



ANNUAL REPORT 2024

Improving the lives of those affected by NF



**Tumour
Foundation**
of BC



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Foundation
of BC**

WHAT IS NEUROFIBROMATOSIS?

Although not well known, neurofibromatosis (NF) results in one out of 2,500 births. There are over two million individuals affected worldwide. NF causes uncontrolled growth of tumours along the nerves of the brain and body, and can lead to blindness, deafness, severe disfigurement, cancer and death.

HISTORY

Paul Ralfs founded the Tumour Foundation of BC in 1984. Paul had a vision that no one living with NF should walk the journey alone. We serve the NF community today because of his dream.

MISSION

To improve the lives of individuals affected by NF.

VISION

To optimize the health and well-being for British Columbians affected by NF.

BOARD OF DIRECTORS

President	Jill Taylor
Treasurer	John Stylianou
Secretary	Colette Madsen
Directors	Edie Dullaghan
	Mischa Miller
	Kirsten Niedner
	Lauren Yip
	Qi Zhang

OUR STAFF TEAM

Executive Director	Desirée Sher
Nurse Navigator	Silvana Rangel
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**Tumour
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INTRODUCTION + HIGHLIGHTS

2024 has been a year of growth, connection, and overcoming challenges for the Tumour Foundation of BC. Through the continued dedication of our supporters and partners, we've made significant strides in advancing our mission to improve the lives of families impacted by NF across British Columbia.

HIGHLIGHTS OF THE YEAR:

We were excited to expand our support services by staffing our NF Health Line with a Nurse Navigator, ensuring that no one has to navigate their NF journey alone. This personalized service has already made a profound impact on patients, providing them with essential resources and emotional support while guiding them through the complex healthcare system.

In addition, we hosted our annual NF Leadership Summit, bringing together leaders from across Canada to deepen collaboration, strengthen advocacy, and create unified messaging around NF. We hosted our first Virtual Town Hall Meeting to provide the community with a platform to engage directly with the Board and to discuss the critical need for an NF clinic in BC.

Our educational resources also grew in reach, with popular guides translated into new languages and new materials developed for both families and healthcare providers. Notably, five of our NF resources were added to Pathways, the BC Physician Online Medical Care Directory, which will improve care and awareness for NF patients throughout the province.

And we can't forget the incredible community events—our Shine a Light on NF campaign expanded to new landmarks, lighting up iconic sites in blue and green to raise awareness, including the Victoria Parliament Buildings. Meanwhile, A Night of Magic and Miracles for NF became one of our most memorable fundraisers, raising over \$45,000 and bringing some much-needed joy to our supporters through entertainment and connection.

CHALLENGES AHEAD:

As we celebrate these achievements, we also acknowledge the challenges we face. Securing adequate funding is an ongoing struggle for charities across Canada, and we are no exception. We're seeing a decline in financial gifts from governments, corporations, and individual donors, which has made it increasingly difficult to raise sponsorships and secure auction items for our events.



Moreover, the urgent need for a multidisciplinary NF clinic in BC continues to drive our advocacy efforts. With nearly 100 individuals on our waitlist, the demand for comprehensive NF care has never been clearer. We're working hard to push for this critical resource while also addressing gaps in care such as long specialist wait times, limited physician knowledge of NF, and financial barriers for families.

LOOKING FORWARD:

Despite the obstacles, we remain steadfast in our commitment to making a difference for the NF community. With your support, we will continue to advocate for improved care, create new educational opportunities, and build a more compassionate, connected world for everyone affected by NF.

Thank you for being part of this journey. Together, we are creating a brighter future for those living with NF.

***"YOU DON'T KNOW
HOW MUCH MY FAMILY
HAS APPRECIATED THE
WORK OF THE TUMOUR
FOUNDATION OVER
THE YEARS. ANY TIME
WE NEEDED SUPPORT,
INFORMATION OR
GUIDANCE YOU HAVE BEEN
THERE - ALWAYS FIGHTING
FOR US."***





HOW WE ARE MAKING A DIFFERENCE

HELPING PATIENTS NAVIGATE THE COMPLEX HEALTH CARE SYSTEM: NF HEALTH LINE

When someone receives a diagnosis of NF, it can feel overwhelming and isolating. The uncertainty about what to expect in the days and years to come can bring on stress and anxiety. The Tumour Foundation of BC established the NF Health Line to ensure that no one has to navigate this journey alone. This confidential service offers individuals across British Columbia a direct line to compassionate, personalized support. Whether someone is grappling with new symptoms, seeking clarity on their diagnosis, looking for information about health care resources, or needing help with treatment options, our goal is to provide a trusted place to ask questions and find guidance.

The Health Line was staffed with a Nurse Navigator this year. Stepping into this role I have had the privilege of walking alongside individuals and their families, offering more than just guidance through the complex medical system. I provide a listening ear, educational resources, and reassurance. My role is to ensure individuals feel empowered, informed, and connected to the care they need at every step of their journey.

Over the past year, I've had the privilege of supporting a diverse community, including both newcomers to the Foundation and long-time members. Individuals openly and courageously share their experiences with NF, along with the challenges

they face in accessing proper care. A shortage of family physicians in the province, combined with limited knowledge of the disorder within the medical community, is further complicated by a lack of access to specialized NF care. Individuals with NF are often left feeling alone and unsupported in our current system.

The Nurse Navigator role has given me the opportunity to be a supportive presence for the NF community. By answering questions about concerning symptoms, discussing guidelines for NF-specific diagnostic tests, and exploring possible specialist referrals, I've helped patients approach their healthcare interactions with the knowledge and confidence needed to seek appropriate care.

Some of the positive outcomes for our community include:

- **receiving recommended specialist referrals**
- **MRI diagnostics**
- **new symptoms addressed and investigated**
- **reduced feelings of isolation**
- **increased confidence to self-advocate**
- **a renewed sense of hope**

We have seen tremendous strength in our NF community and witnessed how offering support along the way has improved the outcomes for many.



Each individual's journey is unique, and as the Nurse Navigator I provide resources tailored to their needs, whether it's information on community services, clinical trials, or mental health resources.

Listening to and understanding each patient's story is key to providing personalized care that empowers and improves their quality of life while navigating NF.

The presence of a Nurse Navigator on the Health Line has enhanced the Tumour Foundation's credibility and trust within the community. One patient was relieved to obtain a referral to the Internal Medicine specialist after I collaborated with the family doctor's office to address the patient's declining health. "My appointment with internal medicine is tomorrow; that was fast. Thank you for your help."

In addition to supporting patients and families, the Health Line also receives inquiries from healthcare professionals looking for resources to better understand NF and improve their ability to care for patients. Physicians, including general practitioners, pharmacists, and neurologists, often turn to the Foundation for guidance, acknowledging their limited experience in managing NF. These healthcare providers face the challenge of managing a complex rare disease like NF without the specialized knowledge or resources they need. They often express frustration with the healthcare system's limited access to NF-specific expertise and specialists.

In response to these tremendous challenges, we have developed additional educational resources for patients and healthcare professionals. These resources are becoming available to doctors online through the Pathways Medical Care Directory and the Tumour Foundation website.

***"TODAY I MADE A LITTLE
HEADWAY WITH MY
DOCTOR THANKS TO
YOUR SUPPORT. MY BONE
DENSITY SCAN IS BACK ON,
AND SHE IS SENDING ME
TO SEE A NEUROLOGIST!
BABY STEPS."***



We also understand there are challenges. The absence of a dedicated NF clinic in BC means we can't refer patients to this vital resource when they call. Additionally, limited access to family doctors, long waitlists for specialists, financial barriers, and the need for better care coordination can make things tougher for families.

Our Health Line and Nurse Navigator are making a real difference, empowering many to manage their care more effectively. You can reach the Health Line at ➔ **1-800-385-2263** or online at ➔ **tumourfoundation.ca/nf-support-line**

While the Nurse Navigator can support you on your journey this service does not offer diagnoses or treatment. We encourage you to seek care from your physician in addition to the support we gladly offer. We're here for you, and together, we can work towards better health and well-being!



*Submitted by Silvana Rangel,
Nurse Navigator*

***"THANK YOU SO MUCH FOR
ALL THAT INFORMATION
AND YOUR TIME... YOUR
TIME TO WRITE TO ME
MEANS A LOT AND MAKES
ME FEEL LESS ALONE."***

***"SO GRATEFUL FOR YOU!
I WILL REPORT BACK
WHATEVER COMES OF
MY APPOINTMENT FROM
VICTORIA. FEELING A LITTLE
HOPEFUL...AND THAT'S
BECAUSE OF YOU!"***





**Tumour
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EDUCATION

DEVELOPING VITAL EDUCATIONAL RESOURCES

At the Tumour Foundation of BC, one of our key goals is to ensure that the NF community has access to up-to-date, relevant information. Providing educational resources empowers individuals, families, and healthcare professionals to better navigate the complexities of NF.

This year, we expanded our reach by translating our popular *Parent's Guide to Learning Disabilities in NF* into French. This essential guide is now available in multiple languages, including English, Chinese, Punjabi, and Portuguese.

In response to the needs we've identified within the community, we developed two valuable new resources this year. The first, *Discussing NF With Your Child*, is designed to help parents navigate the often challenging and emotional conversation about neurofibromatosis with their children.

The second, *Navigating Health Transitions: A Guide for Young Adults with NF*, is specifically tailored for young adults with NF1. This comprehensive resource aims to simplify the complex process of transitioning from pediatric to adult healthcare, ensuring individuals feel supported throughout their journey.

Both of these resources were created with the collaborative support of the NF community.

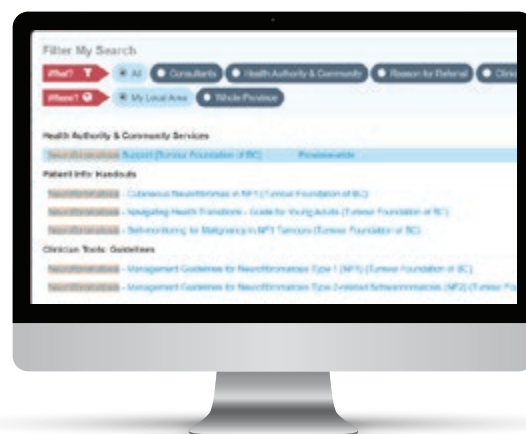
Additionally, we released a *Physician's Management Guide to NF2*, a resource to help healthcare

providers navigate the complexities of NF2 care and improve patient outcomes. The guide was created with support of NF2 BioSolutions and Nerve Tumours UK.

By continuing to create and update these materials, we aim to support everyone affected by NF, whether they are newly diagnosed or long-time members of the community.

PHYSICIAN EDUCATION

We're thrilled to share that five of our NF resources have been added to Pathways, the BC Physician Online Medical Care Directory. Before this, Pathways had no information on NF—now, physicians can not only access these vital resources but also email pamphlets directly to patients, making it even easier to share crucial information. Plus, the Tumour Foundation of BC is now fully searchable on Pathways, helping us expand our reach, raise awareness, and, most importantly, improve care for those living with NF. This is a major win in our mission to enhance care for the community!



EDUCATION

PROVIDING EDUCATIONAL OPPORTUNITIES

SYMPOSIUM

Our annual symposium continues to be one of the most anticipated events for the NF community, bringing together families, patients, caregivers from across Canada, and international leaders in NF research and care. This event serves as a vital platform for sharing knowledge, fostering connections, and providing a sense of belonging for those affected by neurofibromatosis.

In 2023, we returned to an in-person format, rekindling the powerful energy of face-to-face interactions. With a full day of speakers covering a range of topics, the true magic of the event came from the spontaneous conversations that took place between sessions—whether during meals, elevator rides, or downtime at the hotel. These moments of connection allowed participants to bond, share stories, and feel less alone on their journey with NF.

The symposium was a time for learning, community, and hope – a few reflections from attendees are shown here.

The positive feedback from attendees highlights the importance of not just the educational content, but the sense of community and support that the symposium fosters. We look forward to continuing this tradition and expanding the ways we can bring people together in meaningful ways.

“AS SOMEONE WHO IS JUST STARTING THE JOURNEY, IT WAS GOOD TO GAIN MORE INFORMATION ABOUT THE RESOURCES AVAILABLE AND THE RESEARCH BEING DONE.”

“THANK YOU FOR PUTTING ON THIS EVENT. THE JOURNEY IS LONELY, AND HAVING A COMMUNITY IS INCREDIBLE.”

“AN EXCELLENT DAY FILLED WITH GREAT DISCUSSIONS AND PRESENTATIONS.”

“I LOVED EVERYTHING. I LOVED MEETING PATIENTS, CAREGIVERS, AND THE OTHER NF GROUPS.”





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IDENTIFYING & RESPONDING TO THE COMMUNITY

COMMUNITY QUESTION PLATFORM

This spring, we introduced an exciting new feature on our website: the Community Question Platform. This initiative was born out of questions we received from our community on social media. We realized that if one person had a question, others likely wanted to know the answer too.

Now, anyone in the NF community can browse our Q&A section or post their own questions directly on our website. It's a space where you can get reliable information about NF, share your concerns, and engage with others.

Visit the NF Community Q&A platform here:

➔ tumourfoundation.ca/nf-community-qa





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BUILDING A MORE COMPASSIONATE WORLD

SPREADING THE WORD - NFTRUTH CAMPAIGN 2024

In May 2024, we kept the momentum going with our **NFtruth** campaign, aiming to make “NF” a household name! Our goal? To get everyone talking about neurofibromatosis—and we’re making sure they do.

We took things up a notch this year by plastering hundreds of posters all along the bustling Expo Line—one of the busiest routes in the city with over 126,000 boardings every weekday! Whether you were rushing to work or heading out for a day in the city, our posters were impossible to miss.

And guess what? The results were incredible. We saw a significant boost in website visits, donations and volunteer inquiries showing that more people are eager to learn about NF and how it impacts lives. The **NFtruth** campaign is proof that when we raise awareness, we make a real difference.

We couldn’t have done it without you! Whether you shared our message, donated, or took a moment to learn more, you played a key role in turning “NF” into a word that more and more people recognize. Together, we’re shining a spotlight on the challenges faced by those with NF and building a more compassionate, inclusive world.



SHINE A LIGHT ON NF CAMPAIGN 2024

This year, we proudly expanded the Shine a Light on NF campaign to Vancouver Island, lighting up Victoria City Hall and the Parliament Buildings for the first time. We also welcomed new partners, including the Victoria Street Bridge in Trail and the Pacific Coliseum at the PNE, further amplifying the campaign’s reach.

Their addition brought even more visibility to our cause, shining bright alongside iconic landmarks such as the Burrard Street Bridge, Burnaby City Hall, Port Moody City Hall, New Westminster City Hall, White Rock Pier, BC Place, Bloedel Conservatory, Vancouver City Hall, Canada Place, Science World, Lafarge Lake Fountain, Skytrain Guide Pillars & Lights in Coquitlam, Telus Garden, Leckie Building, Rogers Arena, Anvil Centre, Surrey Civic Centre, The Lookout, Vancouver Convention Centre, and the Olympic Cauldron.

Each illuminated landmark in blue or green stood as a symbol of hope, reminding us that by coming together, we can make a profound difference in the lives of those affected by NF. The outpouring of support from these communities reflects the growing awareness and dedication to finding a cure and providing essential support to individuals living with NF.





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ADVOCATING FOR CHANGE

We're continuing to push for a multidisciplinary NF clinic and meeting with various government officials to make our case stronger. With nearly 100 people self-referred to our waitlist, we're showing the growing demand for comprehensive NF care. This year, we focused our discussions with government staff on three crucial areas: the transition from pediatric to adult care, MSP coverage for cutaneous neurofibromas, and increasing physician education.

VIRTUAL TOWN HALL MEETING

In May, we hosted a Virtual Town Hall Meeting to share important updates and initiatives related to the NF clinic. This was an invaluable opportunity for the community to engage directly with the Board and staff, ask questions, and be part of the conversation about making the NF clinic a priority for decision-makers in our province. Over two dozen individuals came together to raise their voices and express concerns about the urgent need for improved NF care.

STRENGTH IN NUMBERS

At the Tumour Foundation of BC, we are dedicated to advocating for those with NF. In 2024, we proudly joined the MedAccessBC Group, a coalition of over 30 patient health organizations across BC and Canada, working to drive awareness and education for fair, equitable, and timely access to medicine for everyone in BC.

Though challenges lie ahead, we remain steadfast in our commitment to being a powerful voice for NF patients. With the support of the NF community and our ongoing efforts, we're working tirelessly to ensure that access to essential treatments and therapies becomes a reality for all those in need in our province.

HONOURING EXCELLENCE: NF STAR AWARD FOR HEALTHCARE EXCELLENCE

In 2024, the Tumour Foundation of BC proudly introduced the NF Star Award for Healthcare Excellence, recognizing the exceptional dedication, compassion, and expertise of healthcare professionals who provide critical care to individuals living with NF. With no specialized NF clinic or experts in British Columbia, these professionals are essential in helping patients navigate the complex healthcare system.

At our June gala, we honoured two outstanding individuals who have gone above and beyond in NF care—Dr. Janice Wong and Naomi Evans, RN. Their tireless work not only improves the lives of their patients but also serves as an inspiration to their peers. Their contributions highlight the importance of exceptional healthcare in the NF community.





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DEVELOPING LEADERS IN NF

PAUL RALFS VOLUNTEER AWARD

The Paul Ralfs Volunteer Award honours the legacy of the Tumour Foundation of BC's founder, Paul Ralfs, who spent over three decades raising awareness of NF, offering support to those affected, and ensuring that no one with NF walks their journey alone.

In 2023 we were thrilled to present the award to Bernice Chan, an exceptional individual who has dedicated countless hours to raising awareness, fundraising, and supporting the Foundation's events. Bernice has been a vital presence at the Scotiabank Charity Run, and has graciously supported the auction at Cocktails for a Cure and A Night of Magic and Miracles for NF. Her generosity extends far beyond her official volunteer duties, as she regularly steps up to help even when attending events as a guest.

In addition to her event contributions, Bernice has been a driving force behind the Shine a Light on NF campaign, reaching out to landmarks across the province and inspiring them to light up in support of NF. Thanks to her dedication, many lives have been touched and countless landmarks illuminated. We are proud to recognize Bernice as the 2023 recipient of the Paul Ralfs Volunteer Award, in honour of her outstanding commitment to the NF community.



LEADERSHIP SUMMIT

In October 2023, we proudly hosted the first annual NF Leadership Summit, bringing together volunteers and leaders from NF organizations across Canada for a day of learning and connection. It was the first time since 2010 that NF leaders came together, and it certainly won't be the last as plans are underway for the 2024 event. During our day together we deepened our understanding of the drug development process, honed our social media messaging, explored advocacy strategies, and forged new strategic collaborations.



BOARD LEADERSHIP

At the end of the year, the Tumour Foundation of BC experienced a significant change in leadership as Jill Taylor, our President, stepped down after seven years of dedicated service to the NF community. Jill was a passionate advocate for the NF clinic, working tirelessly with staff, government officials, and the community to push the virtual NF clinic project forward. She also played a key role in our annual auction, rallying support from family and friends on Vancouver Island. Leading the Foundation through the challenges of the pandemic, Jill's strong leadership ensured we navigated those turbulent times with resilience and success.

Now, more than ever, the Board of Directors needs dedicated and passionate members to lead the organization into the future. We invite you to consider joining our team and making a lasting impact for the NF community.



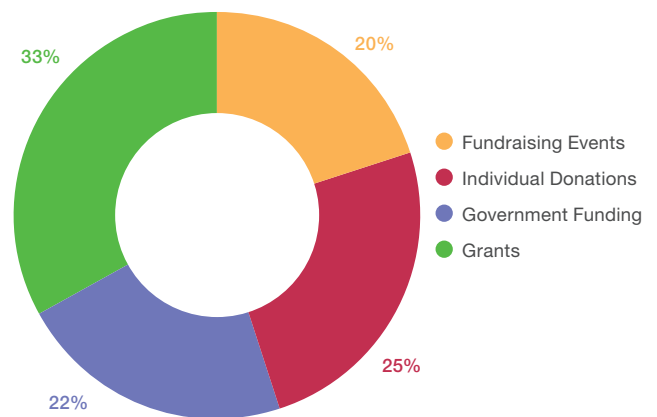
TREASURER'S REPORT

As we look back on the past fiscal year, we're filled with gratitude for the incredible impact your support has made. Despite a national trend of declining charitable donations across all income brackets (as noted in the CanadaHelps 2024 Giving Report), our loyal donor base continues to rise to the occasion. Your unwavering dedication to our mission fuels our work every day, and we're truly humbled by your commitment to making a difference for families facing the challenges of NF – especially during these tough financial times.

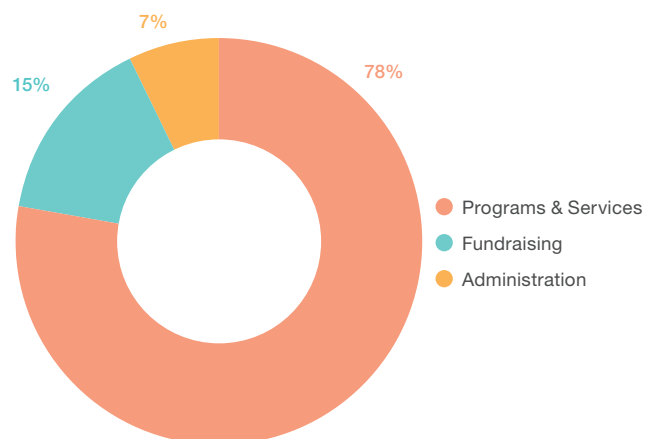
Every dollar counts in a small organization like the Tumour Foundation of BC. Whether you made a one-time donation, joined our monthly giving program, attended a fundraising event, or made a planned gift, we simply couldn't do this important work without you.

In 2024, we decided it was time to refresh our annual dinner and auction. This year's event, A Night of Magic and Miracles for NF, was described by one loyal donor as our "best event ever!" While the auction has long been a focal point of the evening, this time it took a back seat to pure entertainment. Acrobats, dancers, and a magician brought fun and excitement to the night, while our skilled auctioneer, Scott Melville, created an atmosphere where donors felt comfortable and enthusiastic about giving. Thanks to your generosity, the event raised over \$45,000!

REVENUE \$245,484



EXPENSES \$232,693



For full financial statements please visit tumourfoundation.ca



That said, fundraising has never been more challenging. Like many charities across Canada, we're seeing a decline in support from key funding sources—including governments, corporations, businesses and individuals. This trend has made securing sponsorships and auction items for our events increasingly difficult, and it's something we're keenly aware of as we plan for the future.

We would also like to extend a special thank you to Alexion for their continued support. Their generous grants allowed us to expand the NF Health Line, provide scholarships for families attending our symposium, and offer thoughtful touches like a hot breakfast, giving families a chance to unwind and connect during what can be an overwhelming experience.

Lastly, our heartfelt thanks go to the Province of BC for their ongoing support. The funds provided through the community grant program are vital to delivering essential programs and services, and they continue to make a real difference in the lives of those we serve.

Thank you for being part of our journey and helping us achieve so much in 2024. Together, we'll continue to provide support and hope to the NF community.



*Submitted by John Stylianou,
Treasurer*





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YOU CAN MAKE A DIFFERENCE

Ready to be part of something amazing? You have the power to make a real impact in the lives of those living with NF! Here are some exciting ways you can join us in making a difference:

Donate: Every dollar counts! Your contribution—whether big or small—helps us deliver vital programs and services to the NF community. Want to make an even bigger impact? Become a regular supporter! Visit our website → tumourfoundation.ca or give us a call at → **1-800-385-2263** to donate today.

Volunteer: Our volunteers are the heartbeat of everything we do. Whether you're an event planner, fundraiser, or simply want to lend a hand, your time and skills can change lives. Interested in joining our team? Drop us a line at → info@tumourfoundation.ca and let's get started!

Spread Awareness: Help us spread the word! Share our mission with your friends, family, and on social media to raise awareness of NF. The more people who know about NF, the bigger the support network we can build!

Join Our Events: We'd love to see you at our events! Whether it's a fundraiser, an awareness campaign, or an educational workshop, your participation helps us grow stronger as a community.

Be an Advocate: Speak up for those living with NF! By promoting understanding and compassion, you help create a more inclusive world for everyone affected by this condition.

Together, we're unstoppable! Your support—whether through donations, volunteering, spreading the word, or advocacy—drives our mission forward. Let's create a brighter, more hopeful future for everyone living with NF.

