



12 COUNTRIES
15 ORGANISATIONS
ARE COMING TOGETHER TO
**RAISE AWARENESS
FOR NF**



A Voice for NF Patients & their Families **NF Awareness Month**

A Message from our General Manager

As we reflect on the past year, it's evident that NF Ireland has been actively engaged in forging new partnerships with key stakeholders in the state sector, public bodies, and the medical profession. These collaborations are poised to benefit the association in the year ahead, paving the way for enhanced support and services.

Our membership continues to expand, with a growing number of families and individuals joining our community through our strategic use of social media and advancements in our NF Ireland website.

Efforts persist in advocating for improved medical services and facilities for individuals with NF in Ireland, as we work closely with politicians, the Department of Health, and Clinical Directors in Children's Health Ireland. We're excited to announce our plans to send young Irish members to the NF Patient Academy in Rotterdam, Netherlands, later this year, and our attendance at the European NF Conference in Brussels.

As we eagerly anticipate fresh advancements in research in the years to come, let's make the most of NF Awareness Month and continue spreading awareness and support for the NF community.

Here's to progress, partnerships, and a brighter future ahead.

Fergal Griffin

General Manager

Funding Appeal

Revitalizing the Association: A Call to Action

Dear Members,

We're once again reaching out to you, our valued members, for your support in keeping our association thriving. Despite our efforts to streamline operations, financial challenges persist, making it difficult to plan for the future. As the most generous per capita, Irish people have the power to make a significant impact. However, we often find ourselves overshadowed by larger charities with celebrity endorsements and extensive media coverage.

We urge you to consider fundraising for the Neurofibromatosis Association of Ireland. Your contributions are vital to our continued existence. With your help, we can maintain our extensive network across Europe and uphold our reputation as one of the leading NF associations on the continent.

Having a strong support group is essential for advocating for improved services and ensuring access to quality information about the condition. Therefore, we implore you to take action in any way you can.

Whether it's hosting a coffee morning, organizing a jersey day, participating in the VHI 2024 Mini Marathon, holding a church gate collection, hosting a pub quiz night, organizing a raffle, placing collection boxes in local shops, or simply collecting loose change, every effort counts.

Together, let's ensure the sustainability of our association and continue our important work in supporting individuals with Neurofibromatosis.

Warm regards,

Paul Fox

How to Make a Donation and Support NF Ireland

Making a Safe and Secure Donations to NF Ireland

How you can donate to NF Ireland:

NF Ireland's Website: Visit our official website at www.nfaireland.ie and donate directly through our webpage.

iDonate: Support us through our official iDonate page at www.idonate.ie/cause/NFAIreland.

PayPal: Contribute via our official PayPal page at www.paypal.com/IE/fundraiser/charity/4168393.

Direct Debit / Bank Transfer: Account: [07550-200](https://www.bankofireland.ie/07550-200) Sort Code: [93-36-27](https://www.bankofireland.ie/93-36-27) IBAN: [IE73 AIBK 9336 2707 5502 00](https://www.bankofireland.ie/IE73AIBK93362707550200)

Your donations are invaluable to us and are utilized for the operation of our association, including our 24-hour support line. Every contribution is greatly appreciated.

Become an Active Member: Annual Membership

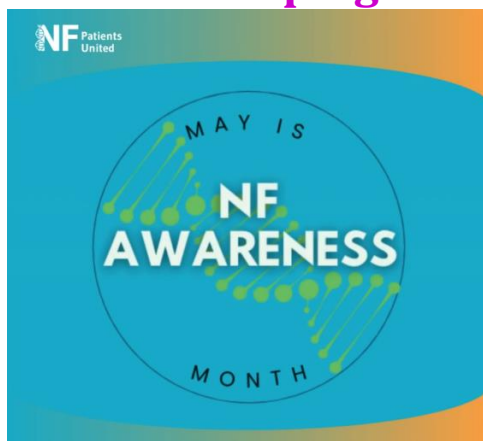
Join Hands with Your Association and Show Your Support!

NF families are encouraged to join and actively participate in our association. Annual membership is voluntary, with a suggested contribution of €20. You have the option to set up a recurring monthly payment or make a one-time payment annually. Convenient payment methods above are available for your ease.

Together, let's make a difference! Join us today.

NF Awareness Month 2024

NFPU Awareness Campaign May 2024, #ofcourse challenge



During the month of May 2023, NF Ireland along with NF Patients United will be running an awareness campaign for people living with Neurofibromatosis in Ireland. People with NF doing everyday normal things and showing that despite NF they are just like everyone else but do have some challenges and looking happy.

This initiative aims to elevate public awareness surrounding NF, fostering understanding of its symptoms and impact. Additionally, it will drive research efforts towards developing effective treatments and medical interventions for individuals living with NF.

How Can You Make a Difference: Throughout the campaign, your engagement is key. Simply interact with our posts, stories, and videos by commenting, liking, and sharing them across our social media platforms with your family and friends. Look out for updates on Facebook, Instagram & Twitter.

Hashtags to use: #ofcourse #NFPatientsUnited #NFAwareness #nf

Your involvement will significantly expand the organization's outreach and impact. Furthermore, our NF Patients Ambassadors Aoife O'Donovan, Cathy Milner and Gillian Dunne Minnock will be actively connecting with our members across social media.

Follow us on the social media links provided below. Not only will you stay informed about our meetups and latest research findings, but you'll also be part of a vibrant community dedicated to making a positive difference.



www.facebook.com/NFAIreland



www.instagram.com/nfaireland/



www.twitter.com/NfIreland

NF1 National Care Pathway Development Update

NF1 Care Pathway in Ireland

NF Ireland is collaborating with the National Rare Diseases Office to develop a comprehensive NF1 National Care Pathway. This pathway will serve as a structured guide outlining the optimal approach to care for individuals with NF1 in Ireland.

Anticipated for later this year, we eagerly await updates from the NCPE and HSE regarding formal approval. Once approved, this pathway will pave the way for significant enhancements in NF1 services provided by the HSE, ensuring streamlined and consistent care for the NF1 community across the country.

The National Care Pathway represents a vital step forward in improving access to specialized care, standardizing treatment protocols, and ultimately enhancing the quality of life for individuals living with NF1 in Ireland.

Topical Gel in the Treatment of Cutaneous Neurofibromas

NFlection's Topical Gel for cNFs, Phase 3

We're pleased to share the groundbreaking results from the Phase 2b Study of NFX 179 Topical Gel in the Treatment of Cutaneous Neurofibromas in Neurofibromatosis Type 1 (NF1). This innovative topical treatment exhibits significant potential for addressing cutaneous neurofibromas. NFlection is currently identifying satellite sites across Europe for Phase 3 development in 2024. NF Ireland are scheduled to meet NFlection at the European NF Conference in Brussels this June, to discuss progressing this initiative, with the aim of bringing the trial to Ireland.

How you can find out more information:

www.ctf.org/news/nflection-therapeutics-announces-positive-results-from-phase-2b-clinical-trial/

NF Ireland Website

Introducing the New NF Ireland Website

We're thrilled to announce the launch of our revamped website! It's more than just a virtual space—it's a vibrant hub connecting you with the wider NF community right here in Ireland. Dive in to discover the latest research breakthroughs and invaluable information on Neurofibromatosis.

Stay in the loop by signing up for our online newsletters, ensuring you never miss a beat in the NF world. Plus, our '**Get in touch**' feature is available 24/7, ready to address any questions or queries you may have. Join us on this exciting journey towards greater awareness and support for NF. Explore our website now at www.nfaireland.ie and let's make a positive impact together!

Selumetinib Submission Update

The New Treatment for Inoperable Plexiform Neurofibromas

Koselugo (Selumetinib) by Astrazeneca has received approval from the EMA for use in Europe, including Ireland! This innovative medicine targets inoperable plexiform neurofibromas in NF patients aged > 3 years, offering promising results in tumour size reduction, pain relief, and enhancing quality of life.

On behalf of all our members who would benefit from this drug, NF Ireland will be making a Patient Organisation Submission to the NCPE. The timeline for patient organization submissions is now set for December 2024. Our team at NF Ireland will spearhead the process, championing the voices of our NF patients and members to ensure this vital treatment becomes accessible.

How can you help? Participate in our Selumetinib Campaign/Questionnaire! Your involvement is crucial in advocating for free access to this life-changing medication. Whether you're a parent, caregiver, family member, or individual with NF and inoperable plexiform neurofibromas, your support matters!

To join the campaign or learn more, contact us at: info@nfaireland.ie or call our Helpline at 085 702 0024.

June Edition of the NFPU Online Magazine

NF Patients Online United Magazine

In this edition, we delve into orthopedic symptoms such as congenital pseudo-arthritis and scoliosis, alongside additional mental health support topics tailored for NF1 patients. Our Mental Health section offers practical insights into navigating life with NF.

Explore these topics and more in the new NFPU Online Magazine. By registering through the following link, you'll receive access to the latest editions and have the opportunity to browse through past issues. Previous editions have covered topics ranging from cutaneous neurofibromas in NF1 to advances in NF1 & NF2 research.

Don't miss out! Subscribe now at: www.nf-patients.eu/nf-online-magazine/

♥ NF Summer Academy 2024 ♥

NF Academy in Rotterdam, Netherlands for Irish Members



Applications are now open for young Irish people aged 19-39 years. This one-week training program brings together individuals with Neurofibromatosis from across Europe to undergo NF ambassador training. Participants will receive education on medical topics related to NF, mental health, and essential skills for advocating for other NF patients. This collaborative event is organized in partnership with NFPU & NF member organizations throughout Europe.

Our Irish Ambassadors, Aoife O'Donovan and Cathy Milner, are here to help and answer any questions you may have.

Young patients, or siblings of patients, will learn about NF1, NF2 / Schwannomatosis, patient advocacy, patient involvement in research and how to deal with the challenges that they are facing. The training will allow participants to become NF Ambassadors and to work with patient organizations on a national level. This is a fully funded event.

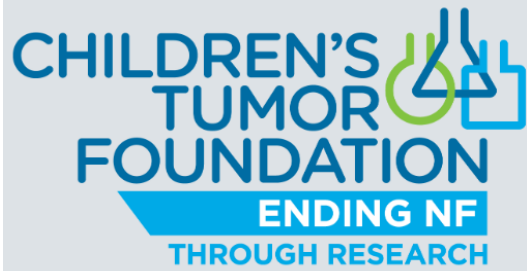
NF Ambassador Training Itinerary:

- **Location:** Rotterdam (Netherlands)
- **Date:** August. 24th – August 30th, 2024
- **Age Group:** 19 – 39 years
- **Participants:** Can be patients, siblings or young parents of children with NF

As spaces are limited, if you're interested in attending, please email info@nfairland.ie. Next, visit www.nf-patients.eu/nf-academy-2024/ to complete the application form by May 17th. If your application is successful, NF Patients United will contact you.

♥ 2024 Global NF Conference Brussels ♥

NF Patient Engagement Day



PATIENT DAY
NF CONFERENCE

This year's NF Patient Engagement Day is hosted by CTF and will take place on *Friday, June 21st, 2024*. The Children's Tumor Foundation is dedicated to involving patients in ending NF by incorporating their input into drug development and research. This year, CTF are hosting their Patient Engagement Day alongside their annual NF Conference. This event connects patients with researchers and clinicians, fostering collaboration to advance the NF field. Attendees will participate in educational sessions on diagnostics, lifestyle behaviours, and patient roles in clinical trials. We'll also engage in collaborative discussions to identify key focus areas and brainstorm solutions for our challenges. It's an opportunity for patients and caregivers to connect and discuss accelerating the development of NF resources and treatments.

Information and registration: <https://web.event.com/event/73f6b50f-21a3-4bfc-ae5f-e4b43c23a1b4/summary>

Shine a Light on NF

♥🌍 May 17th is World NF Awareness Day 🌍♥



Join NF Ireland as we continue to shine a light on this genetic disorder that affects countless lives worldwide. Despite its challenges and the absence of a cure, individuals with NF inspire us daily with their resilience, dignity, and even humour in the face of adversity.

This year, landmarks across Ireland will illuminate in Blue and Green to show their support for our association and the NF community. This visual display not only raises awareness but also instils a sense of pride and unity among those impacted by NF.

NF is a rare disease, and spreading awareness is key to fostering understanding and support. Let's come together to amplify our voices, share our stories, and shine a light on NF this World NF Awareness Day!

This year, NF Ireland is teaming up with Nerve Tumours UK and the Childhood Tumour Trust for this initiative.

May is NF Awareness Month and I invite members of the community to formalize themselves more about campaign by following all our social media channels. We will be posting lots of positive content about living with NF.

Vhi Women's Mini Marathon, 2024

Join us for the Vhi Women's Mini Marathon on June 2nd



The VHI Women's Mini Marathon is back for 2024

Vhi Women's Mini Marathon will be taking place on Sunday June 2nd in Dublin City Centre. Sign up is now open, and we look forward to seeing you on the day. Whether you walk, jog, or run, your participation will help raise vital funds for the Neurofibromatosis Association of Ireland. Experience the magic of this special event while making a difference in the lives of those affected by Neurofibromatosis.

Please visit our iDonate page where you can donate directly or create a personal fundraising page. Your participation in the marathon or donations will directly impact the lives of those affected by Neurofibromatosis, enabling us to continue our vital work: providing support, raising awareness, and funding research to improve the lives of individuals and families living with NF.

If you can't make it to Dublin on June 2nd, you can still join in the fun from anywhere in the world virtually. Donate directly or create a fundraising page: www.idonate.ie/team/nfirelandminimarathon

Advocating for Enhanced Services for Patient

NF Ireland's Fresh Vision for NF Patient Care

At NF Ireland, we're dedicated to championing the needs of our members and striving for improved medical care services in the Children's Health Ireland network. As advocates for individuals and families affected by this genetic condition, we're actively engaging with political parties, healthcare authorities, and stakeholders to drive positive change.

Our priorities are clear: We're calling for immediate action to address the inadequate staffing resources and lack of diagnostic equipment in CHI facilities. We demand that CHI Ireland commits to reviewing and enhancing the quality and equity of care provided to NF patients across all CHI sites.

Here are NF Ireland's key demands:

- Prioritize swift scheduling of initial appointments for new patients referred by GPs
- Vastly improved care for existing patients, including enhanced access to specialist services like Paediatric Dermatology, Neurology, Ophthalmology, and Genetic Counselling.
- Urgent resolution of equipment shortages for NF diagnosis, monitoring, and treatment.
- Continued care for patients transitioning to adulthood, with access to Neurologists and Dermatologists.
- Ensuring treatment for NF children at the New Children's Hospital, with increased capacity and resources.

NF Ireland are confident of a bright future ahead and will keep all our members updated. You can also help by contacting your local TDs to push for better services for NF patients in Ireland.

Advocating for Patients

NF Ireland's Impact on Your Journey

NF Ireland offers an extensive array of services, including a dedicated 24-Hour Patient Helpline and comprehensive literature on Neurofibromatosis. We actively engage in clinical studies and research initiatives across Europe and the US. Our mission is to foster a sense of community among families and patients, alleviating the burden of isolation. We collaborate closely with healthcare professionals and serve as the primary source of NF literature for patients, hospital doctors, GPs, and public health nurses. All our services are provided free of charge, and inquiries are handled with the utmost confidentiality.

-  Sole Provider of NF Literature to Patients & Medical Professionals
-  Patient Helpline & Comprehensive Literature
-  Community Support: Uniting Families & Patients
-  Active Participation in Global Clinical Research
-  Ongoing Liaison with Healthcare Professionals

The aims of the NF Association of Ireland are:

Information & Research Dissemination

Provide NF information to patients, doctors, consultants, and educators. Additionally, raise awareness and enhance understanding of the challenges associated with the disorder.

Community Building & Networking

Unite individuals affected by NF to combat feelings of isolation. Foster connections with similar organizations and medical professionals on both national and international levels. Work towards establishing an NF Patient Registry in Ireland to enhance services offered.

Family Support & Respite Weekends

Create initiatives aimed at enhancing the quality of life for families affected by NF. Organize Respite Weekends specifically designed for NF families, with a focus on catering to the needs of children and young adults.

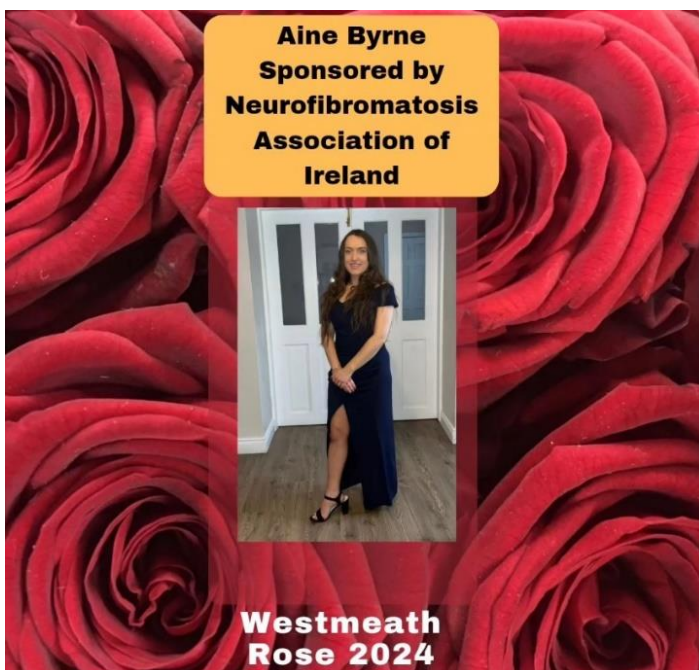
Policy Advocacy with Health Authorities

Contribute positively to the policy-making processes of the Department of Health and other relevant state entities.

Westmeath Rose of Tralee Aine Byrne

Aine Bryne with our new Mascot Patrick

Congratulations to Aine Byrne on your amazing achievement and for stepping out of your comfort zone to participate in the international Westmeath Rose. Aine had an unforgettable experience and met some incredible people along the way. A big thank you to Rachel, Sarah, and everyone else who supported Aine on this journey. NF Ireland were delighted to sponsor you, allowing you to promote such an important cause close to your heart. A big thank you to Aine for shining a light on Neurofibromatosis in Ireland.



Princess Alannah Glowing Adventure

Book for Irish Children Living with NF



Princess Alannah is not like the other mermaids. One day when a glow fish goes missing, Alannah and her friends Scoot, set off on an adventure to find the glow fish and they help him realize being different is a great thing to be! Help your child to see everyone is unique and it is our differences that make us beautiful with this enchanting mermaid tale from the author of The Princess Lily Series. Written by Sarah Bankuti.

Sarah first heard the words NF (Neurofibromatosis) when her daughter Alice was around 6 months old. Her doctors noticed she had 4 cafe au lait spots on her body. Then when Alice was 10 months, they found out she had a brain tumour. People with NF have an increased risk of tumours. When Alice was one, she had genetic testing done but the results showed negative for NF.

Stay tuned for very exciting news about this book and how to get it.

NF Ireland on Newstalk with Pay Kenny

Advocating for Neurofibromatosis on the National Airways



Congratulations to Gillian Dunne Minnock, NF Ireland's Patient Ambassador, and to Vicky McGrath, Chief Executive of Rare Diseases Ireland, for their exceptional advocacy efforts and insightful interview on Newstalk Radio with Pat Kenny. Gillian's personal journey living with Neurofibromatosis, alongside her children, adds a profound depth to her role as our Patient Ambassador. We extend our heartfelt gratitude to Pat Kenny for his remarkable contribution and to the exceptional team at Newstalk for providing a platform to raise awareness about rare diseases like Neurofibromatosis.

Expanding Newborn Screening to More Conditions Like NF

Get Rare Aware Campaign 2024

Ireland does less newborn screening than 75% of European countries. Take Action Today!

www.getrareaware.ie



Did you know that Ireland lags behind 75% of European countries in newborn screening? In the past five years, only one new test has been introduced. This means that the lives of 200 Irish children could be saved or significantly improved each year with a more comprehensive screening program.

Rare Diseases Ireland's latest campaign calls upon politicians to support the expansion of the nationwide newborn screening program in Ireland. Through their Get Rare Aware campaign, Rare Diseases Ireland highlights the urgent need for Ireland to broaden its screening program to include conditions like Neurofibromatosis.

Join us in advocating for change by joining the campaign at: www.getrareaware.ie

Disability Rights Bill Passes Committee Stage

A Step Forward for People Living with Disabilities

We are thrilled to announce that the Tom Clonan Disability (Rights) Bill 2023 has successfully passed the Committee Stage. We extend our heartfelt gratitude to Taoiseach Simon Harris TD and Minister Anne Rabbitte for their crucial support throughout this process. NF Ireland was honoured to be present at Seanad Éireann during these significant proceedings.

This milestone marks a monumental leap forward for all individuals in Ireland seeking care and assistance from the government. It has the potential to be a historic moment for the fundamental human rights of disabled citizens in Ireland.

A huge shoutout to all the incredible advocacy groups and individuals who rallied together to support Tom Clonan. This milestone shows the power of unity and collaboration. Together, we can continue to drive positive change and make a difference in the lives of people with disabilities. Let's keep pushing forward.



Own Your Very Own Patrick 🦒

Own Patrick and Support the Neurofibromatosis Association of Ireland

We invite you to stand alongside us in making a tangible impact for those impacted by NF by supporting the Neurofibromatosis Association of Ireland. NF affects numerous individuals and families throughout Ireland, and your contribution can help us offer essential support and resources to those in need.

Why not organize a small fundraiser, such as a coffee morning or church gate collection, or set up an iDonate page for NF Ireland?

To embrace Patrick, consider making a donation of €100 through any of our donation methods, as outlined on the second page of this newsletter. The simplest method is to visit our website at www.nfaireland.ie, where you'll find a Donate button on the homepage to facilitate your payment. Additionally, please reach out to us via email at info@nfaireland.ie, and we'll promptly send Patrick your way.

Let's unite in making a meaningful difference together!



R.I.P Jimy Corr

Jimmy Corr

The Neurofibromatosis Association of Ireland extend their heartfelt condolence to the Corr family on Jimmy's passing. We remember him as a very intelligent, interesting and kindhearted person who devoted his entire life to helping those who relied on his in-depth knowledge and vast experience in dealing with problems associated with Neurofibromatosis. A former Director, Secretary, Chairman and Board Member of the Association, Jimmy loved his family, we all mourn the loss of such a wonderful person, a true gentleman, may he rest in peace.

The Officers and Committee of NF Ireland

If you require any further assistance from NF Ireland or if you need additional information, please don't hesitate to contact us. You can reach our confidential 24-hour helpline at 085 702 0024 or email us at info@nfaireland.ie. We're here to help.