NF NEWS
THE NEWSLETTER OF THE CHILDREN'S TUMOR FOUNDATION
SPRING 2025

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

NF Awareness Month: Take Action

It's NF Awareness Month
Let's Unlock Progress Together

From fueling life-changing research to lighting up landmarks, your actions this May can make a real impact. Join the movement, show your colors, and take bold steps toward a future without NF. Every effort counts—**and you are the key!**

INSIDE:

"Within 48 hours of my first dose, I felt free—like I was weightless, and my pain couldn't stop me."

— Kendall Reeve, age 14

Read more about Kendall and her journey with NF on page 9.

FROM the CEO

Annette Bakker, PhD

At the Children's Tumor Foundation (CTF), we are driven by one powerful belief: that everyone living with NF deserves a future without limits. And thanks to your unwavering partnership, that future is taking shape. Early 2025 marked a milestone that was years in the making—the FDA approved Gomekli (mirdametinib), the first-ever treatment for adults with neurofibromatosis type 1 (NF1). This is more than a scientific achievement, it's a breakthrough built on our shared commitment to making the impossible possible.

This approval validates the Foundation's bold approach: we don't just support research, we drive it. We advocate for faster drug development, and actively seek out opportunities to repurpose treatments once thought to be shelved. At CTF, we will leave no stone unturned in our quest to find treatments for all forms of NF, including NF1, *NF2*-SWN, and SWN.

As we celebrate this incredible progress, we are also confronting new challenges—most notably, the elimination of federal funding for NF research through the Congressionally Directed Medical Research Programs (CDMRP) for Fiscal Year 2025. This funding has long been a critical driver of scientific discovery. We're working tirelessly to advocate for its restoration, speaking up on Capitol Hill, rallying our community, and reminding our leaders that rare disease research is not optional—it is essential.

In the pages ahead, you'll see that spirit of determination. From innovative research partnerships and investments in companies like Healx, to the launch of our first new company, CureAge, to life-changing educational programs—this community is moving forward together.

You'll also meet extraordinary individuals who are shining a light on NF, especially during May NF Awareness Month. I'm particularly inspired by Giacomo Del Giudice, whose stunning artwork has honored and uplifted our CTF honorees, and by young Kendall Reeve, whose courage and optimism remind us why this mission matters so deeply.

Whether you're running, walking, fundraising, or advocating—thank you for being part of this mission. Together, we are making NF visible. Together, we are building a future without NF.

With deepest gratitude,

Annette Bakker, PhD
CEO

PUBLICATION:

Unlocking Brigatinib's Potential: A Remarkable Case of Drug Repurposing in *NF2*-SWN

A pivotal chapter in *NF2*-related schwannomatosis (*NF2*-SWN) drug discovery has been written—both literally and figuratively—with a new publication highlighting the power of collaboration in bringing brigatinib to patients. Co-authored by a multidisciplinary team, including Dr. Annette Bakker, CEO of CTF, the piece showcases the groundbreaking work accelerating this promising treatment.

To read more, search "chapter" at ***ctf.org/news***

Welcome New Board Members

Colleen Gurda Trigg

Jaishri Blakeley, MD

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CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

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IT'S A GO!

GOMEKLI (mirdametinib) FDA Approved!

On February 11, 2025, the U.S. Food and Drug Administration (FDA) officially approved Gomekli (mirdametinib), SpringWorks Therapeutics' MEK inhibitor, for adult and pediatric NF1 patients with inoperable plexiform neurofibromas (PN). This marks the second FDA-approved treatment for NF1 and the first approved for adults.

This is a game-changing moment for the entire NF community.

It's more than a medical win—it's the result of years of relentless work, driven by partnership and persistence. CTF identified the drug's potential, supported clinical trial recruitment, and partnered with SpringWorks Therapeutics to bring this treatment across the finish line.

But breakthroughs like this don't happen without you. Every patient who participated in a trial, every researcher who pursued new possibilities, every donor who fueled this work—you made this possible. Because of you, NF patients have a new treatment option—and renewed hope.

"We are excited to celebrate the extraordinary milestone of our partners and long-term friends at SpringWorks for the NF community. This FDA approval shows the power of collaboration to advance innovative science for drugs that may otherwise not have been taken forward," said Annette Bakker, PhD, Chief Executive Officer of CTF. "When industry, researchers, and organizations like ours join forces, scientific progress moves faster, and patients gain access to the needed therapies. Every treatment approval is hard-won, built on research, persistence, and partnership. Today, that work delivers a critical new option for NF1 patients of all ages."

"The NF1-PN patient community has a great need for more treatment options. With today's approval, we are honored to serve both adults and children with NF1-PN and provide them with a therapy that has the potential to shrink their tumors and offer meaningful symptomatic relief," said Saqib Islam, Chief Executive Officer of SpringWorks. "We are grateful to each clinical trial participant, their families, the investigators, and the patient advocacy groups involved in the journey toward making Gomekli available in the U.S."

"Patients with NF1-PN often face significant challenges with their health and have had limited treatment options to manage this devastating condition," said Christopher Moertel, MD, lead investigator of the ReNeu clinical trial of Gomekli. "This approval represents an important advance, especially for adults who previously did not have an approved treatment."

This is not the first time the NF community has seen a breakthrough like this. In 2020, CTF helped pave the way for the first-ever FDA-approved treatment for NF, Koselugo (selumetinib), working alongside researchers, industry, and the NF community to ensure its success. That approval was driven by a relentless pursuit of progress, collaboration, and the belief that NF patients deserve options.

These FDA approvals have caught the attention of pharmaceutical companies, who now see that it's truly possible to develop successful treatments for NF. As more companies get involved, we're moving faster toward our goal: **approved treatments for all forms of NF, including *NF2*-SWN and all types of schwannomatosis.**

This FDA approval marks another huge step forward—and we're not stopping here.

BioSpace: Gomekli's Road to Approval

The Children's Tumor Foundation was recently featured in *BioSpace*, highlighting our pivotal role in bringing Gomekli (mirdametinib) from an abandoned compound to an FDA-approved treatment for NF1-PN.

The two-part story shares how CTF's advocacy and collaboration helped revive a shelved drug and connected it to SpringWorks Therapeutics, sparking a journey that led to this significant breakthrough. "We couldn't have done this without CTF," said Jim Cassidy, Chief Medical Officer at SpringWorks, in the *BioSpace* article.

This isn't just the story of a drug—it's a powerful example of how patient-driven research can reshape the future. No promising treatment should sit on a shelf while patients wait, and thanks to the relentless efforts of our community, this one didn't.

The future of NF treatment is accelerating. And this is just the beginning.

CureAge Therapeutics Launches to Advance Genetic Therapies for NF

A first-of-its-kind biotech company, CureAge Therapeutics, has officially launched to develop curative therapies for NF1. The UK-based company was formed through a strategic collaboration between CTF and Deep Science Ventures (DSV), uniting scientific expertise and venture creation to address one of the most pressing unmet needs in rare disease treatment.

CureAge was born from a unique partnership combining CTF's leading role as a catalyst in NF drug discovery and development with DSV's expertise in building innovative biotech ventures. Recognizing the urgent need for next-generation therapies, CTF and DSV identified gene therapy as the most promising path forward.

CureAge's approach leverages lipid nanoparticles (LNPs) to precisely deliver therapeutic genetic material to Schwann cells, the key cells involved in NF1 tumor growth. With a dual-action strategy, CureAge aims to restore gene function and eliminate non-targeted tumor cells—providing a long-term cure for NF1 while developing a scalable platform for related diseases.

"At CureAge, we are committed to finding better solutions for NF1 patients," said Dr. Gonzalo Fernández-Miranda, CEO and Co-founder of CureAge Therapeutics. "By leveraging the latest advances in genetic therapies, our goal is to offer a transformative solution that not only treats NF1 but also paves the way for future treatments in other peripheral nerve disorders."

The launch of CureAge marks another milestone in CTF's mission to end NF, turning ambitious ideas into new possibilities for patients.

"The CTF community does not wait for solutions—we create them," said Annette Bakker, PhD, Chief Executive Officer of CTF and Board Chair of CTF Europe. "By launching CureAge with Deep Science Ventures, we are ensuring gene therapy for NF moves forward with purpose and determination to get cures into the hands of patients faster."

CTF Board Member Montse Montaner joined the Board of CureAge. Montaner is a visionary strategic advisor with over three decades of experience in the global pharmaceutical industry. As the former chief quality officer and first chief sustainability officer of Novartis, she has led high-performance teams across various therapeutic areas.

"I am honored to join this effort at such a pivotal time in NF research," said Montaner. "CureAge brings together world-class experts to pinpoint the underlying cause of NF1—and develop a life-changing treatment."

The name CureAge was chosen by NF1 patients and families. It represents both courage and hope for a cure and reflects the determination to end NF.

HEALX ANNOUNCES FIRST PATIENT DOSED IN PHASE 2 TRIAL

Healx has dosed the first patient in its Phase 2 trial for HLX-1502—the first AI-derived treatment for NF1. This is an essential achievement for Healx, whose innovative approach pushes the boundaries of rare disease treatment and brings new hope to NF patients. CTF has been a proud partner and investor in this journey, bringing our preclinical and clinical research expertise, deep patient insights, and commitment to accelerating breakthroughs. This milestone is a testament to the power of collaboration to drive new treatments forward.

"This trial represents an important step in determining the potential of HLX-1502 as a treatment option for patients," said Simone Manso, Head of Neurofibromatosis Therapy Development at Healx. "We are grateful for the support from CTF, a vital partner in this journey, and to the Neurofibromatosis Clinical Trials Consortium for making this clinical trial a reality."

HLX-1502 was discovered using Healx's proprietary AI platform, which accelerates the identification of potential drug candidates. The therapy has received Fast Track, Orphan Drug, and Rare Pediatric Disease designations from the U.S. FDA, underscoring its potential significance for the NF1 community.

New Meningioma Model in Development in CTF Preclinical Hub Unlocks Opportunities for *NF2*-SWN Brain Tumor Therapies


Liyam Laraba, PhD, Research Fellow at the University of Plymouth

Researchers at the University of Plymouth are leading an innovative initiative to advance the study of meningiomas in *NF2*-related schwannomatosis (*NF2*-SWN).

Meningiomas, often linked to loss of the *NF2* gene, are a hallmark of *NF2*-SWN and can severely impact patients' lives despite being typically non-malignant.

This new project addresses two critical gaps in meningioma research: the development of effective therapies that improve outcomes, and the lack of systems to study how human immune cells interact with meningioma tumor cells before advancing therapies to clinical trials.

With funding from CTF, scientists at the University's Brain Tumour Research Centre of Excellence will develop a humanized meningioma model for *NF2*-SWN. This will enable researchers worldwide to study these complex interactions and accelerate new therapies.

"Developing therapies for meningioma and other brain tumors is a significant challenge," said Dr. Liyam Laraba, Research Fellow and lead researcher. "Even when promising immunotherapies are found, no model currently exists to evaluate their effectiveness or side effects in a living system. We believe this project could play a vital role, offering a platform to test therapies and potentially shorten the timeline to patient treatment."

Built as a public-private partnership and led by a dedicated preclinical director, the CTF Preclinical Hub builds on the Foundation's groundbreaking programs such as the NF Preclinical Consortium and Synodos for NF2, which identified clinically effective treatments.

Led by Dr. Laraba along with Professor Oliver Hanemann, Professor David Parkinson, and Dr. Matt Banton, the multidisciplinary team will study immune cells from meningioma patients and create a humanized meningioma model using mice with human immune cells. Once ready, the model will be shared with researchers worldwide.

This partnership is a key step toward improving clinical trials and bringing better treatment options to people with *NF2*-SWN.

CTF and **CureNFwithJack** Announce Next Phase of Groundbreaking Biomarker Project

The Children's Tumor Foundation, in collaboration with CureNFwithJack (CNFWJ), recently announced the next phase of an innovative biomarker project aimed at revolutionizing the detection and monitoring of cancerous tumors in patients with NF1.

This project builds on earlier research funded by CTF, which demonstrated that analyzing cell-free DNA (cfDNA) – tiny fragments of tumor DNA circulating in the bloodstream – can effectively distinguish cancerous tumors, known as malignant peripheral nerve sheath tumors (MPNSTs), from benign or premalignant tumors in NF1 patients. MPNSTs are one of the most serious complications of NF1, affecting approximately 1 in 10 NF1 patients over their lifetime. This non-invasive approach offers the potential for earlier, faster, and more precise cancer detection. It could significantly reduce the reliance on invasive biopsies and frequent imaging scans.

In the initial phase, researchers demonstrated that cfDNA analysis can differentiate between benign, pre-cancerous, and cancerous tumors, validated the approach using patient samples, and showed that dynamic cfDNA patterns could predict relapse months before traditional imaging.

The next phase focuses on expanding cfDNA testing through targeted testing of high-risk NF1 patients, serial testing to track tumor changes, and biobank expansion tied to clinical data. The goal is integration of the blood test into routine care.

"This phase represents a bold step forward in how we care for NF1 patients," said Annette Bakker, PhD, CEO of CTF.

"We are incredibly proud to support this critical phase of research," said Elizabeth O'Brien, Co-Founder and CEO of CNFWJ.

The success of this phase brings us closer to a future in which cancer in NF1 can be detected earlier, treated more effectively, and monitored with less burden on patients and families. With continued collaboration and support, this groundbreaking blood test could soon become a powerful, life-saving tool in the standard care of NF1.

CTF CLINICAL RESEARCH AWARDS

The CTF Clinical Research Awards have supported early-stage clinical trials and interventions for NF1, SWN, and *NF2*-SWN since 2008. In 2024, CTF committed approximately $600,000 to these patient-centered research studies.

Laura Lehman, MD, MPH
Boston Children's Hospital

Identifying Moyamoya: MRI and TCD in Children with NF1 (MATCh) Study

Moyamoya is a brain blood vessel problem in children with NF1 that can cause stroke. This study will use MRI to see if NF1 children with symptom-free moyamoya have brain tissue changes. Since MRIs require sedation for children, researchers will test ultrasound (TCD) as a screening tool that doesn't need sedation. If successful, TCDs could help determine when an MRI is needed, allowing earlier treatment before stroke or cognitive problems develop.

Konstantina Stankovic, MD, PhD
Stanford University School of Medicine

Temporal Trends in Plasma Biomarkers: Implications for Hearing and Tumor Progression in People with Vestibular Schwannoma

Vestibular schwannoma tumors can cause hearing loss in *NF2*-SWN patients, but tumor size doesn't always match hearing loss severity. This study will follow patients for two years, tracking hearing, tumor growth, and blood markers previously identified by Dr. Stankovic's team. The goal is to determine if these markers can predict worsening symptoms, helping doctors make better treatment decisions to preserve hearing.

Stephen Gilene, MD
Cincinnati Children's Hospital Medical Center

Identification of Biomarkers in Children and Adults with NF1-associated Plexiform Neurofibromas Treated with Binimetinib

This study will identify blood markers in NF1 patients with plexiform neurofibromas treated with binimetinib. Researchers aim to find markers that change during treatment, offering an easier way to monitor drug response. Markers that don't respond may suggest targets for new medications. Results will be compared with mouse models, creating standards for testing future treatments before human trials.

Pamela Wolters, PhD, and Julia Finkel, MD
National Cancer Institute and Children's National Medical Center

Evaluation of a Novel Physiologic Biomarker of Pain in NF1

Pain affects many NF1 patients, especially those with plexiform neurofibromas. Current treatments shrink tumors but don't eliminate them, making pain assessment crucial. This study will test the AlgometRx Nociometer, a device that measures pain by assessing nerve fibers, and could give doctors an objective way to monitor pain and improve treatment.

ADVOCACY: Stand Strong Together

In March, advocacy took center stage as the NF community responded to an urgent development: the NF program within the Congressionally Directed Medical Research Programs (CDMRP) was excluded from the Fiscal Year 2025 budget—along with many other critical disease areas. This program plays a vital role in advancing high-impact NF research and supports the NF Clinical Trials Consortium. Its absence threatens to stall momentum at a time when progress has never been more possible.

CTF and our advocacy partners are deeply concerned by this cut. We know that medical research cannot advance without strong, consistent funding—and when we speak together, our voices carry further. We believe that by uniting our voices, we can protect not just NF research, but all research that improves lives. The Children's Tumor Foundation remains committed to advocating alongside our fellow NF organizations, and we call on you—our supporters, donors, and families—to help. By acting now, you can make a difference.

Take Action Today at ctf.org/takeaction, and use our simple tool to contact your members of Congress.

Together, we are stronger. Together, we will end NF.

Access CTF's Newest Resource:

Diagnosed with Schwannomatosis
Brochure
in English and Spanish

ctf.org/education

CTF CLINICAL CARE ADVISORY BOARD: Improving Access to Quality Care for NF

The CTF Clinical Care Advisory Board (CCAB) consists of committed NF clinicians and patient representatives collaborating with CTF to identify ways to improve NF clinical care, educate patients and clinicians, and research relevant clinical care topics.

The CCAB operates by selecting strategic projects and creating subcommittees to focus on each project for one year. The groups meet regularly throughout the year to establish goals and communicate progress back to the CCAB. Subcommittees for 2024 included:

- NF Clinic Network
- NF Registry
- CCAB Membership
- Clinical Care Program (hosted annually at the NF Conference)
- Adult Clinic Program
- Patient Education
- Virtual Case Conference

On February 8, the CCAB met in Dallas, Texas to review the progress of each subcommittee and identify priorities for 2025. Progress highlights from 2024 include the launch of the clinic designation system to assist families, expansion of the Clinical Care Program held annually at the NF Conference, and the review of new CTF patient education resources.

The CCAB agreed that their driving purpose for 2025 and beyond is to improve access and quality of care for NF patients throughout their lifetime.

We are incredibly grateful for the time and expertise of the CCAB, which is guiding CTF in its mission to drive research, expand knowledge, and advance care for the NF community.

CCAB Members

Clinicians

Laura Klesse, MD, PhD (Chair, 2025)
Scott Plotkin, MD (Chair Emeritus)
Oliver Adunka, MD
Jaishri Blakeley, MD
Gary Brenner, MD, PhD
Jan Friedman, MD, PhD
Bonnie Klein-Tasman, PhD
Jennifer Janusz, PsyD, ABPP-Cn
Justin Jordan, MD, MPH
Tena Rosser, MD
Pamela Trapane, MD
Nicky Ullrich, MD, PhD
David Viskochil, MD, PhD

CCAB Contributors

Vanessa Merker, PhD
Katie Metrock, MD
Kaleb Yohay, MD

CTF Board of Directors

Steve McKenzie,
Liaison to the CCAB

The CCAB also includes individuals living with NF1, *NF2*-SWN, and SWN who serve as Patient Representatives.

YOU ARE THE KEY TO UNLOCK NF AWARENESS

It's NF Awareness Month:
TAKE ACTION!

This May, NF Awareness Month is about more than spreading the word—it's about unlocking progress. Research holds the key to better treatments, and together, we can drive progress toward life-changing solutions.

What can you do to take action this May?

Unlock Breakthroughs with a Gift
Too many promising drugs are sitting on shelves, waiting to be tested as potential treatments for NF. Your donation fuels critical research, including drug repositioning efforts that could bring treatments to NF patients faster.
ctf.org/donate

Unlock Awareness
On May 17, wear blue and green, and on May 22, wear green and blue, to show your support for the NF community! Need gear? Grab official NF merch from the CTF Store and make a statement.
ctf.org/store

Unlock Community
NF is personal, but you're never alone. Join forces with others who understand. Gather with families, friends, and advocates at local events, secure a proclamation for your city, light up landmarks in blue and green, or rally your community to spread the word.
ctf.org/nfawareness

Unlock the Photo Contest
We know NF fighters are everywhere. Show how you're taking action by entering our "I Know a Fighter" photo contest and sharing your story.
ctf.org/photocontest

Unlock Research
Join the NF Registry or update your record. Every participant helps scientists uncover new insights about NF and brings us closer to better treatments.
nfregistry.org

Unlock Advocacy
Washington, D.C., needs to hear from you! Every message counts in making sure NF research is a priority. Make your voice heard and send your letter to Congress through our site today.
ctf.org/takeaction

Every action—big or small—brings us closer together and strengthens our collective impact.

You are the key - take action today!

ctf.org/nfawareness

Your Donation is Matched Today thanks to the Snipes Family Charitable Fund

KENDALL REEVE: A Story of Strength and Hope

When Stephanie and Matthew Reeve welcomed their daughter Kendall into the world, they sensed something was different. As a nurse, Stephanie's instincts told her to look closer. But doctors reassured her—perhaps she was just being overly concerned. Still, she couldn't shake the feeling that something wasn't right.

At just 10 weeks old, Kendall Reeve was diagnosed with NF1. Tumors had already wrapped around her spine, bladder, and stomach. What followed were years of surgeries, chronic pain, and limited mobility keeping Kendall confined to her bed, unable to enjoy the childhood every child deserves.

But then something remarkable happened—something YOU made possible.

Kendall began taking **Koselugo**, the first-ever FDA-approved treatment specifically for NF1 tumors. This breakthrough medication didn't just appear overnight. It was the result of years of strategic investment in research that the Children's Tumor Foundation championed—research that donors like you funded.

"Before Koselugo, I was in so much pain. I couldn't get out of bed, and I couldn't do things," Kendall recalls. "When I started taking it, I noticed that I wasn't hurting as much anymore. I felt like I could do a lot more things. I just felt free—like I was weightless, and my pain couldn't stop me."

Our family of Children's Tumor Foundation donors funded the critical research that led to this moment. CTF's strategic investments in MEK inhibitor research and scientific collaboration created the foundation for Koselugo's historic FDA approval in 2020—the first-ever approved treatment for NF1 plexiform neurofibromas. More recently, this support helped advance Gomekli, a second FDA-approved treatment for NF, expanding options for patients like Kendall.

With Koselugo, Kendall's tumors have stabilized, and her pain has diminished significantly. Now 14 years old (soon to be 15), she is able to attend school regularly, engage with friends, and embrace a more typical teenage life—**a transformation that your donations helped make possible.**

More breakthroughs are on the horizon for all types of NF:

Brigatinib, originally developed for lung cancer, is showing promise for ***NF2*-related schwannomatosis**. NFX-179, a topical gel for **NF skin tumors**, will soon enter final trials. And HLX-1502, the first **AI-discovered NF therapy**, is now in clinical testing.

Pharmaceutical companies are now interested in NF, investing in research that will lead to **even more treatments for all forms of NF, including *NF2*-SWN and other SWN.**

Despite the medical challenges she has faced, Kendall does not let NF1 define her. She loves singing, listening to music, and playing games on her iPad. She loves to read and enjoys swimming whenever she gets the chance.

With the many recent funding cuts in medical research, your continued support is the key that will make a difference.

That's why we are excited to tell you that the Snipes Family Charitable Fund has generously offered to match all donations, through June 30th and up to $50,000, made at ctf.org/key

Thanks to groundbreaking treatments, relentless advocacy, and a supportive community of donors like you, Kendall is forging her own path. With every step, she is proving that NF may be a part of her story—but it will never be the whole story.

Your donation today at **ctf.org/key** unlocks more treatments for all types of NF, giving children and adults like Kendall a chance to define their own stories beyond NF.

SCAN THIS CODE TO DOUBLE YOUR DONATION TODAY

Extraordinary Spirit: **GIACOMO DEL GIUDICE**

The Artist Who Transforms Dreams into Bronze

Art has the power to inspire, to tell stories, and, in the case of **Giacomo Del Giudice**, to honor extraordinary individuals who are shaping the NF community. A sculptor rooted in the noble traditions of his grandfather and father, Giacomo has spent his life working with bronze, shaping raw material into timeless pieces of poetry and imagination. Today, his artistry is woven into the very fabric of the Children's Tumor Foundation's mission.

In 2023, CTF Europe inaugurated the **Cloud Carrier Award**, a recognition given to individuals whose efforts are reshaping the landscape of NF research, advocacy, and awareness. Each award is a unique sculpture, handcrafted and donated by Giacomo himself, symbolizing the honorees as "cloud carriers"—those who carry dreams that have the power to transform the world.

For Giacomo, the concept of the **cloud carrier** is deeply personal. He was inspired by childhood stories his grandfather told while gazing at the sky. He envisions the cloud as a universal language—one that transcends borders, evoking wonder and possibility. His sculptures capture this vision: a figure moving forward, gently balancing a cloud filled with dreams, hopes, and change.

Beyond the Cloud Carrier Award, Giacomo's artistry continues to shape CTF's most prestigious honors. For other awardees, he created the **Ladder of Knowledge** sculpture—another extraordinary piece designed to symbolize the journey of discovery, perseverance, and progress.

Each sculpture is meticulously handcrafted, making every piece unique—just like the changemakers they honor. Giacomo intentionally sculpts the human figure without distinct features, allowing it to represent a universal entity—a symbol of anyone who supports, chases, and achieves dreams.

As the owner of **Del Giudice Artistic Foundry in Greve in Chianti, Italy**, Giacomo carries forward a family legacy while forging his own path in the art world. His craftsmanship has graced some of the most revered places in Italy, from Florence's Duomo to the Vatican Museums. Yet, despite these prestigious commissions, Giacomo remains devoted to simplicity and poetry—qualities he fears are disappearing in today's world.

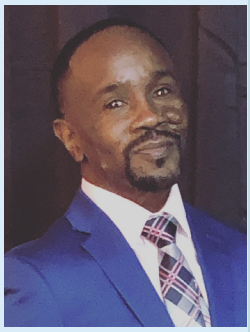
"I started working as a boy with my grandfather and father," he reflects. "Unfortunately, I am not and will never be at their level, but I do this work with passion. I look for simplicity and poetry, because I think that unfortunately they are slowly, slowly disappearing."

Through his generosity and vision, Giacomo has given the NF community something profound—more than just an award, but a tangible symbol of hope and transformation. Whether through the Cloud Carrier Award or the Ladder of Knowledge, his sculptures tell a story of dreams taking flight, of knowledge lifting humanity, and of perseverance forging a brighter future.

CTF is honored to celebrate **Giacomo del Giudice** as an **Extraordinary Spirit**—a man whose hands shape bronze, but whose heart lifts the dreams of a community determined to **End NF**.

stories OF NF

Terrence
NF1



I was diagnosed with NF1 at the age of eight.

Sometimes, it challenges me to go harder because I don't look at it as a disease but as an opportunity to show people that if I can do it, you can do it too. If I can stay strong, you can stay strong. If I can keep the faith, you can keep the faith.

There was one defining moment after having an operation on my spine. I had to realize that my life is different from any other person's. I had to learn how to walk all over again, how to run, and how to play basketball all over again.

For a living, I try to motivate others. I write music to motivate others, and I have actually written a book about my faith and living with NF1. I am a motivational speaker. I live my life to motivate others, exercise, and share faith-based content.

One fun fact about me is that I love to sing. I will randomly burst out in a song anywhere.

Georgia
NF1

I was diagnosed with NF1 when I was two years old, and at three and a half, I was also diagnosed with optic nerve tumors. In those early days, my mom took me to oncology all the time for chemotherapy. They would put needles in my port. It felt a little weird, but it didn't really hurt.

NF1 has impacted me by making me blind. Every day and every night, I have to take a medicine called Koselugo (selumetinib). Living with NF sometimes feels invisible because it's just my normal life — I forget I have it sometimes.

Going blind has defined my life in many ways. I need to use a cane everywhere I go, and when I want to write a letter, I use a braille writer. Being blind means relying more on hearing my surroundings and feeling what's beside me and around me to stay safe.

What makes me happy is having nice friends, listening to music while I walk to keep me entertained, and spending time with my amazing pet dog. My family helps me a lot too. If I hurt myself when I get older, I know they'll be there to support me.

NF Knowledge Series
Patient Webinars

CTF is proud to host a new monthly webinar series for families and individuals living with any form of NF. Join us monthly for the latest NF research and expert guidance on clinical care issues. Live captions will be available.

Upcoming webinars

May 7	Genetics & Reproductive Options in NF
May 22	CTF Research in *NF2*-SWN
July 10	AI in Healthcare: What is it?

Fall and winter webinars will be scheduled soon and will include topics such as *Back to School: Advocating for Yourself and Your Child, NF Registry, Breast Cancer Risk in NF1,* and *Pain in SWN.*

Topics and dates may be subject to change. Please join our mailing list at ctf.org/newsletter to watch for news and registration links, or visit our education calendar at ctf.org/educational-events

CUPID'S UNDIE RUN

cupids.org

Year after year, thousands of pantless do-gooders hit the streets, sidewalks, and beaches in over 30 cities throughout the month of February for Cupid's Undie Run! Having raised more than $1.7 million this season (and still climbing), this unique event continues to evolve and grow its audience, connecting new families and support networks across the country.

Many of our cities were able to not only reach, but exceed their fundraising and participant goals this season, including Austin, Boise, Charleston, Chicago, Cincinnati, Cleveland, Denver, Detroit, New Jersey, Phoenix, Pittsburgh, Reno, San Francisco Bay, Virginia Beach, and Wilmington.

We owe much of our success to those who supported us nationwide! Thank you to our selfless and hardworking Event Directors, committees and volunteers, local partners, and to our National Underwear Partners, **Pair of Thieves** and **Woxer**.

CUR NEWCOMER: Heather Ek

NF mom, Heather Ek, joined us for her first-ever Cupid's Undie Run in Chicago this season. She says, "Two years ago, we had no idea what NF was and now we are doing everything we can to help our daughter thrive and educate ourselves and others." At five years old, Evie was diagnosed with NF1, and the family felt lost. After finding out about the event on Instagram, Heather started a team, Evie's Warriors, and thanks to a small town with a big heart, they raised over $23,000 this season. "I am always championing for Evie. I want to share her journey and NF1 to educate our friends and families. Cupid's felt like a great way to do that while enjoying a fun day out with friends, supporting our sweet Evie and raising money for a future cure."

Special EVENTS

Dancing With Our Stars: Northwest Arkansas

What an incredible night! Dancing with Our Stars Northwest Arkansas raised more than $210,000 for the Children's Tumor Foundation. Six NWA community leaders competed in a fundraising and dance competition on March 8th at Crystal Bridges Museum of American Art. A huge congratulations to Kati Moore of Google for being crowned the Champion, taking home the coveted Mirror Ball Trophy, and to Jessica DuQuesne of Hershey for earning the Best Performance trophy.

Along with our trophy winners, Kimberly McGee of Walmart, Lauren Blass of Sage Partners, Dustin Doty of Wright Lindsey Jennings, and Tiffany Benitez, founder of Women+ in Technology, filled the room with their friends, family, and supporters to help fuel our mission to End NF. We are truly grateful to our Honorary Chair, Greg Cathey, and our Presenting Sponsor, O'Gary Construction Group, for their generous support.

NF Endurance Runner Profile:

Brittany Iskula,

who lives with NF2-SWN

Can you tell us about your NF journey?
I am a wife, mom, school nurse, runner, and now, advocate for NF research! I was diagnosed with *NF2*-related schwannomatosis (neurofibromatosis type 2) at 30 years old. I was pregnant with our third child when I first started noticing symptoms. It started with odd facial sensations that I didn't think too much about. Then, I noticed diminished hearing in one ear. I started getting worried when I became unsteady on my feet. After the birth of our baby, my symptoms only worsened. Within less than a week, I had an MRI, was diagnosed with NF2, and had emergency brain surgery to remove a large vestibular schwannoma.

How does NF impact your life now?
Having a chronic condition is exhausting and never-ending. NF impacts my life every day. I have since been dealing with unilateral deafness, facial paralysis, vision, and balance issues, and adjusting to this diagnosis mentally. My biggest challenge or fear is the ultimate deafness that I will likely face in my future. I am afraid that I will forget what things sound like. I try to soak up my kids' little voices and cherish every conversation with my loved ones. The emotional toll has been tough, but I have an amazing family who support me and help pick me back up whenever I need it.

What does running mean to you? How did you "discover" running?
I ran cross country in high school, and as a hobby, for a few years after that. Then for almost 10 years, I took a break from it. Life became busy with three kids. Then came a new diagnosis and even more challenges. Getting back into running has been so humbling and life-giving. It has helped me come back to the surface, rebuilding myself with each mile, and given me a way to handle my challenges in life. It feels so good to be back to doing what I love, and giving myself the gift of running again!

What does it mean to you to run the Chicago Marathon with the NF Endurance team?
My sister, Brooke, and I are honored to have the opportunity to run the 2025 Chicago Marathon with The Children's Tumor Foundation NF Endurance Team! Living with NF has its challenges, but because of this diagnosis, I have become even more passionate about health and running. It reminds me of what I have overcome and what I am still fighting. I will not let NF slow me down or keep me from chasing my dreams. Rather, I will use this motivation to help seek something much, much greater! I am proud to be a part of this team, to spread awareness, and help make NF visible.

EARN YOUR WORLD MAJORS STARS

The CTF NF Endurance team has expanded our presence across the prestigious Abbott World Marathon Majors (AWMM) and now offers entries to six of the seven iconic races. NF Endurance provides the opportunity of a lifetime: guaranteed entry to some of the world's most sought-after races, personalized fundraising support, exclusive CTF-branded race gear, and, most importantly, the chance to change lives for those living with NF.

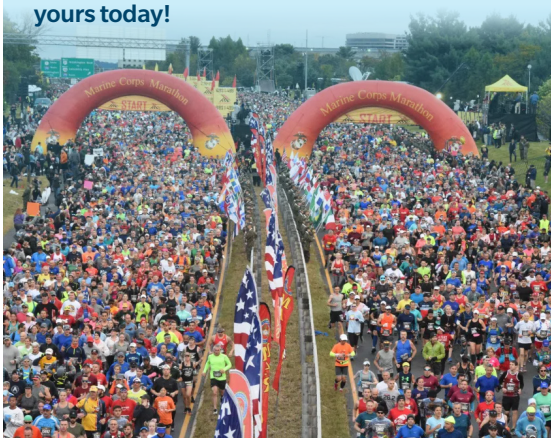
Tokyo Marathon	March 1, 2026
TCS London Marathon	April 26, 2026
Cape Town Marathon	May 24, 2026*
TCS Sydney Marathon	August 2026
BMW Berlin-Marathon	September 2026
Bank of America Chicago Marathon	October 11, 2026
TCS New York City Marathon	November 1, 2026

*Cape Town Marathon has applied to become the 8th AWMM event; notification is expected in November

Apply today at
nfendurance.org/apply2026

Run with CTF at the 50th Marine Corps Marathon!

Join NF Endurance runners at the iconic race supported by the U.S. Marines. MCM is the largest marathon that doesn't offer prize money, making it beloved as "The People's Marathon." Run past national monuments, through Rock Creek Park, and across the Potomac while you celebrate the military and raise awareness and funds for NF.
Team spots are limited and include complimentary race entry—secure yours today!



For more info, visit **nfendurance.org** or contact Lydia Vanderloo at **lvanderloo@ctf.org**

SHINE A LIGHT **NF** WALK

Thank you to over 4,500 participants who walked with CTF in 2024 and helped raise close to $1.4 Million! From coast to coast, 23 events brought together thousands of passionate supporters, all united by one purpose: to celebrate our NF Heroes and advance the mission to end NF. This outpouring of support would not be possible without our incredible local heroes, Walk Directors, volunteers, donors, fundraisers, and participants.

2025 Season

We're already looking ahead to Fall 2025 with excitement and determination. With even more Walkers expected to join us, we aim to raise critical funds that will accelerate research, improve diagnostics, and advance treatments for everyone living with NF. We thank our National Walk Sponsors, Alexion AstraZeneca Rare Disease and SpringWorks Therapeutics, whose continued support helps drive this mission forward.

ALEXION
AstraZeneca Rare Disease

SpringWorks
THERAPEUTICS

2025 Walk Dates & Locations

- 8/23/25: Utah
- 9/13/25: South Dakota
- 9/13/25: Washington State
- 9/14/25: Cincinnati
- 9/14/25: Michigan
- 9/20/25: Chicagoland
- 9/20/25: Iowa
- 9/20/25: Philadelphia
- 9/27/25: Boston
- 9/27/25: Kansas City
- 9/27/25: Southern California
- 10/4/25: Carolinas
- 10/4/25: Denver
- 10/4/25: New Jersey
- 10/4/25: New York
- 10/11/25: Cleveland
- 10/18/25: Atlanta
- 11/1/25: Houston
- 11/2/25: Arizona
- 11/9/25: Florida
- TBD: Minnesota
- TBD: Virginia

Register Today at:
shinealightwalk.org

FLORIDA

Florida had a fantastic year in 2024, raising close to $85,000! It was a day full of engagement and fun for everyone. Special thanks to Mark Ehrli for putting on the prestigious Bay Hill Golf Tournament, where proceeds go toward Shine a Light NF Walk Florida, and to Jersey Mike's Subs for sponsoring us in many of their Jacksonville and Orlando stores and for providing food at the Walk. Congratulations to Walk Director Farida Timal on another successful event!

CTF EUROPE

The city of Jena, Germany, came alive with science last November during the "Long Night of Science." Over 12,000 visitors explored more than 500 activities, including at the Leibniz Institute on Aging - Fritz Lipmann Institute (FLI), where more than 1,400 people visited the lab of CTF-funded researcher Lars Björn Riecken.

Riecken's Preclinical Team, part of Helen Morrison's "Nerve Regeneration" group, focuses on **finding treatments for *NF2*-SWN**. Their work spans drug screening, delivery methods, and gene therapies aimed at repairing the disrupted communication between neurons and Schwann cells that leads to tumor growth.

To make their science accessible, the team turned to LEGO. They designed buildable models of neurons and Schwann cells to explain how these cells work—and what happens when they don't. Visitors learned how treatments like protein replacement or gene therapy may help stop tumor formation, and they got to take home their own LEGO "happy neuron."

"This playful approach helped us explain complex science in a simple way," said Lars Riecken. "We want everyone to understand what we're working toward: a cure."

Michael Reuter added, "We were deeply inspired by CTF's #MakeNFvisible campaign, having had the honor to participate in 2024 ...it left a long-lasting impression on us that keeps motivating us every single day. I believe it is important to #MakeNFvisible, to shine a light on NF heroes, to give hope to those affected, and to rally everyone else to support this cause."

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**.

NF News Editor, Vanessa Younger
NF News Design Director, Susanne Preinfalk

The Children's Tumor Foundation (CTF) is the drug discovery engine for NF. Everything we do is to bring treatments to patients as we work toward a cure. By connecting patients, doctors, scientists, and pharma, we drive treatments, advance care, and deliver results for millions affected by neurofibromatosis or schwannomatosis, collectively referred to as NF. Our patient-first collaborative approach accelerates drug development and brings life-changing therapies to patients faster, driven by our mission to end NF.

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Philadelphia, PA 19170 - 0001

NF REGISTRY

May is NF Awareness Month, a perfect time to join or update the NF Registry. You'll have access to the latest discoveries about NF1 and SWN, including *NF2*-SWN. Take action to stay informed, improve care, and advance NF research. Join the NF Registry today.

Stay informed. Improve care. Advance NF research.

nfregistry.org

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

—**SEQUOYAH DANIEL-ROBINSON WHO LIVES WITH *NF2*-SWN**