

NF NEWS

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION
WINTER 2018

Fall Fundraising Festivities:

\$1.6 Million Raised at the Ruby Anniversary Gala

Children's Tumor Foundation (CTF) supporters gathered for festive fundraising events and galas across the country in celebration of the Foundation's 40th anniversary year.

\$1.6 million dollars was raised for NF Research at the Ruby Anniversary Gala in New York City on October 22. At this beautiful evening full of inspiration and celebration, McKinnon Galloway from Charlotte, North Carolina was named CTF's 2019 National NF Ambassador. McKinnon was diagnosed with NF2 at age 16, and has lived the last 10 years of her NF journey showing only her brave face, while hiding the brutal reality of her condition from most. She hopes that her decision to tell the world about her experience living with NF2 will be a source of encouragement and comfort to others. As ambassador, she plans to spend the next year sharing her story in order to raise funds and awareness, while educating the greater community to help find a cure.

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**2019 NF Ambassador
McKinnon Galloway at
CTF's Ruby Anniversary Gala**

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FROM the President

Annette Bakker, PhD



As the 40th anniversary year of the Children's Tumor Foundation (CTF) comes to a close, I am deeply grateful to the individuals who established and then grew this meaningful organization over the years. This Foundation has momentarily impacted the NF research landscape, and has improved the lives of all those living with neurofibromatosis (NF).

In November, after an enormously successful gathering of more than 850 researchers and clinicians at the Joint Global NF Conference in Paris, I found myself reflecting upon the events of that important week. While this newsletter must go to print before we are able to fully recap

and explain the incredible advancements that were shared, what you should know is that we are on the brink of something really fantastic. We are closer than ever to the potential for approved treatments for NF, and we are not giving up.

And this is because of the devotion of you, our supporters and partners, who for 40 years have backed the most significant and promising research into neurofibromatosis. I am so full of pride to represent such a wonderful group of patients and families, and a group of experts so enthusiastic about serving them.

At our Ruby Anniversary Gala in New York City, our incoming NF Ambassador, McKinnon Galloway, spoke so passionately about her journey with NF2. She said, "I am fully aware of what I'm up against, but instead of discouraging me, it has given me my biggest strength. . . . My family and I were motivated to get involved with the Children's Tumor Foundation to support its mission and end NF."

That is the kind of dedication and commitment that has made this Foundation what it is today. The words from two of CTF's founders, Joel Hirschtritt, Esq. and Allan Rubenstein, MD, were equally as inspiring. Our illustrious honorees that evening were Carol Harrison Kalagher, philanthropist

and funder of Synodos for NF2, and Francis S. Collins, MD, PhD, the Director of the National Institutes of Health, whose far-reaching work has changed the course of NF research, and hugely contributed to the wealth of research into rare disease.

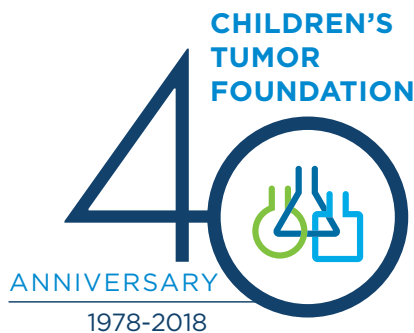
Finally, as you will read in these pages, I am thrilled to share the announcement of the new Children's Tumor Foundation Europe. We kicked off this new initiative in Brussels following the NF Conference. By further expanding our partnership with our colleagues across the ocean, we are preparing to build a larger, stronger global community that will drive research forward at an unprecedented rate.

All of this is thanks to you. It is because we join together as a united front of researchers, volunteers, parents, donors, fundraisers, and patients that we will fulfill our mission, committed to end NF.

Gratefully Yours,

Annette Bakker, PhD
President, Children's Tumor Foundation

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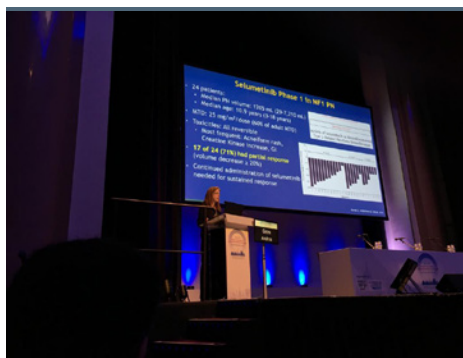
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2018 NF Conference Held in Paris

The Children’s Tumor Foundation’s annual NF Conference took place in Paris from November 2-6 as the Joint Global NF Conference, in partnership with the European NF Group and supported by Association Neurofibromatoses et Recklinghausen. With more than 850 NF researchers and clinicians across a wide range of scientific disciplines attending from around the world, it was the largest NF meeting in history. Experts gathered to share the latest in NF research, to meet and collaborate with colleagues, and to advance NF research. As this newsletter is going to print just as the Conference is reaching its conclusion, detailed Conference updates will be available in a special NF Conference digital newsletter this January at ctf.org.

Below are some highlights of the five-day Paris meeting:

- The NF Conference kicked off with an energetic pre-conference session on the important topic of cutaneous neurofibromas. Sponsored by NTAP (Neurofibromatosis Therapeutic Acceleration Program), REiNS (Response Evaluation in Neurofibromatosis and Schwannomatosis) and the Children’s Tumor Foundation, the packed auditorium had a lively discussion which included input from the patient perspective, and researcher updates on basic science, animal models, and clinical trials.
- Day Two in Paris began with a tremendous presentation by Andrea Gross, MD of the National Institutes of Health (NIH), on the ongoing success of the MEK inhibitor clinical trial. In an illustration of how science has impact on real lives, she relayed the example of an NF patient who prior to the clinical trial could barely lift his arms over his head, but now is joyously able to do so.
- Keynotes on the second day were focused



on “Epigenetics: One Genome, Multiple Phenotypes”; “Schwann Cell Biology”; schwann cells and neurofibromas; surgery in NF; and the psychosocial impact of NF.

- Day Three highlights included sessions on “NF2 and Schwannomatosis: State of the Art”; “Genotype/Phenotype in NF1”; “Glioma: In/Out of NF”; “Functional Genetics and Classification of Variants”; “Learning Disabilities”; “MPNST”; “Mutations in Other Cancers” and a session hosted by AstraZeneca called “Are we MEKing Progress?”
- NF Ambassador McKinnon Galloway opened the NF2 session with a passionate speech that stressed the importance of bringing together patients, families, caregivers, researchers, clinicians, doctors, and pharmaceutical companies to make sure we move as fast as possible to end NF.
- The dynamic pace of the Global NF Conference continued unabated on Day Four, with big news for NF2: the therapeutic brigatinib is showing progress in animal model testing, and will continue to be analyzed as a potential option for NF2 patients. This promising candidate is a direct result of CTF’s Synodos for NF2 collaborative that brought together ‘dream teams’ from 12 academic centers to openly



work together and share data. This further proves the Synodos concept, and is very exciting news.

- The Conference closed with a memorable series of presentations called “NF: past, present, and future”, which looked at how the field has grown from a handful of scientists to where it is today, with the potential of approved treatments for NF on the horizon.
- Other important topics focused on pain, as well as gene therapy options for NF.
- Ludwine Messiaen, PhD was honored with CTF’s von Recklinghausen award for her extraordinary contributions to NF research.

The common thread among all these advancements is that they were initially funded and made possible by your support of the Children’s Tumor Foundation. From the NF Preclinical Consortium that led to the promise of MEK, to Synodos for NF2 leading to a potential new drug candidate, to proving phenotypes may correlate to genotypes – all are essential in our quest to end NF.

Watch for full coverage of these research updates in a special NF Conference digital newsletter this January at ctf.org



NF ANIMAL MODEL WORKSHOP

On October 4-5, 2018 the Children's Tumor Foundation hosted the second Neurofibromatosis Animal Model Workshop in Palm Springs, California. More than 20 animal models were presented at the United States and Canadian Academy of Pathology (USCAP) learning center. Pathology slices of murine lesions were carefully evaluated by a group of 10 pathologists to create a single, universal pathological classification. Since our research community has developed a number of models that recapitulate many aspects of NF1, NF2, and schwannomatosis, it was necessary to classify those models based on their histopathological features by expert pathologists. This was important for the validation of the models, for their analysis and comparison with other models, and for their future effective use in preclinical treatment trials.

The first NF animal model workshop was held by the National Neurofibromatosis Foundation in Boston in 2003, and since then many NF models have been created with the aid of new technology. Also for the first time, two pig models of NF1 (created with funding from CTF's Synodos NF1 program) were reviewed.



More NF Clinics, but Patients Still Travel Far for Care

Since 2008, efforts to expand access to specialized NF care through CTF's NF Clinic Network (NFCN) led to a 56% increase in the number of NFCN clinics and a 51% increase in the number of patients they serve. Yet people with NF still travel long distances to reach a NFCN clinic, according to a study led by Vanessa Merker, Annie Dai, and Scott Plotkin of Massachusetts General Hospital recently published in the journal *BMC Health Service Research*. The study examined anonymized data from two CTF-sponsored programs, the NF Registry and the NF Clinic Network, and showed that while the number of NFCN clinics providing comprehensive care has grown, many NF patients do not attend specialty clinics and/or travel a significant distance for care.

The study found that only 43% of people in the NF Registry reported receiving care in a NFCN clinic, with especially low rates of NFCN clinic attendance in the Southwest and Far West. This points to a health care disparity that may put people

at risk. Lack of appropriate disease-specific care may contribute to delays and inaccuracies in diagnosis and treatment, which can cause a substantial burden to people with NF.

“ The NF clinic network is an exceptional resource, particularly for families who don't live near a large NF center or who don't know where to go for excellent care. ”

— NICOLE ULLRICH, MD, PHD

To address this need, CTF seeks to expand the number of NFCN clinics. We recently welcomed the RASopathy & Neurofibromatosis Clinic at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware. This clinic is led by directors Karen Gripp, MD, geneticist, and Gurcharanjeet Kaur, MD, neurologist, with clinic coordinator Laura Baker, LCGC.

ANNOUNCING THE LAUNCH OF CHILDREN'S TUMOR FOUNDATION EUROPE

The Children's Tumor Foundation is proud to announce the formation of the new European-based medical research NGO, called Children's Tumor Foundation Europe. The United States based organization, with headquarters in New York City, was founded in 1978 and is the largest non-governmental funder and catalyzer of neurofibromatosis research in the world, with its mission

benefited from CTF support. This new organization will further strengthen bonds between experts and research opportunities worldwide, in line with CTF's emphasis on open collaboration and open data.

Additionally, as a research catalyzer, CTF organizes the largest international NF meeting in the world. With this being the Foundation's 40th anniversary year, CTF partnered with European NF groups to organize the 2018 Joint Global NF conference in



to drive research, expand knowledge, and advance care for the NF community. CTF Europe will serve as a partner organization to CTF in the United States.

NF affects 1 in 3,000 births and impacts all populations, genders, and ethnicities equally, meaning that NF affects approximately 125,000 Americans and 250,000 Europeans.

Throughout its history, CTF has funded the best and most promising research globally, regardless of location, and as a result many European laboratories and clinicians have

Paris this November, with over 850 experts in attendance, the largest gathering in NF history.

The Children's Tumor Foundation is also an associated partner of the Innovative Medicines Initiative (IMI), as well as the NF package lead for the IMI Integrated Research Platforms call focused on the design of innovative clinical trials. This call's focus on NF is serving as a test case for other rare diseases as well.

While there is no cure yet for NF, Children's Tumor Foundation research is making great progress, including



encouraging clinical trial results for selumetinib, which recently received orphan drug status from both the European Medicines Agency and the U.S. Food and Drug Administration, and may possibly become the first approved drug for NF.

The focus of Children's Tumor Foundation Europe will be to further build out relationships with European agencies and partners, including EFPIA (European Federation of Pharmaceutical Industries and Associations), while maintaining its commitment to funding and driving innovative research worldwide that will result in effective treatments for NF.

The Foundation envisions a day when NF patients can live their lives free of the pain and difficulties that come with NF, and that day is on the horizon

because of its innovative team-based approach, and its nonprofit-enabling platform aimed at accelerating research and development. CTF aims to advance cures not only for NF but expand their approach to other rare disease areas as well.

The Children's Tumor Foundation hosted the inaugural launch event for Children's Tumor Foundation Europe on November 9, 2018 at the Musical Instruments Museum in Brussels. Magda Chlebus, Executive Director, Science Policy and Regulatory Affairs, European Federation of Pharmaceutical Industries and Associations (EFPIA) was the keynote speaker.

To learn more about Children's Tumor Foundation Europe, please go to ctf.org/europe.



Fall Fundraising Festivities

[continued from cover]



The Ruby Anniversary Gala took place at the American Museum of Natural History.



From left: Allan Rubenstein, MD; Francis S. Collins, MD, PhD; McKinnon Galloway; Annette Bakker, PhD; Carol Harrison Kalagher; Joel Hirschtritt, Esq.; and Rick Horvitz.

This honor was passed down to McKinnon from last year's Ambassadors, **Olyvia and Frankie Moriguchi**. These two courageous young siblings have a long history with CTF and an incredible bond as a family triumphantly living with NF.

Held at the historic American Museum of Natural History in New York City, the Ruby Anniversary Gala paid homage to the origins of the Children's Tumor Foundation. Forty years ago, a small group of committed individuals joined together to build an organization dedicated to the search for treatments and a cure for a then little-known disorder called neurofibromatosis, or NF. That group – an NF patient named Lynne Ann Courtemanche, her physician Allan Rubenstein, and the attorney Joel Hirschtritt – established the National Neurofibromatosis Foundation, now known as the Children's Tumor Foundation.

The Foundation presented **Humanitarian Awards** to two individuals for their active participation with the Foundation. The first award was presented to **Carol Harrison Kalagher**, a philanthropist from Fort Lauderdale, Florida. Carol is a primary benefactor of CTF's Synodos for NF2 project, and an NF advocate. Inspired by her grandson Hunter, and focused on helping all who live with NF, Ms. Kalagher's vision to provide funding for the Foundation's Synodos for NF2 team science initiative has resulted in promising treatment candidates for those living with NF2.

Francis S. Collins, MD, PhD, Director of the National Institutes of Health (NIH) was also presented with a CTF Humanitarian Award. Dr. Collins is a renowned physician-geneticist noted for his landmark discoveries of disease genes – including the NF gene – and for his leadership of the Human Genome Project.

Correspondent and NBC host **Raina Seitel** served as Master of Cer-

emonies at the Ruby Anniversary Gala. For the second year in a row, she illuminated the evening with her warmth and humor.

In Detroit, the sixth annual **Detroit beNeFit** was "A Soaring Soiree to End NF," held downtown at the Cobo Center on November 17. Esteemed CTF patrons Jennifer and Dan Gilbert were once again the hosts of this not-to-be-missed evening, which was well attended by many leaders and celebrities in the Detroit community, and benefits NF Forward and the Children's Tumor Foundation.

The hugely successful Detroit beNeFit is a highlight of the year. As this newsletter went to print prior to the event, please visit **ctf.org** and our social media pages to learn more about this event's inspiring honorees and distinguished attendees.

In Cleveland, Quicken Loans Arena turned into the 'School for Witchcraft and Wizardry' on Tuesday, October 9 for a very special group of kids. Forty pediatric cancer survivors were the stars of the night when the Cleveland Cavaliers hosted the 10th annual **Big Shots and Little Stars** fundraiser, to benefit Flashes of Hope and the Children's Tumor Foundation. The highlight of the evening was watching the kids walk the runway escorted by Cavs basketball players as well as Cleveland area business and civic leaders in a fashion show.

The event is supported by more than 1,200 business and community leaders and raises money for childhood cancer research. Flashes of Hope is a volunteer-driven organization focused on children's cancer, which was founded by Kip and Allison Clarke. Thanks to Big Shots and Little Stars, a donation will be made to the Children's Tumor Foundation.

In Arkansas, the annual **Dancing With Our Stars** event was held on September 6 and raised \$220,000 for NF research. Local celebri-



Ellen Williams performs a swing dance with her partner Stephen Stone at Dancing With Our Stars. (Photo courtesy David Lewis)



Ben Browdy, Rachel Healey, Deborah Robbins Estabrook, and Richard Estabrook at the New England Gala.



The 2018 Dancing with Our Stars competitors, from the left, Aaron Perkins, Dr. Anne Trussell, Michelle DuVall, Nick Brown, Ellen Williams, and Dr. Ali Krisht. (Photo courtesy Carper Photography)



At the "Big Shots and Little Stars" benefit, the fashion show is the highlight of the evening.

ties showed off their dance moves as they competed for the coveted mirror-ball trophy. Months of rehearsals with local dance instructors culminated in a one-time performance with the purpose of raising money to fund critical NF research, supporting local NF clinics, and sending Arkansas teens to NF Camp.

The 2018 Mirror Ball Champion is Dr. Anne Trussell, owner of Sei Bella Med Spa, and the 2018 Best Performance trophy went to philanthropist Ellen Williams.

For the second year in a row, competitors were partnered with local NF Heroes who visited during dance lessons, provided encouragement and cheered from the sidelines during each performance. The Stars had a great time getting to know their NF Heroes and our heroes' families received a great sense of hope that together, we are making a difference in the fight against NF.

Thanks to Lesley Oslica and the event committee for their continuing work on this wonderful event, which has raised more than \$1.2 million in its 11-year history.

The **New England Gala** continued the celebration of the Foundation's 40th Anniversary, and honored those that were an active part of the Massachusetts Chapter's 40-year history. Those recognized included past chapter presidents, national board members, and those who were instrumental in helping build the chapter through advocacy, patient support, and fundraising to assist the early research efforts of the National Office. Thank you to all those early pioneers of the New England region that came out and celebrated at the Boston Marriott Newton, and raised \$94,000 for NF research.

The Children's Tumor Foundation humbly extends our gratitude to the attendees, donors, honorees, and organizers of all of these fantastic fall fundraising events.

DOUBLE YOUR IMPACT TO END NF: Your gift today will be matched dollar for dollar!

Dear Friend,

I have known that I have neurofibromatosis, or NF, for as long as I can remember. I was diagnosed as a baby at a time when even doctors knew very little about this disease. With no knowledge about what the future could hold, my family searched for answers, where few were to be found.

My parents got involved with the National Neurofibromatosis Foundation, now called the Children's Tumor Foundation, not long after it was founded in 1978. My mother, Joan Engel, served as the Foundation's president from 1981-1984. As a child growing up, I had the benefit of this Foundation, and the knowledge, research, and community that it brought to my family. Now I have the privilege to serve the Foundation on its Board of Directors.

In an early Foundation newsletter, published in 1982, not long after I turned thirteen, **I wrote the letter to the right to encourage people to give to the Foundation**, and join my parents and me in our search for a cure for NF. And I am writing to you today to ask that you join me in giving now. **An anonymous donor has generously offered to match your gift dollar for dollar, from now until year-end, up to \$400,000.**

Living with NF was never easy, and as a child the challenges were particularly palpable. I was born missing the tibia in my left leg, and that leg was amputated when I was two years old. I broke my arm when I was six, and it never healed properly, leaving me in an orthotic since then. As a young child, what is now a large plexiform neurofibroma started to grow on my face, and it continued to grow throughout adolescence and young adulthood, causing me to appear significantly disfigured. I, like many others with NF, have other manifestations as well.

Today, those living with neurofibromatosis still need many answers, as they must watch and wait to see what course this disease will take. But our options are far better! Thanks to the Children's Tumor Foundation, we now have NF Clinics, informed doctors, a vibrant community of NF families, promising treatments in the clinical pipeline, and FDA-approved drugs on the horizon.



Dear kids,
I'd like to let you know about a thing I did recently. I am the son of the foundation's president. But that is irrelevant. Earlier this year I had my Bar-Mitzvah. I gave a portion of the money I received in presents to the N.F. foundation. I urge you to do the same, even if it is only a small amount of money. Research needs to be done to help those with N.F., and those who are unborn, who, when they are born will have it. I myself have N.F. but that is not the only reason I am giving money, the other reasons are those I've listed above.
For those of you who don't feel you know enough about N.F., or why you should give money, ask your parents. If they don't give you a satisfactory explanation, write the foundation. (The address is on the top of this news letter.) Again, I urge you to give.



Thank you sincerely,
Henry Rudd

This year we celebrate the Foundation's 40-year history as a beacon of hope for over 2.5 million people worldwide who live with NF. Because of your support and participation, today we are leading the way in the fight to find treatments and an end to NF.

For over 40 years, thanks to the generosity and hard work of donors and supporters like you, we have seen incredible advances in NF research, and tremendous growth in our Foundation's programs for NF patients. From the Foundation's acceleration of drug discovery methods, to work on cutting-edge gene editing, Children's Tumor Foundation researchers are building a path to effective treatments. Our collaborative "Synodos" team-science projects, openly shared NF data, the NF patient registry, and new animal models—all essential for NF research—are realities because of your support.

Additionally, a clinical trial for the MEK inhibitor selumetinib has resulted in over 70% of patients seeing tumor shrinkage from 20-53%. This is a time of great optimism for NF treatments—tumors are shrinking in clinical trials, and we are closer than ever to the first FDA-approved drug for NF!

Our work is not done. Much has been accomplished, but we urgently need your help to make treatments and a cure a reality for all who live with NF.

This early Foundation newsletter was printed in 1982 and includes a message from the President of the Foundation and Ken's mother, Joan Engel.

Please join us in our fight to end NF. **YOUR GIFT TODAY WILL BE MATCHED DOLLAR FOR DOLLAR** by an anonymous donor, from now until year-end, up to \$400,000. Please mail a check in the enclosed envelope or give online at www.ctf.org/match2018.

With Gratitude,



Ken Rudd

Member, Children's Tumor Foundation Board of Directors



"Only 2% of the charities we rate have received at least 9 consecutive 4-star evaluations, indicating that the Children's Tumor Foundation outperforms most other charities in America. This 'exceptional' designation from Charity Navigator differentiates Children's Tumor Foundation from its peers and demonstrates to the public it is worthy of their trust."

— MICHAEL THATCHER
Charity Navigator President and CEO



IN MEMORY
Ken's mother, Joan Engel, sadly passed away earlier this year. In April, she and Ken celebrated the Foundation's 40th anniversary together.



Ashlynn Wauchope

I first learned about my diagnosis in December 2017, after weeks of doctor's appointments, travelling to the hospital, and finally seeing a specialist. When I was rushed

I went through a stage where I couldn't accept who I was, and I became very antisocial - I cried all the time and stayed at home. After that year of hardship, I began to accept who I am,



knowing I have friends who love and support me. I know that I have lifelong friends who understand.

I enjoy doing hippotherapy (physiotherapy on horseback) and in general, I like riding my horse,

to the hospital in 2016, I had developed drop foot, and my hand had clawed into a fist. Although I didn't want to acknowledge it, I lost peripheral sight in my left eye. Multiple tests were done, and they finally found the cause - I was diagnosed with NF2. To find out that I had developed a benign brain tumor the size of a mandarin orange was a huge shock. I thought, "Wow, that's something!" Then to find out that I needed to have major brain surgery was the worst thing someone with severe anxiety, like me, could hear. When I had my surgery, they not only had to cut through my head, but they had to cut into my brain as well. I had only a ten percent chance of surviving. I came through, and I'm here now!

Although I have long-term special needs, I've learned to deal with them. Now I need to wear an AFO (Ankle Foot Orthosis) brace all the time, and a back brace for certain things. The first year after my diagnosis

River. I enjoy writing, I write ten pages a day on a biography about myself. I enjoy drawing, painting, and anything artistic. My motto is:

"Survive and thrive, don't victimize and cry, turn the page."

Gabriel Forestiere

My son was diagnosed with NF1 at 2 months of age after we noticed several café au lait spots. Upon genetic testing, the NF1 diagnosis was confirmed. Gabriel struggles on a daily basis with learning his ABCs and numbers as he is now in kindergarten. He has also been diagnosed with Autism and ADHD. Despite these medical problems, Gabriel has a happy, bubbly personality and always has a smile on his face. He always tells his parents and his 2-year-old sister, "I love you to the moon and back..." Gabriel loves to travel and is obsessed with trains. To combine his two passions, we took him to Edaville Family Amusement Park just outside



of Boston, to visit Thomas the Train theme park in July. Despite the hot and humid weather, Gabriel had a blast! Gabriel also loves going to Disneyland, and his most recent travel was to Argentina to visit my family.

- Roxanne Forestiere, Gabriel's mom

NF

Q&A

Q: When and how is NF2 diagnosed?

A: Neurofibromatosis type 2, or NF2, affects approximately 1 in 25,000 people. Currently there are an estimated 10,000 people living with NF2 in the United States, so while a diagnosis can feel very overwhelming, it is important to remember that you are not alone.

NF2 is generally diagnosed in early adulthood, though not always. For example, juvenile cataracts in childhood can be an early indicator of NF2, and are usually treatable. The hallmark sign of NF2 is the development of benign tumors, called vestibular schwannomas, on the

nerve which carries both sound and balance information from the ear to the brain. The most common early symptoms of NF2 are tinnitus (ringing in the ears), gradual hearing loss, and balance problems.

Q: Is there a blood test for NF2?

A: Genetic testing for NF2 is available. However, the inheritance pattern (how NF2 is passed from parent to child) is complicated by mosaicism, which makes testing more difficult. For the most part, genetic testing cannot predict the way NF2 will affect your health, but this is an area into which research is being focused. Currently, genetic results are used most often for testing other family members or for making reproductive decisions.

If you have a question about any type of NF, contact Kate Kelts, CTF's Patient Support Coordinator, at kkelts@ctf.org.

Extraordinary Spirit / JACK BURKE

At 13 years old, Jack Burke has already made a tremendous impact on neurofibromatosis research.

Diagnosed at two years old due to café au-lait spots and vision difficulties, it was later discovered that Jack also had a plexiform neurofibroma on his left eye orbit. In the 11 years since his diagnosis, Jack has inspired thousands of people to join him in the fight to end NF and helped raise over \$1 million toward research benefiting others living with neurofibromatosis.

In an effort to channel their anxiety and helplessness into something positive, Jack's parents Jake and Beth Burke started CureNFwithJack, and focused on building the NF community and raising funds for research. They host many fundraisers in multiple cities, including golf tournaments in Washington, DC and Atlanta. CureNFwithJack surprised the Foundation with a generous \$190,000 donation (which was \$40,000 more than expected, in honor of our 40th anniversary) to support NF research and help the Foundation continue to fund innovative research that is helping kids just like Jack.

Jack exemplifies the spirit of our NF Heroes. Having bravely faced a long NF fight, including a number of surgeries, he is tough in the face of adversity, tenacious in his medical journey, and compassionate towards others facing difficulties. He and his siblings, Luke and Grace, who are in this fight right beside him, possess a strong desire to use Jack's story and his voice to help others.



SHOP to End NF

This holiday season (and all year round), your online purchases can benefit the Children's Tumor Foundation.

Here's how:

The Children's Tumor Foundation Official Store

Whether it's an End NF T-Shirt or a Children's Tumor Foundation baseball cap, you'll look great and spread awareness. Buy for your friends as well! ctf.org/store

Ralphs You can support the Children's Tumor Foundation with your Ralphs Supermarket Rewards Card! A percentage of your purchase will go to help end NF.

ralphs.com

AmazonSmile You shop. Amazon gives. Amazon will donate a percentage of your purchases to Children's Tumor Foundation. smile.amazon.com



Regional NEWS

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

FLORIDA

The 26th annual Children's Tumor Foundation Golf Scramble was attended by 120 golfers on October 8 at Arnold Palmer's Bay Hill Golf and Lodge, home of the PGA tour event, The Arnold Palmer Invitational. For the past 19 years, this event has been hosted by the Ehrl family in honor of their son Joe, who lives with NF1. Joe is now an Eagle Scout and currently a senior at the University of Central Florida. With the sponsorship help of Wireless Zone Foundation for Giving, the Ehrl's have raised nearly \$550,000 since the event began. Brian Murtari, President of the Wireless Zone for Giving, and Dave Staszewski, Executive Vice President of the Wireless Zone, presented CTF with a check for an additional \$25,000 to sponsor next year's event.



COLORADO



Iron Butt

Every summer, over a dozen motorcycle riders trek hundreds of miles across the country to raise awareness and funds for the Children's Tumor Foundation. The idea for Iron Butt 4 NF, a marathon motorcycle ride, surfaced shortly after young NF Hero Tyler Neppi started a voluntary chemo treatment encompassing 52 weeks, one session of chemo per week. Tyler's strength and will to fight is what inspired this challenging ride to show support and love for him while raising awareness about neurofibromatosis. Greg Davis, the founder and one of the first Iron Butt riders, said of the event, "It's special for all of us, something we won't miss!"

COLORADO

End NF with Ian Desmond

Colorado Rockies baseball player Ian Desmond has been generously spending time with NF patients and families at dozens of stadiums around the country. Beginning in April, when he met with 30 NF patients at Nationals Stadium in Washington DC, and continuing through August, when he met with over 25 NF patients at Angels Stadium in California, Ian has given of his time to bring joy to NF families. When he was unable to meet the families attending games, he often sent a token or a video to say hello and let them know he was sorry to miss them. This incredible generosity of spirit is in keeping with Ian's longtime support and commitment to the Children's Tumor Foundation.



PENNSYLVANIA

Tekking 101 Charity Live Stream

YouTuber Matt Crawford, also known as Tekking 101, hosted a Charity Live Stream event on his YouTube Channel, where he has amassed a following of over 300,000 subscribers. One of those subscribers, NF1 patient Aidan Fraser, made the suggestion to include the Children's Tumor Foundation as the benefiting charity. Matt included several guests in the live stream, including Aidan, who talked about his NF journey. Matt went live for over eight hours and raised more than \$7,000 for NF research. We are also very proud to have Aidan interning out of our New York office this year.





San Antonio NF Walk

More than \$38,000 was raised at this year's San Antonio NF Walk on Saturday, October 13. For the third year in a row, Mary Margaret Mellen, the 14-year-old founder of Cakes For A Cure, was recognized as the Walk's Top Fundraiser, bringing in \$1,200 for this year's event. She has raised over \$3,000 for CTF since she started Cakes For A Cure.

Inspired by her cousins who live with NF, Mary Margaret takes cake orders for any occasion and bakes a custom cake for the recipient. She only asks that a donation be made to one of the four charities whose work is important to her, including the Children's Tumor Foundation. Her goals are to raise awareness, contribute financially, and inspire others to be charitable in creative ways. Incredible job, Mary Margaret! Thank you for your dedication and your support of the Children's Tumor Foundation!



SAN JOSE NF WALK

On June 23, 150 people attended the San Jose NF Walk at Vasona Lake County Park in Los Gatos, California. The event raised more than \$16,000 and was a fun morning filled with face painting, Star Wars characters, a kid's dash, and a community of friends, families, and supporters coming together for a wonderful cause.

Los Angeles NF Walk



On October 20, more than 700 people gathered at the CBS Studio Center in Studio City, California for the annual LA Glow Walk. This year, a timed 5K run was added to the festivities, with over 90 runners participating. The event raised more than \$50,000 and featured Star Wars characters, a "Thriller" flash mob, a soccer kick-off, and a kid's carnival. NF families and friends were able to connect with each other and celebrate the many NF Heroes participating that day.

Seattle NF Walk

More than 250 people gathered at Point Defiance Park in Washington State on September 29 for a fun-filled morning of face painting, a kids dash, karaoke, and much more. The community joined together to raise more than \$104,000, making it one of the biggest walks in the country. NF Hero Ryder Gordon was honored at the event. Thank you to Christa Castanon and Michele McMillin and their fabulous committee for putting together such a heartfelt morning of activities.



Tour de Peaks

On September 22, two longtime NF Endurance alumni, Kirstin and Brendon Lynch, participated in the Tour de Peaks road bike event, representing the Children's Tumor Foundation. They fundraised for CTF in honor of their son Hayden, who lives with NF.

The road has not been easy recently

for the Lynch family. Hayden continues to have endocrine complications, an eating disorder, fatigue, concentration difficulties, weakness, and significant learning disabilities that make high school very challenging. Additionally, Hayden's father Brendon was recently diagnosed with stage four melanoma. He has undergone several grueling treatment regimes, with many debilitating side effects. But currently he is tolerating targeted chemotherapy and keeping the disease progression at bay. Thank you Lynch Family, for your courage and perseverance in the face of so much adversity, and for taking action in the fight to end NF.



NFE Alumni Compete Around the Country

Throughout the last weekend of September, NFE alumni were competing in triathlons all over the country. Seth Habberfield is now a three-time IRONMAN after crossing the finish line in Maryland. Katy Wakin dusted off her bike for her Olympic Triathlon in Texas, and IRONMAN Kona finisher Mitch Zelman completed the Escape to Miami Triathlon while partnering with Special Compass. Congratulations to these incredible champions!



Bank of America Chicago Marathon

Congratulations to athlete Yulian Menyaev who completed his sixth marathon major at the Bank of America Chicago Marathon while running for CTF's NF Endurance team. Yulian's six marathon majors include London, Berlin, Boston, Tokyo, Chicago, and New York. What a remarkable accomplishment, Yulian! Thank you so much for representing CTF on such a monumental day.



Little Heroes 5K of Oklahoma City

On September 29, over 90 runners participated in the Little Heroes 5K of Oklahoma City event in Newcastle, Oklahoma. It was a fun, family-friendly day that included a 5K race and a 1-mile Hero Dash for the kids. Race director Susan Bennett spearheaded the event, which raised \$10,000 for the Children's Tumor Foundation. Susan has been organizing this event for many years in honor of her son Alex, who lives with NF.





LEAVE A LEGACY...BE A LEGACY

THE NF LEGACY SOCIETY

The NF Legacy Society consists of individuals who have taken the extra initiative to ensure the future of NF research, by including the Children's Tumor Foundation as a beneficiary in their will or trust, retirement account, or life insurance policy.

Make no mistake about it—the progress that has been made in the fight against NF is because of people like you, who are working to improve the lives of those with NF. It is a legacy of which you can be proud.

To learn more about making a planned gift, please reach out to
Melissa Sosa-Longo,
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NF News is the official publication of the Children's Tumor Foundation. All issues are available on our website at www.ctf.org. Please direct any questions or feedback to info@ctf.org.

The Children's Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to 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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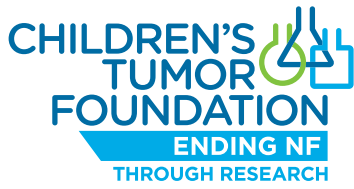
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