet unique experiences of the NF community.

- **3rd place: DeepWalk Based Gene Clustering**

This team will develop a framework to accurately segment genomic data and tumor samples for neurofibromatosis patients and patients with other rare pediatric cancers.

Expanding on last year's successful NF Incubator launch, this year additional funding was made available through the Rare Incubator, with support from the Children's Tumor Foundation, Neurofibromatosis Therapeutic Acceleration Program (NTAP), the Gilbert Family Foundation (GFF) and CFC International. The qualifying teams who may choose to continue working on their projects for up to a total of $38.5K in incubation funding include:

- **Synthetic MRI Imaging (NF track)**
- **Apptivity (NF track)**
- **Deep Walked Based Gene Clustering (NF track)**
- **Let's Talk About NF.com Podcast (NF track)**
- **Track Pain (RASopathies track)**

Hack4Rare was the third hackathon that the Children's Tumor Foundation has hosted. In September 2019, data scientists, artificial intelligence experts, and engineers gathered at the Google Launchpad in San Francisco, California to 'hack' genomic, research, and imaging/clinical data from the NF Data Portal, in order to bring their unique insights and experiences to help accelerate NF medical research.


The 2021 Hack4Rare Award Presentation

NFlection Therapeutics Announces Orphan Drug Designation of NFX-179 for Cutaneous NF1

NFlection Therapeutics, Inc., a clinical-stage biopharmaceutical company focused on developing novel drug candidates for rare RASopathies, recently announced that the Food and Drug Administration (FDA) has granted the company Orphan Drug Designation for NFX-179 for the treatment of cutaneous neurofibromatosis type 1. NFX-179 is a topical, first-in-class, "soft" MEK inhibitor that is currently being evaluated in Phase 2 clinical trials in patients with cutaneous NF1. The prevalence of cutaneous NF1 is estimated to be between 100,000 and 120,000 in the United States. Cutaneous neurofibromas are tumors that grow from small nerves in the skin or just under the skin and appear as small or larger bumps typically beginning around the time of puberty. Individuals commonly develop more cutaneous neurofibromas as they get older. These may be disfiguring, itchy or painful when bumped. Despite their benign nature, they may cause significant problems (e.g., depression, isolation, etc.) and may require surgical removal.

About NFX-179

NFX-179 is an investigational mitogen-activated protein kinase (MEK) inhibitor. NFX-179 is a "soft" (metabolically labile) drug, which, when formulated as NFX-179 Gel for topical application, is designed to concentrate at the dermal site of action but degrade in systemic circulation, thereby significantly reducing side effects compared to systemically available MEK inhibitors. NFlection is developing NFX-179 Gel for the treatment of RASopathies such as cutaneous NF1, immunosuppressant-mediated cutaneous squamous cell carcinoma, and congenital birthmarks.

ResearchNEWS

NF Registry Now Available in Spanish

NF REGISTRY

ÚNASE A LA LUCHA CONTRA LA NEUROFIBROMATOSIS

nfregistry.org

MANTÉNGASE INFORMADO. MEJORE LA ATENCIÓN.
COLABORE CON LAS INVESTIGACIONES SOBRE LA NF.

"Hay días buenos y días malos, pero es cuestión de dar un paso a la vez. Acompáñese del registro de NF en su travesía".

SEQUOYAH DANIEL-ROBINSON
que vive con NF2

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

The NF Registry is now available in Spanish! This is a first step forward in expanding the NF Registry to non-English speakers in the U.S. and elsewhere. CTF plans to release more non-English versions to come, starting with French, Portuguese, and Italian in the near future. To participate in the NF Registry in Spanish, go to **NFregistry.org**, click "Language" at the top right side of the home page, and select Español.

What is the NF Registry? CTF created this patient registry to involve families in solving the puzzle of NF. To participate, you complete a yearly health survey for yourself, your child, or both. This data, stored securely to protect your privacy, helps researchers study how NF affects everyone differently and how it can change over time. You then choose whether to receive personalized emails about:

- Clinical trials and research studies relevant to you or your child
- Updates to NF care recommendations
- Research announcements and news
- Surveys designed to get patient input on key NF challenges
- Educational materials specific to you
- Resources to help you on your path with NF

Even if you choose not to be contacted, your participation helps researchers learn from the real experts – the NF community.

So far, the NF Registry has enabled over 50 research studies. CTF designed the NF Registry as a two-way street. You provide your experiences with NF, and we give study results back to you when possible. For example, a study of genes associated with cutaneous (dermal) neurofibromas is now recruiting people over age 40 with NF1. This type of study needs over 1,000 participants in order to succeed. Patients complete an online survey, and then a saliva test kit to collect DNA is mailed to your home. After you send it back, test results are given to you at your request.

Do you have questions? We would love to hear from you. Contact either **Pam Knight** at **pknight@ctf.org** or **Kate Kelts** at **kkelts@ctf.org**.

The more Registry members, the more significant the impact on the future of NF research! Visit **NFregistry.org** today.

CTF, FasterCures/Milken, and CureSearch Publish Article on Nonprofit Marketplace for Shelved Drugs

The Children's Tumor Foundation is excited to share news of the publication of our co-authored article (with our partners at FasterCures, a center of the Milken Institute and CureSearch for Children's Cancer) on how nonprofits can play a critical 'matchmaking' role in getting needed drugs to patients.

Despite robust safety data and pharmaceutical characteristics, many promising medicines are discontinued by drug companies for nonscientific reasons, including strategic, organizational, and financial considerations. Gaining access to these shelved drugs—to investigate intended or new indications—is challenging. Meanwhile, patients and families wait for new therapies for their conditions, including all types of neurofibromatosis and schwannomatosis.

A new approach to solving this challenge assigns patient advocacy groups and other nonprofit organizations as matchmakers between discontinued drug assets and capital sources. To read the full article, go to **ctf.org/matchmaking**.

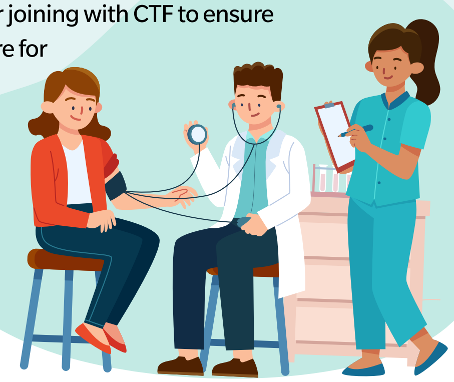
NF Clinic Network Expands

The Children's Tumor Foundation would like to welcome two new clinics into the NF Clinic Network (NFCN), including our first one in Canada.

Dell Children's Medical Center in Austin, TX
Clinic Directors: Manikum Moodley, MD, FRCP and Virginia Harrod, MD, PhD
Clinic Coordinator: Karla Robles Lopez, PhD, MSc, MD

Centre Hospitalier de l'Universite de Montreal (CHUM) in Montreal, Quebec
Director: Sarah Lapointe, MD

The addition of these two clinics brings our current NFCN clinic number to 67. Thanks to these clinics and their staff for joining with CTF to ensure excellent care for NF patients!



stories
OF NF

Jake NF1

Jake was diagnosed with NF1 at six months old; he is now six years old. During Jake's six-month checkup, the doctor noticed the café au lait spots, which we thought were birthmarks, over Jake's back, neck, and chest. The doctor told us about NF and that we should take Jake to the dermatologist to get a better idea of whether or not Jake had NF. As parents, we were scared, nervous, and anxious to see if our newborn had a condition we had never heard about. After meeting with the dermatologist, they confirmed that Jake did have NF, based on the amount of café au lait spots. At that point, we were devastated. We are very thankful to the doctor who told us about the NF when he was six months old because we could have gone on thinking that everything was okay, and then it could have been too late to treat his optic nerve tumors.

NF does impact Jake in a few different ways. Before the pandemic, we found out that one of his legs is a little shorter than the other. That is something that we have to check every year, so we go back around October to see how his legs are growing. In November of 2020, Jake started his 24-month-long journey taking a MEK-inhibitor drug to help treat the optic glioma that could steal his eyesight. July 21, 2021, Jake had his eye exam which came back with positive news—no growth!

Jake is a silly six-year-old who loves to draw, paint, build things, especially with Magnatiles, and cook but not clean. He enjoys hiking especially in the 12 National Parks he has visited so far, and most importantly, spending time with his friends.

Rachel Bienert NF1

I was first diagnosed with NF when I was about a year and a half old, so I do not remember much about it. However, my mother noticed some things were different, like my café au lait spots, a small nodule above my right eye (that was a neurofibroma), and freckling under my arms. We were in Canada at the time, and the doctors could not give me a diagnosis. My mother was at a friend's house, and they had a parenting magazine with an article about birthmarks, and that is where she learned that NF was a possible diagnosis. She took me back to the states to see a specialist, where I was officially diagnosed.

Because I have a reasonably prominent tumor on my face, I often get questions about my appearance. I used to come up with different excuses to try and "explain it away," but as I have gotten older, it has become something that I have embraced and used as an opportunity to educate others.

My desire to share my perspective and help others led me to become a nurse. As a patient growing up, I always admired nurses. My doctors were terrific, but I have a special place in my heart for the great nurses that I have encountered. They helped me when I was sick post-op and always supported me if my family wasn't there. The nurses were always there when I needed them most, and I wanted to be one of those nurses for others. I worked with adults for the first part of my career and then transitioned to the ER, where I continued to work with adult patients and the occasional pediatric patient. After a few years in that role, I moved to Minneapolis to work at a children's hospital. The pediatric population has my heart, but I enjoy all aspects of nursing and love what I do.

Fall Fundraising Events
TO END NF

2021
NATIONAL GALA


Eddie Purtell


Leslie & Dick Kates


Raina Seitel

2021 NATIONAL GALA

The Children's Tumor Foundation 2021 National Gala took place on Monday, November 15 to celebrate another remarkable year in our shared efforts to fund vital NF research. This year's beautiful event was held in person at Cipriani in New York City, and at the Four Points by Sheraton in Norwood, Massachusetts.

The evening's program also livestreamed globally for the entire NF community to enjoy. The co-hosts for the evening were TV host/NBC correspondent Raina Seitel and actor/producer Jonathan Sadowski in New York, and popular Boston radio personality Ron Della Chiesa in Massachusetts. Guests enjoyed a beautiful evening of cocktails, fine dining, and entertainment by alternative pop rock band My Silent Bravery featuring Shana Shwachman.

The evening's program began with an impassioned speech from CTF president Annette Bakker, who presented the 2021 Innovation in Medicine Award to **SpringWorks Therapeutics.** An industry partner with the Children's Tumor Foundation since the pharmaceutical company formed, SpringWorks is making great strides into research for new treatments for neurofibromatosis and other rare diseases. SpringWorks CEO Saqib Islam accepted this award with eloquent remarks.

2021 Humanitarian Award was presented to **Leslie and Dick Kates,** who have a long and dedicated history with the Children's Tumor Foundation. The Kates family was instrumental in organizing a Massachusetts CTF Chapter and hosted a New England Gala for many years. Their drive to fund NF research was ignited by their daughter Stacy's NF1 diagnosis when she was a child.

Raina Seitel was presented with the 2021 CTF Champion Award by the 2019 and 2021 CTF Champions, Ian Desmond and Jonathan Sadowski. Raina has engaged CTF Gala attendees as the annual event's host for five years. With her contagious smile and sparkling personality, Raina's warmth and care for the Foundation and the NF community bring joy and enthusiasm to this yearly event.

Eddie Purtell was acknowledged as CTF's 2022 National Ambassador by Lilly Ann Brooks, who passed on the Ambassador title with heartwarming remarks about her tenure as the 2021 Ambassador. Eddie Purtell is a young professional living with NF1 who has been an active participant with the Children's Tumor Foundation and the NF Endurance team for many years. After attendees viewed a lovely video about Eddie and his family, he expressed his thanks in a speech about his journey with NF and his dedication to the Foundation's mission to end NF.

Our utmost thanks to an esteemed team of Gala Co-Chairs, who made the evening spectacular and inspirational: Mady Donoff, Erica Hartman-Horvitz, Shelley Haughton, Tila Falic Levi, Liz Rodbell, and Clara Wilpon.

This newsletter was sent to press before the evening's festivities. For photos, videos, additional details, and fundraising totals, go to **ctf.org/gala.**

BENEFIT IX

In Detroit, the beNeFit IX, the annual event of NF Forward, was hosted by Dan and Jennifer Gilbert on Saturday, November 20. The festive, campground-themed evening took place at the TCF Center in Detroit and was also livestreamed so that attendees could join from the comfort of their homes.

In the past eight years, the beNeFit has raised more than $37 million


Dancing With Our Stars

Travis Carpenter and his parents, Scott and Kelly

BENEFIT IX
MAKING MEMORIES TO END NF

to end NF. Together, thousands of amazing supporters have broken all fundraising records to advance research toward a cure for neurofibromatosis. This extraordinary outpouring has provided hope to the over 2.5 million kids and adults worldwide who battle this relentless disorder every day.

The Strength and Honor Award was presented to **Travis Carpenter**, an NF Hero who made the brave decision to amputate his leg earlier this year because of complications with NF. Travis and his family are active in the NF community and have been a vital part of the Children's Tumor Foundation family for many years. Travis is a courageous NF fighter, and we extend our congratulations on his well-deserved recognition, as well as our ongoing gratitude to the Gilberts for creating this tremendous event each year to benefit the NF community.

This newsletter was sent to press before the beNeFit had taken place. Please watch for further news about the beNeFit on the CTF newsfeed at **ctf.org/news.**

DANCING WITH OUR STARS

The annual Dancing With Our Stars events raised more than $300,000 for the Children's Tumor Foundation this fall. Hosted for the first time in two locations, the events took place in Little Rock, Arkansas for the fourteenth time, and for the first time in Northwest Arkansas. Twelve dancers took the stage in pairs that included one local celebrity and a dance instructor in both Little Rock and in Northwest Arkansas to compete for the Best Performance Trophy and the Championship Trophy, which is awarded to the top fundraiser.

In Little Rock, Susie Morgan won the Best Performance Trophy and Ted Mullenix won the Championship Trophy. In Northwest Arkansas, Rob Williams, the Arkansas Children's Hospital Northwest's Chief Medical Officer, won for Best Performance while Jamie Daniel of McLartly Daniel Dealerships won the Championship Trophy.

Special thanks to Governor Asa Hutchinson and First Lady Susan Hutchinson for attending both events, and their special support of the Northwest Arkansas inaugural event. The Governor shared a few words congratulating the people of Arkansas on the advancements that are being made because of the support of the Dancing With Our Stars community.

Plans are already underway for the 15th Annual Dancing With Our Stars Little Rock to take place on September 8, 2022 as well for the second annual event in Northwest Arkansas. To learn more about these events go to **ctf.org/dwos.**

CTF JUNIOR BOARD FUNDRAISING EVENT

The first annual Junior Board fundraising event was held virtually on October 27. Supporters joined together in the kitchen to create culinary masterpieces with longtime supporter Bourbon Charity and Chef Gale Gand, host of Food Network's "Sweet Dreams." Chef Gale Gand is the recipient of two James Beard awards, which recognizes exceptional talent and achievement in the culinary industry, and co-founder of the Michelin two-star restaurant "Tru" in Chicago.

Chef Gale Gand and all those who attended cooked savory soy glazed chicken with broccoli, then gooey chocolate lava cake for dessert. Before the feast, Bourbon Charity shared two classic cocktail recipes to perfectly complement the meal. Also on the itinerary was entertainment, a silent auction, and lots and lots of heart. Mission was at the forefront of the event as Junior Board members shared their stories and their talents.

Thanks to all those who attended, whether in person or online, to make these fall fundraising events a touching and important part of our experience together. Your donations will continue to fuel NF research and your warmth and community binds us together in our collective efforts to end NF.

Year End GIVING

Addison, Marcus, and Dale are **Making NF Visible**

Join us in the fight to find hope for all those living with neurofibromatosis (NF).

Throughout the global pandemic, the Children's Tumor Foundation has been working with you, our dedicated donors and friends, to **Make NF Visible.** We want to make sure the world sees NF, and sees each person living with it.

One in every 3,000 people is born with some type of neurofibromatosis or schwannomatosis. That means there are 2.5 million people around the world living with NF manifestations like disfigurement, blindness, deafness, bone abnormalities, learning disabilities, disabling pain, or cancer.

Addison, who lives with NF2, with her mother, Amanda

Left, Addison, just after surgery

We are doing everything we can to fulfill our commitment to the CTF Discovery Fund, a promise to fund $3 million in research grants every year. We are still $1 million away from this vital goal, and we need your help. Your donation today at **ctf.org/donate** is more critical than ever!

With your support, we can advance the research and discovery that will generate improved treatments, improved care, and improved lives **for people like three-year-old Addison who was diagnosed with NF2 at just 16 months old.**

NF2 is usually discovered in a person's teens or young adulthood, so it was very unusual for Addison to be diagnosed at such a young age. Since she was born with problems in her right eye, she was carefully followed by her doctors. At just 10 months old her eye symptoms started changing, so she had her first MRI that Christmas Eve:

"We were told that not only did she have deficits with the right eye, but she also had a 'mass' on the left side of her brain. After six months of genetic testing, we received Addison's NF2 diagnosis; she was only 16 months old," said Addison's mother, Amanda.

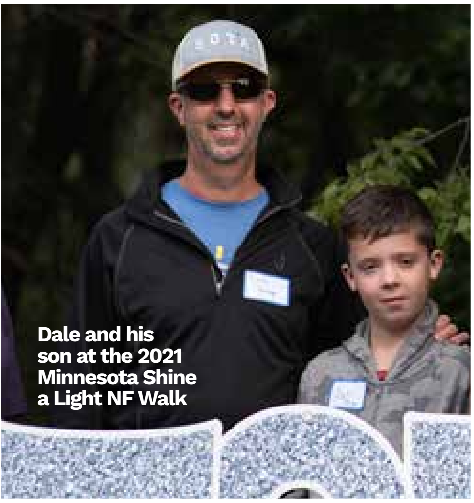
Your help will speed the path toward treatments for Addison and thousands more, who are desperately in need of approved treatments for their tumors.

We count on your donations each year to fund the vital CTF programs that have made a difference **for patients like Marcus who live with NF1.**

Marcus is now thirty-six years old and was diagnosed with NF1 when he was just two months old. Marcus was the only person in his family with NF, and neither his parents nor his sister had ever heard of the disorder.

"I have a plexiform tumor wrapped around my pelvis, so sometimes I have pain. Recently it really impacted my walking and my mobility and balance. When I walk into a room where I don't know anyone, I'm nervous about how they are going to perceive me. But I just make sure to focus on the things that I have accomplished in the past and remember who I am, that I'm a fighter. I'm a good person," Marcus told us.

Make your donation now to help fund more treatment options for Marcus, and thousands more who live with all types of neurofibromatosis, including schwannomatosis, the least common of the disorders associated with nerve sheath tumors.


Dale and his son at the 2021 Minnesota Shine a Light NF Walk

Schwannomatosis patients like Dale need your help today. Dale was diagnosed with schwannomatosis at age 45. His journey began ten years before his diagnosis, when he had an MRI due to his increasing lower back pain.

"I chose to live with increasing pain for 10 years before my general practitioner urged me to get new imaging. Finally, I was diagnosed with schwannomatosis, only to discover there is still no FDA-approved treatment for schwannomatosis tumors or the pain they cause. Surgery to remove three tumors has helped reduce the pain levels, but additional tumors and pain persist," Dale told us.

Your donation today will give hope to patients like Dale, who desperately need a treatment option for schwannomatosis pain. Treatments for all types of NF are now being sought after by scientists passionate about neurofibromatosis research, **including postdoctoral fellow at Stanford University, Kevin Bruemmer.** Kevin is a the recipient of a CTF Young Investigator Award, or YIA, which are a part of the CTF Discovery Fund.


Marcus, who lives with NF1

"I would like to focus my independent research on addressing less common diseases such as NF. Foundations like the Children's Tumor Foundation are critical in allowing scientists to pursue new ideas and therapeutic opportunities to help patients with rare diseases," Kevin shared with us.

Thank you so much for your past support. CTF has invested in research and care that has led to significant breakthroughs in NF, but we are not done yet. Please return the attached envelope, or donate online at **ctf.org/donate** so that hundreds more researchers like Kevin can be drawn to the field of NF research.

Patients like Addison, Marcus, Dale, and thousands more are counting on your help to continue the life-changing progress that has been made for patients with NF. **There is so much more work to be done — and we need your help this year more than ever before.**

CTF YIA Awardee Kevin Breummer

CUPID'S CHARITY

CTF Welcomes Cupid's Charity into its Business Operations

The Children's Tumor Foundation recently announced that it is absorbing Cupid's Charity into CTF's business operations. Cupid's Charity is best known for its annual Cupid's Undie Run event, proceeds of which go exclusively to NF research funded by the Children's Tumor Foundation. The union reflects mutual agreement by the Board of Directors of both organizations to fully bring the Cupid's program into CTF.

The first Cupid's Undie Run took place in 2010 in Washington, D.C. as a 'crazy idea' by co-founders Brendan Hanrahan, Chad Leathers, and Bobby Gill to raise awareness for NF, which affected Chad's brother, Drew Leathers. What started as a unique 'let's put hilarity into charity' twist on traditional charity walks/runs turned into a national phenomenon attracting wide attention and increased funding for NF. Cupid's Charity soon established its own 501(c)(3) non-profit with a mission to fund NF research. In the decade since it has raised and donated millions of dollars to the Children's Tumor Foundation for NF research.

The announcement reflects the belief that with a shared vision to end NF, and with many NF patients and families passionately involved in one or both organizations, Cupid's and CTF will continue to strengthen the NF community's efforts to raise awareness and funds for NF.

Cupid's program offerings will be integral amongst the variety of CTF's signature programs and event offerings, including Shine a Light NF Walk, NF Endurance, Classrooms for a Cure, and other special events. Registration for the February 2022 season of Cupid's Undie Run, which is anticipated to be in-person once again, has already begun and will remain unaffected.

"We are very proud and excited to officially welcome Cupid's Charity into the Children's Tumor Foundation family," said Tracy Galloway, Board Chair of the Children's Tumor Foundation. "Today's news reinforces what we know to be true – that CTF and Cupid's working together hand-in-hand will bring more awareness and funding to NF so that we can more quickly develop treatments for our loved ones."

"When we started Cupid's over a decade ago, our goal was to make sure more people knew about NF, and that more money was raised to fund research," said Brendan Hanrahan, Board Chair of Cupid's Charity. "We have seen much success, and we believe that by formally joining with the Children's Tumor Foundation, together we can give both those goals an even further boost."

For more details and frequently asked questions, go to **ctf.org/ctfcupids**.

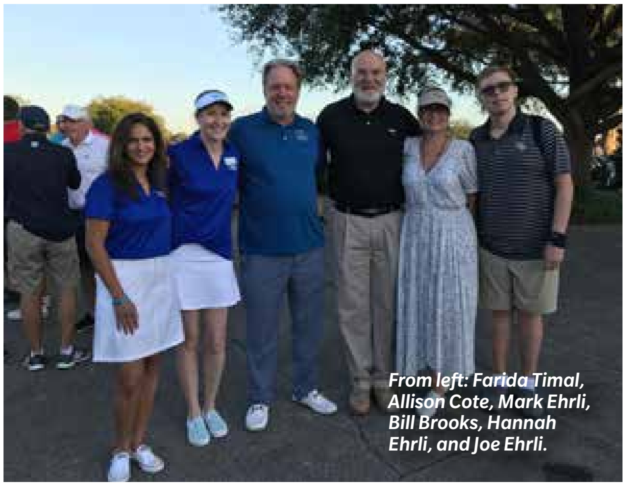
Register for a Cupid's Undie Run Near You!

Registration for the 2022 Cupid's Undie Run is open! While there is still a lot of uncertainty about what the future holds, we remain optimistic that we will be able to party pantless in person in February 2022. We are continuing to monitor all national, state, and local public health guidelines to give you the Cupid's event you know and love. Special thanks to Cupid's Undie Run sponsor, Joe Boxer. To register, go to cupids.org/register.

SPECIAL EVENTS

Orange Hills Golf Tournament

Diane and Jeff Owens hosted their 7th annual Orange Hills Golf Tournament in Connecticut on October 4 in honor of their son Alex who has NF1. The event raised $35,000 for the Children's Tumor Foundation.



From left: Farida Timal, Allison Cote, Mark Ehrli, Bill Brooks, Hannah Ehrli, and Joe Ehrli.

Bay Hill Golf Tournament

Mark Ehrli hosted his annual Bay Hill Golf Tournament in Orlando, Florida. Special thanks to Planet Hollywood and Premier Sotheby's International Realty for their help in making the day such a huge success! The event was sponsored by Wireless Zone and brought in more than $70,000.

SAVE THE DATE: NF SUMMIT 2022

July 21-24, 2022, Chicago, Illinois

In 2022 CTF will host a new all-inclusive conference called the **NF Summit**, which will merge the NF Forum and the Volunteer Leadership Conference, and bring together volunteers, organizers, researchers, clinicians, patient advocates, friends, and supporters who have a connection to NF.

Join us for education, empowerment, networking, and a way to connect with others on a similar journey. The atmosphere will be energetic, interactive, and enriching with customizable agendas and access to experts. No matter where you are along your NF journey, you will find content relevant to your individual situation.

Save the date for the first annual **NF Summit in 2022!** Watch for more information coming soon, or reach out to **info@ctf.org** with questions.

Connect2Fight Combats Bullying

October is Stop-Bullying Month, and to take a stand against bullying, the Children's Tumor Foundation's Connect2Fight program hosted a Minecraft Competition which focused on team-building, interactivity, creativity, and fundraising as a team.

Sixteen NF Heroes worked on teams of four in a bracket-style competition over three weeks, playing Minecraft and working together to build a structure while raising funds to end NF and spreading awareness about bullying.

We brought four content creators together, each with a team of four NF Heroes, to compete in a three-hour time period. Team Captain @PurpleVacktor_ led The Purple Pirates and challenged @RealJaneyLaney and her team The Best Seahorse Coalition in Round One. Round Two included @RedVacktor leading Team Red Force versus @MacNcheeseP1z and her team The Noodle Bowl.

Our judges scored teams based on teamwork, creativity, interactivity and fundraising. In the Final Round of the competition, Team Red Force (pictured) went head-to-head with Team Seahorse Coalition to build a Superhero Lair and the victor was Team Red Force. The event overall raised more than $7,500 to end NF and was hugely successful in spreading awareness about living with NF and the effects of bullying.

SHINE A LIGHT **NF** WALK

shinealightwalk.org

We were excited to see the majority of our Shine a Light NF Walks return to in-person events this fall and couldn't be happier to gather together once again. Shine a Light NF Walks continued to offer a virtual option for all sites by giving participants the opportunity to share their Walk-day experiences on our Facebook Event pages, allowing friends and extended family members around the country to create awareness and raise funds. With 26 Walks engaging more than 4,000 people and raising more than $1.3 million to fund NF research and patient programs, we have exceeded our national goal in 2021 and are still going! Thank you to all of our local volunteers, fundraisers, donors, and most importantly, the families who support their NF Heroes in ways big and small. Special thanks to AstraZeneca who was our National Luminary Sponsor.

Minnesota

We still feel the amazing energy and enthusiasm from all the families who participated in the Shine a Light NF Walk - Minnesota! As a new Walk, NF Heroes met one another for the first time and celebrated loudly, raising more than $48,000 – nearly double their fundraising goal. This community was ready to come together to end NF and we are so excited to welcome these 18 teams into the CTF family! We cannot wait to see how this event continues to grow in the coming years.

The Carolinas

The Carolinas came together in a big way to celebrate their first in-person Shine a Light NF Walk this fall. More than 200 people attended and the day was filled with new families meeting one another, sharing fun activities, and walking together to end NF. We were so thankful to have Honorary Chairs, Dr. Robert Greenwood from University of North Carolina and Dr. David VanMater from Duke University Medical Center, who were there to interact with patients and answer questions. Thanks to our organizer, Nicole Domazos, and her committee Tracy Galloway, McKinnon Galloway, and Maureen Hussey. With an original fundraising goal of $55,000, they have raised more than $124,000 and are still going strong!

New Jersey

More than 200 people gathered along the Seaside Heights Boardwalk on the Jersey Shore to celebrate the Shine a Light NF Walk in New Jersey. Many thanks to the tremendous Walk organizers, Jeanne Glodeck and Lara Mukabenov. This year's Walk broke all fundraising records and has raised $125,000 to date, more than doubling its $55,000 goal.

Kansas City

More than 260 walkers from Kansas to Missouri gathered on a beautiful sunny day in Kansas City and raised more than $45,000 for CTF. Their spirit and energy were infectious as returning families reunited with each other, and new families were able to meet others in the NF community for the first time. Many thanks to our Honorary Chair, Dr. Keely Fitzgerald from Children's Mercy Hospital, and a huge round of applause to organizer Hannah Duby for her tireless leadership and commitment to this Walk!

NF ENDURANCE

nfendurance.org

NF Hero
Dave Camiolo

His first race since 2019, Dave ran the Philadelphia Distance Run (13.1 miles) on September 19 and has run over a dozen half marathons plus the JFK 50-miler for the NF Endurance Team. For the last 17 years, he and his wife Kristin, along with several family members and friends, have run in honor of their daughters' mightiness! Dave and both of his daughters live with NF1.

He says, "I am running in honor of my daughters Genna and Rosie who have bravely lived with the effects of NF all of their lives, [who] inspire me every day with how strong they are and how they have valiantly faced all the challenges that NF has brought to their lives."

TD Five Boro Bike Tour

On August 29, NFE Athletes Jordan Siegel, Alex Tolpin, and Mike Laykind rolled through the streets of New York City at the 2021 TD Five Boro Bike Tour. Cycling 40 miles on car-free roads and five bridges, our NFE riders started in Manhattan, then toured the Bronx, Queens, and Brooklyn boroughs before finishing in Staten Island. What's more, they can't wait to ride again for CTF next year and raise more funds to end NF!

Virtual Facebook Challenge

More than 1,400 people accepted our Facebook Challenge and committed to "3,000 Squats in October." With support and encouragement from fellow participants throughout #Squatober, this incredible #SquatSquad raised more than $32,000.

Rock' n' Roll Virginia Beach

On September 5, Scott Radik ran the Rock'n'Roll Virginia Beach Half Marathon. Scott joined the NF Endurance Team in 2018 for his first marathon. He ran the Marine Corps Marathon in honor of his son Kole, who lives with NF1. Scott hung up his racing shoes for a few years, but after learning earlier this year that he too has NF1, he came out of racing retirement to run for CTF again. Scott has raised nearly $7,500 since 2018.

NF ENDURANCE TEAM SIGNATURE EVENT WEEKEND

Calling all NF Endurance Team members! The 2022 NFE TEAM Signature Event will be the 20th Annual Little Rock Marathon, Half, 10K & 5K, taking place on March 5-6, 2022. This will be a race weekend for all old and new NF Endurance Team members to come together and run NF out of town! Sign up at **nfendurance.org/littlerock**.

UPCOMING NF ENDURANCE EVENTS

Rock' n' Roll Las Vegas 5K, 10K & Half-Marathon
February 26-27, 2022

Little Rock Marathon, Half, 10K & 5K
NF ENDURANCE TEAM SIGNATURE EVENT
March 5-6, 2022

United Airlines NYC Half | *March 20, 2022*

TD Five Boro Bike Tour | *May 1, 2022*

BMW Berlin Marathon | *September 25, 2022*

Bank of America Chicago Marathon |
October 9, 2022

TCS New York City Marathon |
November 6, 2022

Choose Your Own Challenge - *Pick the adventure of your choice!*

For more information, go to nfendurance.org or email nfendurance@ctf.org

Make NF Visible Photo Contest Winner: **The Ride to End NF**

Extraordinary Spirit LaShannon Spencer (center) surrounded by her family (clockwise from upper left), husband Josh, son Brendon, daughter Cali Rae, and son NF Hero Owen.

Extraordinary Spirit / **LASHANNON SPENCER**

LaShannon Spencer's youngest child Owen was just over one year old when he was diagnosed with NF1. Though others were shocked by the diagnosis, LaShannon knew he had it. "I had already spent many nights curled up researching all of Owen's symptoms. NF came up nine times out of ten." In the five years since then, life has been the whirlwind of specialists, MRIs, and drug trials that NF parents know all too well. When Owen's genetic microdeletions were discovered, the Spencers were told to "just wait and see." LaShannon vividly remembers rejecting this directive. "You don't understand," she said to the doctor. "I need to know what we do NOW. You don't know me. I need a plan!"

Gregarious, warm, passionate, and outspoken, LaShannon soon realized she could channel these natural gifts into building awareness of NF. "I was given Owen because I'm loud and I can talk to anyone. That is my thing. My thing is raising awareness."

And so, the Ride to End NF was born. The first ride took place in 2017, shortly after Owen's diagnosis. About 20 motorcyclists – mostly family – gathered in the Spencer's small town of Mount Sterling, Kentucky, and rode a long loop through the area's beautiful natural scenery. They raised $1,500 the first year. The following year they did it again. And then again, with more riders joining each year.

Fast-forward to Summer 2021 and the Fifth-Annual Ride to End NF. Expecting a smaller turn-out due to COVID, the Spencer family was stunned as over 140 people rolled into town. "They just kept coming," says LaShannon. And it wasn't just the number of riders that shook her. The ride has become the big event in Mount Sterling, with everyone chipping in. Buildings are illuminated in green and blue; a local designer created this year's shirts; newspapers do write-ups; the mayor and governor issue proclamations; a local police officer with NF in his family leads the ride to help keep riders safe; local businesses make trophies, plaques, patches, and bandanas; a local baker donates cupcakes; and refreshments are provided by Kentucky's regional soda Ale-8 (the ginger-citrus soda is a personal favorite of Owen). And, of course, all the local motorcycle clubs keep it on their calendar. "From February until the day after the ride, it's constant chaos," says LaShannon. "Chaos in a good way."

On the day of the ride, everyone gathers at the family's church in Mount Sterling. There is a ceremonial "blessing of the bikes," the riders get the first card for their poker hand, and they roar off. LaShannon's father-in-law Daniel rides in front as Road Captain, a mighty "End NF" flag waving behind his bike. LaShannon rides on the back of her husband Josh's bike, snapping photos (one of which won this year's CTF Photo Contest). "We want people to see our shirts, patches, pins, flags, and look it up," says LaShannon. "How else do you raise awareness? Awareness raises funds to help CTF do the amazing things they do."

The riders follow Daniel to Natural Bridge State Park in the beautiful Red River Gorge, and after many planned stops along the way, finally reconvene at the Odd Fellows Lodge for BBQ, Ale-8, and cupcakes. Owen gets to present an award to his favorite motorcycle. Six years old now (and doing great), he is starting to remember faces from the ride, and to vaguely understand that this event has something to do with him.

Together, the 2020 and 2021 rides raised an amazing $11,000 towards the fight to end NF. "I am so thankful for this community of ours that continues to grow," muses LaShannon. "They're all our family now."

INFER Masterclasses

Recognizing that their first contact with a medical professional for many NF patients is their local doctor, the Children's Tumor Foundation Europe has developed INFER – International NF Educational Resources. These virtual classes deliver the best and most up-to-date NF expertise directly to all medical professionals who seek it. These workshops are part of an inaugural series of NF Masterclasses, led by the world's leading NF experts and presented to medical professionals across clinical and care disciplines. Each Masterclass will focus on a specific condition or manifestation affecting NF patients, presented in a medical format, connecting participants and NF experts on that particular topic. For example, the first Masterclass took place on October 6 and focused on NF1 cutaneous neurofibromas. This topic may be of specific interest to dermatologists in addition to general practitioners, medical school students, and more.

The Masterclasses occur online approximately once a month, each on a different topic, and include real-time interaction between the expert presenter and the participants. The presentations are in English, with real-time audio interpretation available in six additional languages: French, German, Italian, Portuguese, Spanish, and Russian. A recording of each INFER Masterclass is available online in each language for those who could not attend an event.

INFER is an initiative of Children's Tumor Foundation Europe, supported by an educational grant from AstraZeneca.

To learn more, register, or watch the Masterclasses videos in various languages, go to **ctfeurope.org/nfmasterclasses**.

MASTERCLASSES IN NF

A series of online educational lectures for medical professionals by leading neurofibromatosis experts

Reserve your spot today:
ctfeurope.org/nfmasterclasses

INFER is an initiative of Children's Tumor Foundation Europe, supported by an educational grant from AstraZeneca.

INFER
INTERNATIONAL NF EDUCATIONAL RESOURCES

NF News is the official publication of the Children's Tumor Foundation. All issues are available on our website at **www.ctf.org**. Please direct any questions or feedback to info@ctf.org.

The Children's Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to funding and driving innovative research that will result in effective treatments for the millions of people worldwide living with neurofibromatosis (NF), a term for three distinct disorders: NF1, NF2, and schwannomatosis. NF causes tumors to grow on nerves throughout the body and may lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and cancer. NF affects 1 in every 3,000 births across all populations equally. There is no cure yet – but the Children's Tumor Foundation mission of driving research, expanding knowledge, and advancing care for the NF community fosters our vision of one day ending NF. For more information, please visit www.ctf.org.

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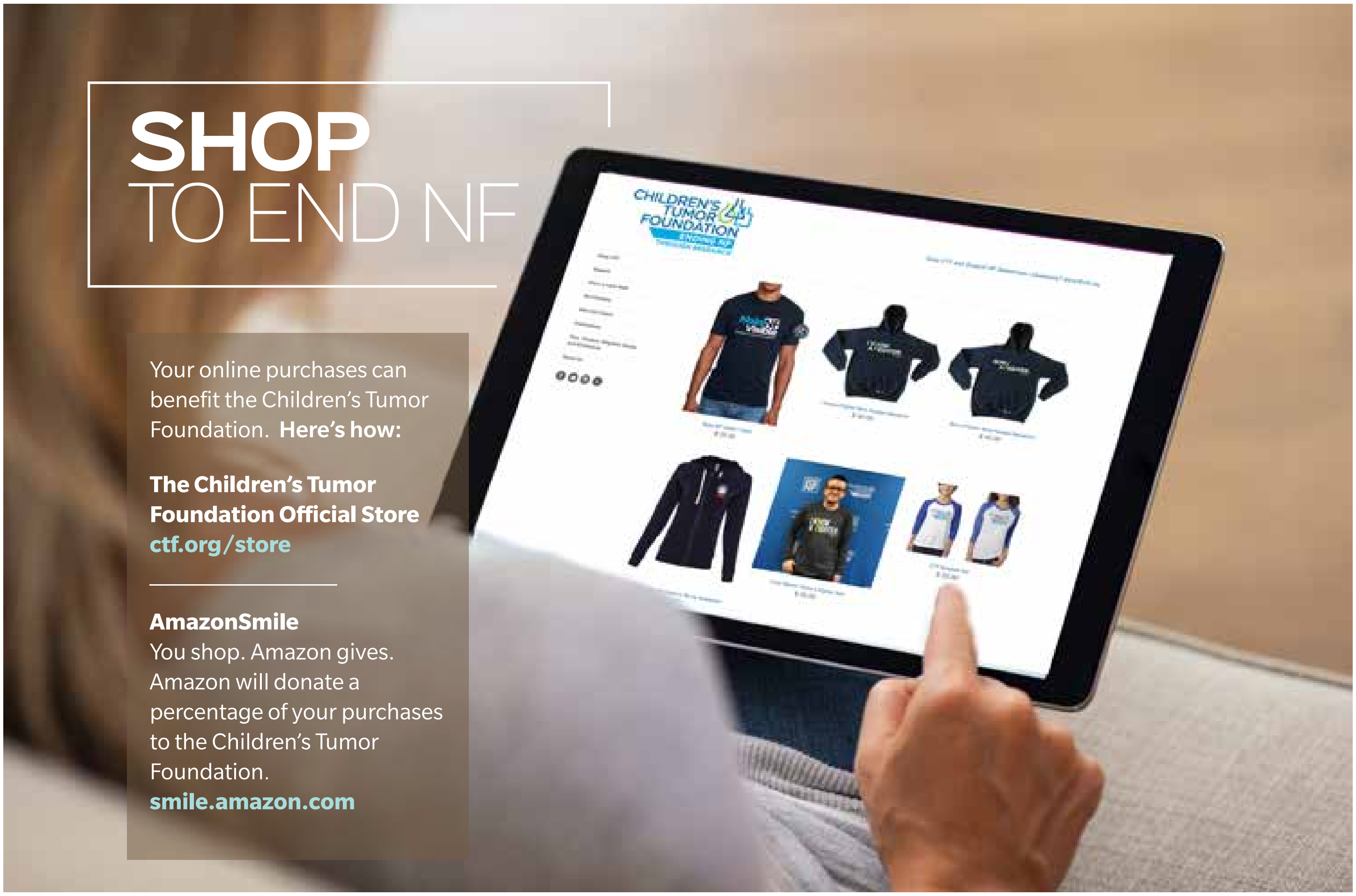

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