Children's Tumour Foundation
CONQUERING NF

24/25 ANNUAL REPORT

CONTENTS

THE CHILDREN'S TUMOUR FOUNDATION IS THE ONLY DEDICATED NEUROFIBROMATOSIS ADVOCACY AND SUPPORT SERVICE IN AUSTRALIA FOR CHILDREN, ADULTS, AND THEIR FAMILIES.

NF AFFECTS MORE THAN JUST PHYSICAL HEALTH - IT CAN IMPACT MENTAL WELLBEING, SOCIAL RELATIONSHIPS, WORK, AND EDUCATION.

WITH EXPERT KNOWLEDGE AND SPECIALISED CARE LIMITED, MANAGING THE CONDITION CAN BE CHALLENGING.

CTF PROVIDES FREE, SPECIALISED SUPPORT, CONNECTION PROGRAMS, GUIDANCE NAVIGATING HEALTHCARE, ADVOCACY, AND RESEARCH TO HELP PEOPLE WITH NF AND THEIR FAMILIES THRIVE.

NOTE FROM THE CHAIR
PETER DOWDING

FY2025 has been another landmark year for the Children's Tumour Foundation (CTF), defined by growth, collaboration, and tangible progress for Australians living with neurofibromatosis (NF).

Over the past year, we have continued to expand and enhance our support programs, connecting more families and individuals than ever before with tailored information, care navigation, and opportunities to engage with others who truly understand their journey. These services remain at the heart of everything we do, ensuring that no one faces NF alone.

We have also strengthened our commitment to enabling research, supporting studies that expand knowledge of how NF affects health, wellbeing, and quality of life. By connecting researchers with our community, we ensure that the patient voice guides research design, priorities, and outcomes. These insights are already shaping better support, advocacy, and clinical care across Australia.

Our advocacy efforts have grown in scope and impact, with ongoing engagement with government, healthcare professionals, and community partners. By championing the perspectives of people living with NF, we are helping to drive improvements in specialised healthcare and resources nationwide.

Building on the outcomes of our Health & Social Impact Study and inaugural NF Models of Care Workshop, CTF is now leading the development of Australia's first National Standards of Care Guidelines for NF - an 18-month project delivered in partnership with a multidisciplinary panel of clinicians and people with lived experience. Together, the study, workshop and forthcoming guidelines form a coordinated advocacy strategy to drive consistent, high-quality care for people living with NF across Australia.

Looking ahead, we remain determined to build on this momentum — expanding knowledge, connecting the community, and delivering programs that make a real difference in the lives of people living with NF. Together, we will continue to champion this community with purpose, dedication, and heart.

P. Dowding

Peter Dowding
Chair of the Board

OUR IMPACT IN FY25

9,500+

support interactions with hundreds of families.

1200+
phone calls made and received on our National Support Line.

77%
increase in families reaching out for support in the past year

358
individuals joined us for 42 NF Connect sessions throughout the year.

15
training and education events held for Health Care Professionals

PROGRAMS + SERVICES

OUR WORK

ADVOCACY

As the only patient advocacy organisation and support service for Australians with NF, we work tirelessly to make life more equitable for everyone living with this complex condition.

- Reduce diagnostic delays
- Improve healthcare education and care provision for NF
- Push for greater supports for complex NF care
- Timely access to effective and affordable treatments
- Increase investments into NF research

Activities:

- Engaging health and community sector
- Collaboration with business and therapeutics sector
- Government representation
- Individual advocacy support
- Public awareness initiatives
- Clinical Symposium
- Research enablement and recruitment

SUPPORT

We care for families, educate them on the condition and help them access supports. We bring kids and their families together via virtual meetups and camps across Australia.

- Provide personalised support
- Empower families with health resources and knowledge
- Provide opportunities to connect and peer support avenues
- Ease personal burden of managing a complex condition

Activities:

- Helpline
- NF Clinics
- NF Connect
- Camps
- Health kits
- Resources
- Webinars
- Information days
- Community days
- FB support group
- NDIS navigation

RESEARCH

We support research that investigates the complexities of the condition, advances access to effective treatments and progresses the search for a cure. Our research efforts focus on funding Australian treatment and clinical trials and supporting investigative studies into the many complexities of NF. We also engage in research participant recruitment.

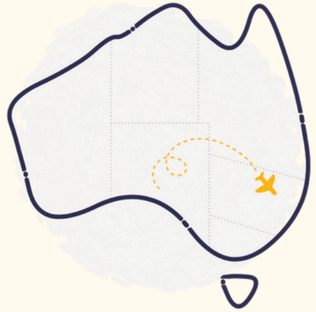
NF Clinical Symposium
Held biannually, this one of a kind event showcases both Australian and international speakers, stimulates new collaborations, demonstrates progress and fuels new ideas to conquer NF.

OUR PROGRAMS AIM TO:

Support research that will increase treatment options, and the search for a cure.

Care for families, educate them on the condition and help them access supports.

Bring kids and their families together via virtual meetups and camps across Australia.



Make NF a national priority and life more equitable for everyone living with NF.

SUPPORT AT EVERY STAGE

Every experience with NF is unique. We're here to meet you where ever you are at on your journey.

NATIONAL HELPLINE

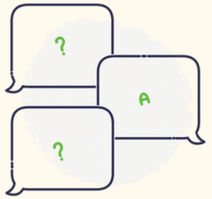
Our team of support coordinators are compassionate and caring individuals, all from health backgrounds who have a wealth of knowledge about NF.

INFORMATIVE RESOURCES

Our resource centre helps you learn more about NF, with general statistics, fact sheets, webinars and videos on a wide range of related topics.

NF CLINICS

NF clinics offers families a lifeline, providing comprehensive diagnostic evaluations, follow upcare and genetic counselling for kids, teens and young adults.

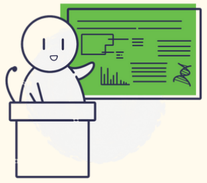


WEBINARS

Learn about advancements in health care and support, directly from those on the ground, including researchers and medical professionals.

INFORMATION EVENTS

Staying up to date with new clinical information, research trials and treatment methods is made easy by our information days that provide numerous presentations on NF.



INDIVIDUAL ADVOCACY

NF can impact a person physically, as well as their learning and development. Our team support families with NDIS applications and inform educators of individual needs.

NF CONNECT

NF Connect is an opportunity for members of our community to virtually connect with one another and our Support Team to help alleviate some of the stresses, fears and anxieties they may be experiencing.

PARENTS AND CARER SUPPORT

Neurofibromatosis is a big word when you are a little person. The love, care and support you provide along the way will allow them to face whatever challenges may occur.

RESEARCH

Families are kept informed about developments in treatments and investigative studies, as well encouraged to participate in clinical trials that are recruiting participants.

COMMUNITY DAYS

Spending time with others who share the condition promotes inclusion and allows families to relax, learn and expand their support network.

CAMPS

Community camps offer kids, their siblings and families a break from the complications of NF and a chance to get back to the joy of childhood.

ADVOCACY

As the only patient advocacy organisation and support service for Australians with NF, we work tirelessly to make life more equitable for everyone living with this complex condition.

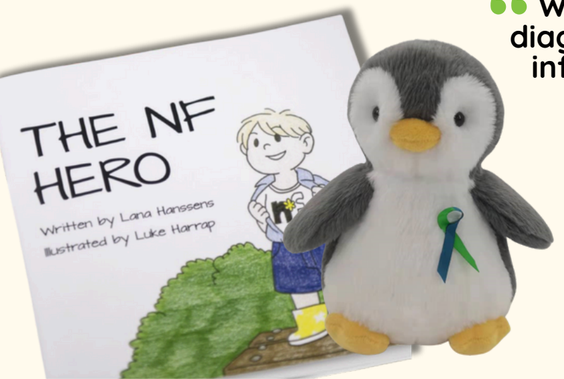
EXPANDING KNOWLEDGE

HEALTH MANAGEMENT KITS

In the past year, we have provided hundreds of resources and sent out 172 physical and digital Health Kits, to newly diagnosed individuals and families.

Health Management Kits provide basic, accurate information such as diagnostic criteria, frequently asked questions, medical checklists, resources for parents and teachers, cancer screening recommendations and everything in between. While many of the kits contain similar information, they are tailored to each individual based on the current diagnosis.

With the support of community grant funding we are able to send a Pebbles the Penguin toy, a cape and NF Hero book to children impacted by NF. This small but impactful gesture can have a huge impact on how children perceive their NF. They are designed to give children a way to find power in their NF diagnosis, rather than being defined by it. These small items help give children a way to find their own voice and to learn how to explain their NF to others. The penguin can also provide comfort on hospital visits.



“We have a child that has NF1 and since his diagnosis the CTF has been so supportive and informative as we have navigated our way through the challenges”

-Rachel

WEBINARS

Our NF Webinar Series presentations are hosted in collaboration with Australia’s leading clinicians and experts on NF and are available for free on our website. The topics cover a range of health and learning issues that are specifically tailored for people living with NF or caring for children with NF who are experiencing learning difficulties.

Key sessions held in FY2025 were:

- A powerful one-hour webinar exploring feelings of loss and grief that may come with an NF diagnosis and how to navigate them, with Dr. Nathan MacArthur.
- A webinar on the Strength Study - a clinical research study looking at whether L-carnitine can improve bodily functions and treat muscle weakness and fatigue in eligible children with NF1.

RESOURCES

Our resource centre available on our website provides information about NF, with general statistics, fact sheets, webinars and videos on a wide range of related topics.

For Health Care Professionals we released an NF GP module in late 2024 that explores NF Type 1 (NF1) and the GPs role in the complex diagnosis and management journey of patients and their caregivers. This was updated with Paediatric content in May 25. To date it has received more than 200 views.

We sent out 68 Teacher Toolkits in the past year that assists schools and teachers with NF1 or NF2-SWN students (Primary or Secondary). Five separate school presentations were also conducted by our Support Services Team

CONNECTING THE COMMUNITY

CAMPS AND COMMUNITY DAYS

Our camps offer kids and adults with NF, along with their families, a break from the complications of their condition and a chance to have fun, relax and meet other families.

Coming together for a free and fully-catered weekend of excitement, activities and adventure, families can unwind, enjoy quality precious time together, make positive new memories and build special connections.

NF camps enable children with NF to bond with others in similar circumstances and play in a safe environment, free from bullying and discrimination. With outdoor activities to enjoy from flying foxes and giants swings to canoeing and archery, children can develop new skills and confidence in themselves that assist in their development.

Parents can connect with knowledgeable CTF staff and with each other, often meeting for the first time other parents with a child with NF.

In the past year we hosted camps in WA, QLD, NSW and VIC. Over 347 people attended our camps in 2024 which is an increase of 18%.

“ We attended our first NF Camp and we instantly felt welcome and supported. We made connections and our son felt free to be himself. We left feeling more aware of the condition and how it affects people in different ways, especially helpful as we have had a recent diagnosis. We are now much more aware of the good work of CTF and how they can support us. ”

2025 WA Camp Attendee

CANBERRA COMMUNITY DAY

On the 17th of May 2025 - World NF Awareness Day - we hosted out first Adult Meet Up Community Day in Canberra. with 25 attendees.

From exploring the National Portrait Gallery, to enjoying afternoon tea, dinner and a trip to the Bus Deport Markets. We also saw Canberra's landmarks light up in blue and green for NF Awareness Day. The weekend was filled with connection, conversation, and community.

“It's like a whole new world has opened up. Yes they may not all have the same type of NF as me but we are united by NF. We are now connected - it's fabulous. It felt like one big family! ”

2025 Canberra Meet Up
Participant

DAMIANO'S STORY

Damiano was a healthy baby, but by eight months old he had more than 19 café au lait marks. A paediatrician confirmed NF1 soon after, and life changed quickly. By early 2022, his first MRI revealed an optic nerve glioma. Today, tumours affect both eyes, and he undergoes regular scans, eye reviews and ongoing genetic care.

Alongside NF1, Damiano lives with autism (level 3), severe language impairment and major developmental delays. He relies on formula feeding and works with a full team of therapists under the NDIS. The load on the family is constant and heavy, especially for his two older siblings, who've had to grow up fast.

His mum says the stress of appointments, school planning and financial pressure is relentless—but what lifted the weight was finding community.

Their first CTF camp was a turning point. For the first time, they felt understood and supported, surrounded by families living the same reality. The information, resources and connection have become a lifeline.

Damiano is now preparing for kindy in 2026, and the family continues to navigate the ups and downs. Through it all, they remain motivated by Damiano's happiness and resilience, and by knowing they're not facing NF alone.

> **"Our first camp was in 2023 and there was no judgement, and just to meet parents, carers and children all going through the same things and every one of us have our own stories to tell, just made me feel we are not alone."**
>
> Damiano's Mum

ARCHIE BROTHERS COMMUNITY DAY

For the fourth year running, we were thrilled to partner once again with Archie Brothers at locations around Australia to bring joy, laughter, and a whole stack of fun to NF families for NF Awareness Month.

Attended by **328 kids, parents and caregivers**, it was a chance for our community to come together, connect, and just have fun.

A huge thank you to Archie Brothers for continuing to support those impacted by NF.

89%

Stated connection to others was limited prior to camp

100%

Stated connection had improved following the NF Camp.

VIRTUAL CONNECTION

NF Connect is a monthly online peer support program, providing a safe space to talk to other people in similar circumstances. The sessions are facilitated so participants can ask questions of staff and each other. This also allows them to increase their knowledge and understanding of NF, with conversations flowing naturally based on what matters to the people in the (virtual) room.

These programs have been increasing on average 10% per annum. Participation in our virtual peer support and connection program, NF Connect, grew by 15% in FY2025, with 358 attending 42 sessions offered throughout the year.

Connecting with others with lived experience and sharing information about health and disability services and supports is valuable for families as it provides them with information and reduces their sense of isolation. Each month, we host distinct sessions for several groups, including, Teens and Young Adults, Parents and Carers, Adults with NF as well as Adults with NF2 and Schwannomatosis.

“There’s a great sense of community and belonging in these sessions where we can bond over our shared condition that no one else would understand. What is most rewarding for me was talking to people who had gone through surgeries or taken medication that I was about to myself, so I could learn about the process and what to expect from someone that experienced it first hand.”

Michael - 2025 NF Connect attendee

FB GROUP

The closed Facebook Group continues to be an important online space for people living with NF and their families to connect with others who truly understand their experiences. It provides a safe and supportive environment where members can ask questions, share advice, and offer encouragement to those navigating similar health challenges or life events.

Over the past year, conversations have ranged from recommendations for NF-aware specialists and local services, to sharing personal stories of diagnosis, treatment, and resilience. The group has also become a hub for discussing upcoming community events and raising awareness initiatives, helping members feel less isolated and more connected to the wider NF community.

In FY2025, the private group grew by 134 new members – an increase of almost 12% – bringing total participation to 1,270 people. This growth highlights the ongoing value of the group as a trusted source of peer support and information.

SOCIAL MEDIA

In addition to the private Facebook group, members of the NF community can reach out directly to our Support Services team via messages on our social media pages. In FY2025, we responded to over 150 enquiries, covering a range of topics including questions about symptoms, requests for resources, and simply seeking support following a new diagnosis. These interactions provide another important way for the community to access guidance and reassurance from our experienced support team.







EDELRID


NT
CAMP


Ashton









NAVIGATING NF

KNOWLEDGE AND EDUCATION

Beyond medical care, navigating NF can involve educational, emotional, and social challenges. This year, our team has worked to provide guidance and raise awareness across these areas.

CTF was invited to present at the NSW Genetic Counselling Education Day at Royal North Shore Hospital, discussing the role of CTF in supporting families beyond an initial diagnosis.

In addition, our team participated in professional development opportunities to enhance the support we provide, including sessions on grief counselling, navigating difficult conversations, accidental counselling, and trauma-informed care within diagnostic environments. These initiatives help ensure that families and children with NF receive informed, compassionate, and holistic support.

In February, our Support Services Team, sat down with Megan on the Live and Learn podcast by Missing School to chat all things NF and the ways schools could better support children with chronic and genetic conditions.

PAEDIATRIC TO ADULT CARE

The time for transitioning from paediatric to adult health services can be concerning for parents and adolescents and being prepared can help ease the burden. We interact with people at critical life stages, which includes early childhood and development, starting school and high school and transitioning to adult care and then into the workforce or further education.

NF CLINICS

CTF part-funds two Clinical Health Nurse roles at Children's Hospital Westmead and the Royal Children's Hospital, Melbourne, supporting complex paediatric patients with coordinated, multi-disciplinary care.

These tertiary clinics see hundreds of children each year, improving health outcomes through surveillance, early intervention, and easier access to treatments and clinical trials. The hospitals also host NF1 Learning Clinics, bringing together neurologists, geneticists, nurses, genetic counsellors, and researchers to provide expert care and advice to families, GPs, and paediatricians.

22% **increase in patients through the Sydney Westmead NF Clinic**

HELPLINE

The NF Helpline is the only place to go for comprehensive support, care and information. And as NF affects not only physical health, but also relationships, mental health, school, career and every aspect of life, the Support Services Team is equipped to support people through a range of issues.

Our person-centred approach to care, means we cover a broad range of topics, which can include health concerns, grief and learning supports. The demand for the NF Helpline has continued to increase as awareness of our services grows, so does the number of people with NF seeking support.

> **"My child has NF1 and having a network that goes above and beyond for those connected and interested in NF is absolutely amazing. The communication, information and interest is so heart warming."**
>
> Gillian

ADVOCACY

DRIVING CHANGE FOR THE NF COMMUNITY

A first-of-its-kind study in Australia, the 2024 Health and Social Impact Assessment in Neurofibromatosis provides a comprehensive understanding of the physical, psychosocial, and financial impact of all types of NF on individuals, families, and the broader community. The findings have given CTF a strong evidence base to advocate for improved support services, identify gaps in care, and shape future initiatives.

Building on the report's outcomes, we hosted the first **NF Models of Care Workshop** in Sydney on 22 November. The workshop, supported by our partners Alexion Pharmaceuticals and Whiteley, brought together over 60 specialists from across the country, including oncologists, paediatricians, neurologists, neuropsychologists, genetic counsellors, ophthalmologists, and clinical nurse coordinators.

Participants collaborated on ways to create better clinical pathways and more coordinated care for people living with NF. The day demonstrated a shared commitment to improving patient outcomes through a unified, national approach.

As a result CTF are leading the development of National Standards of Care Guidelines for NF, working with a multidisciplinary panel of clinicians and people with lived experience. This 18-month project will involve a systematic literature review and a Delphi consultation process, resulting in evidence-based guidelines.

Together, the study, workshop, and development of National Standards of Care form a coordinated advocacy strategy, ensuring consistent, high-quality care for people with NF across Australia.

SUMMARY OF RECOMMENDATIONS

Based on the key findings from the Health and Social Impact Report, the following six recommendations were developed to tackle the inequities that people living with or caring for those with NF experience in Australia.

1. **DEVELOP AND IMPLEMENT A NATIONAL STRATEGIC APPROACH THAT DRIVES EQUITABLE AND TIMELY CLINICAL CARE FOR NEUROFIBROMATOSIS.**
2. **ENSURE DELIVERY OF COORDINATED CARE ACROSS A PERSON'S NF LIFESPAN AS PEOPLE WITH NF REQUIRE ACCESS TO A RANGE OF MEDICAL AND SOCIAL SUPPORT SERVICES.**
3. **DELIVER TARGETED SUPPORTS FOR THE MENTAL HEALTH AND WELLBEING NEEDS OF NF PATIENTS AND THEIR CAREGIVERS.**
4. **INCREASE NATIONAL AWARENESS AND EDUCATION OF NF TO ELEVATE KNOWLEDGE OF CONDITION IMPACT, AND VARIABLE HEALTH AND SUPPORT NEEDS OF THE NF COMMUNITY.**
5. **ADDRESS KNOWLEDGE GAPS AMONG HEALTHCARE PROFESSIONALS OF NF TO IMPROVE DIAGNOSIS, TESTING AND TREATMENT, AND FURTHER ENABLE HEALTHCARE PROFESSIONALS TO MEET THE HEALTH AND SUPPORT NEEDS OF THOSE DIAGNOSED WITH NF.**
6. **INCREASE DATA COLLECTION, INVESTMENT IN GENOMICS AND RESEARCH INTO NF, AND ACCESS TO CLINICAL TRIALS TO DRIVE INNOVATION AND NF INTERVENTIONS AND CARE.**

INDIVIDUAL ADVOCACY

In the past year we have distributed Teacher's Toolkits to parents and educators throughout Australia. Our Support Team has also zoomed in to classrooms around the country connecting with teachers and schools to explain how NF can impact on attention, executive function, sensory processing and even hearing and sight.

We have posted out thousands of **iNFormation Community Cards** that can be easily carried in a wallet or purse and shared as a quick and easy way to introduce someone to the condition, Neurofibromatosis.

COMMUNITY ADVISORY PANEL

The Community Advisory Panel (CAP) was established to help guide all the work we do at the CTF.

The CAP meets four times a year and is the driving force behind every decision made at the CTF. It's a volunteer panel and we appreciate every hour of time that people donate to helping us to create awareness and improve health outcomes.

HEALTH PROFESSIONAL CONNECTION

In addition to launching the NF GP Module in 2024, our team participated in a series of targeted education and engagement sessions with health professionals across Australia, strengthening clinical understanding of NF and fostering improved pathways for patient care. Over the year, we joined four dedicated training sessions for paediatricians, educating more than 100 clinicians; an education meeting with six genetic counsellors at Monash Children's Hospital; and several individual meetings with specialists, including a neurosurgeon, a Clinical Research Manager, and a neuropsychologist from The Children's Hospital at Westmead. We also engaged with two additional clinicians — a neurologist and a paediatrician from Westmead — to support multidisciplinary care approaches. These interactions continue to build awareness, collaboration, and consistency in NF care across the country.

MEDICAL ADVISORY PANEL

The CTF's Medical Advisory Panel consists of leading clinical and scientific experts in the field of NF who sit on a volunteer board. This group play an active role in providing expert guidance, evaluation and recommendations, strategic input, clinical insights, and collaboration to deliver an annual NF Clinical Symposium.

In the past year, the MAP has worked alongside CTF to approve resource and info sheets and to help create a Models of Care Workshop to ensure that care for NF patients around the country is equitable and accessible. They also worked alongside us to ensure that the NF Health and Social Impact Assessment of Neurofibromatosis in Australia was a report that can be widely disseminated.

GOVERNMENT

Throughout the year, we actively engaged with officials at all levels of Government, Local, State and Federal, to ensure the voices of the Australian NF community were heard. Whether it's dealing with individual matters in regard to people living with NF (access to care, NDIS, social services, education) or working on broad systemic issues. CTF ensures that the NF community is represented, as we know that with awareness comes the opportunity to create change.

Our Support Services Team met with representatives from the Department of Health and Aged Care, along with Ministers and Advisors with a range of different portfolios and interests, including Child and Adolescent Health and NDIS.

Ruth and Speaker of the House, Hon Milton Dick MP

Ruth and Meredith pictured with Ms Sally Sitou MP

We also participated in the Rare Voices event at Parliament House and a Missing School Event with the ACT's Australian of the Year.

Highlighting the impact of NF, CTF presented our new Health and Social Impact Assessment at the 2024 Genetic Alliance Forum at NSW Parliament House, showcasing the realities faced by Australians living with NF and the importance of ongoing support.

Ruth and Meredith pictured with Hon Ed Husic MP and Dr Michelle Ananda Rajah MP

HEALTH CARE ADVOCACY

In August, the first and only medication, Koselugo (selumetinib), was listed on the Pharmaceuticals Benefit Scheme (PBS) for children 2- 18 years with inoperable plexiform neurofibromas (PNs)

The drug targets tumour growth by acting as a MEK inhibitor that blocks specific enzymes (MEK1 and MEK 2) which are involved in stimulating cells to grow. More than a third of individuals with NF1, develop complex tumours known as plexiform neurofibromas (PNs).

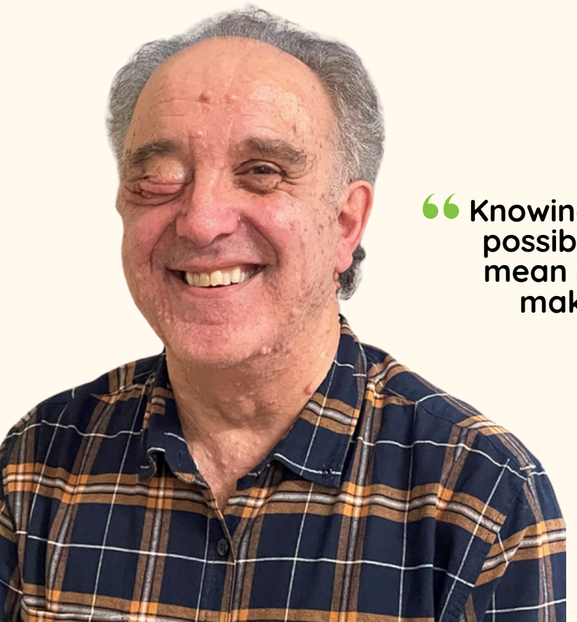
The CTF team partnered with the NF community to provide lived experience evidence to the Pharmaceutical Benefits Advisory Committee (PBAC) which helped the PBAC evaluate the value of innovative treatment where there is high unmet clinical need.

RESEARCH

CTF is dedicated to ensuring that the voices of people living with NF are central to research. We actively connect researchers with members of the NF community, whether as panel members to support co-design or as participants in research studies, ensuring patient perspectives shape research priorities and outcomes.

This year, we have supported participant recruitment across our platforms for several key research initiatives, including the **Strength Study**, **Metis Healthcare Research into Adults with Neurofibromatosis**, and the ongoing **NF1 Project**.

For the project "**Defining NF1 Clinical Variation at the Microscale to Discover New Therapeutic Targets**", CTF established a specialist Community Advisory Panel—separate from our own CAP—to provide Professor Andrew Ellisdon with dedicated guidance and feedback, ensuring that the study remains closely informed by lived experience.



> **"Knowing that effective treatments for NF1 are a possible outcome of studies such as this would mean such a relief for so many people like me making our lives easier and less stressful."**

Brian Shaw - NF1 Project Participan

VOLUNTEER RESEARCH COORDINATOR

CTF is proud to welcome Anke van Eekelen as our new Volunteer Research Coordinator.

With an impressive career in neuroscience research, scholarly publishing, science communication and medical research integrity, Anke brings a wealth of expertise to our community.

Originally from the Netherlands, Anke has worked in leading institutions across Europe, the US, and now calls Western Australia home. She has a strong passion for making complex research more accessible and meaningful—something we know will be invaluable for the NF community.

We're thrilled to have her on board to help us keep families informed about the latest developments in NF research and care.

CTF BRAND REFRESH

As an organisation, we have a clear message: to conquer NF. With the introduction of our refreshed brand identity in late 2024, we can now communicate this cause in bolder, more playful and inclusive ways.

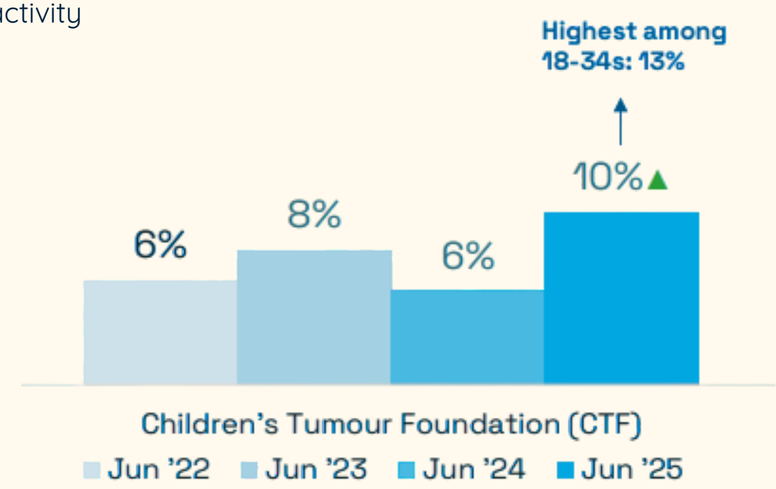
The penguin remains our enduring symbol of loyalty and community, while blue and green continue to anchor our brand as our core colours. To better reflect the diversity and vibrancy of the NF community, we have introduced a wider colour palette, new fonts and rounded graphic shapes that bring warmth and energy to our communications.

A key milestone in this refresh was the launch of our new website. This is now the central hub for people living with NF, their families, health professionals and supporters. The updated design not only reflects our new identity, but also delivers an improved user experience. Navigation is clearer, making it easier to find resources, information and services. We have simplified pathways to support, added stronger storytelling through community voices, and made it easier for the public to learn about NF and how they can get involved.

This investment ensures our digital presence is as strong and welcoming as the community we serve.

CTF BRAND AWARENESS

CTF brand awareness is at an all time high, increasing by **4%** since last year. As well as seeing **12%** increase in awareness of CTF's channels since last year. Awareness of the colours and month associated with NF continue to lift, reaching new highs in 2025, reinforcing the positive impact of CTF activity



EWAN'S STORY

AS TOLD BY HIS MUM, LAURA

Ewan is 10 years old. He's non-verbal, wears nappies, and now receives nutrition through a PEG tube after a lifetime of relying on thickened Sustagen. Despite his challenges, he's a happy, arm-flapping little guy who loves his iPad, bead toy and his plush cat "Kitty." He enjoys dancing in front of the mirror, simple songs, and reading books.

Ewan's birth was normal, but from early on he struggled with weight gain, low muscle tone and developmental delays. Café au lait spots led to genetic testing, and at one year old, Ewan was unexpectedly diagnosed with Neurofibromatosis Type 1 (NF1), with a major deletion.

By two, Ewan had also been diagnosed with autism and was still only drinking from a bottle. He received early intervention therapy, but continued to face significant developmental delays. At four, puberty began prematurely due to brain tumours on his pituitary gland, and he required hormone blockers.
Ewan started at a special needs school, where he's thrived socially and emotionally. However, his medical needs have grown over time. He has six-monthly MRIs, and just before turning 10, a scan revealed that his optic pathway glioma had doubled in size. He started oral treatment with Trametinib, but complications from illness meant he had to be NG tube fed. He later received a PEG and now benefits from a blended diet.

Treatment side effects have included painful skin conditions and infections, causing temporary halts in therapy. Through it all, Ewan remains resilient and joyful. His diagnosis has meant significant changes for the whole family—his dad leaving full-time work, daily travel for appointments, chronic sleep deprivation, and a constant need for advocacy.

NF has impacted nearly every part of Ewan's life, but it hasn't taken away his smile or his love of life's simple joys.

"Since connecting with CTF, we've found an NDIS support coordinator with NF experience, gone to events like the Colour Run, attended camp and most importantly - we don't feel alone anymore."

Laura, Ewan's Mum


RAISING FUNDS
AND AWARENESS

RAISING FUNDS AND AWARENESS

CONQUER NF IN COLOUR

Over three weekends in November and December, more than 750 participants in Sydney, Melbourne and Brisbane came together to raise awareness and celebrate the strength of the NF community, supported by 120 volunteers and spectators.

Conquer NF in Colour is a flagship event in the CTF calendar, funding vital support and advocacy for people living with NF. Beyond fundraising, the events created a powerful space for connection and empowerment.

Network Nine broadcast the event to a potential audience of 674,000 through six live weather crosses, while 70+ media articles, news and radio stories shared our message across the year.

NF AWARENESS MONTH

NF Awareness Month in May 2025 was launched with the theme of #BeyondLimitations, encouraging the community to look past the challenges of NF and celebrate possibilities.

One of the most powerful activations was Shine a Light on NF, which saw more than 140 buildings and landmarks across Australia illuminated in blue and green, thanks to the tireless efforts of volunteer Thomas.

The campaign generated outstanding support, raising over $70,000 and securing more than $200,000 in pro bono outdoor advertising from QMS Media, helping NF reach audiences well beyond our usual channels.

Online, engagement broke all records. Social media posts regularly reached more than 5,000 accounts, with one achieving a reach of 42,500 and over 70,000 views. This unprecedented visibility gave the NF community a stronger voice than ever before.

Photography by Thomas William Photography

STEP UP FOR NF

This year's physical challenge received a fresh look and a new name, reinvigorating participation and community spirit. Held throughout May, the event saw over 100 individuals and 21 teams come together to walk, ride, or run 150km—symbolically representing the 150 children diagnosed with NF each year.

Participants embraced the challenge with enthusiasm, sharing their journeys, motivating one another, and helping to raise awareness for NF across the country. The event fostered a sense of connection and celebration within the NF community, while also engaging friends, families, and supporters along the way.

In total, 639 gifts were received, raising over $60,000 to fund vital support services and initiatives for people living with NF. Beyond the fundraising, the refreshed event provided an accessible, fun, and empowering way for the community to step up and make a tangible difference.

THANKS MELINDA

A huge shout out to Community member, Melinda Shrimpton and her family for not only raising $12k as part of Step Up for NF, but also walked 340 km in a month whilst holding multiple fundraising events and shining a light on NF far and wide during NF Awareness Month!

Melinda is proud mum to Jack who is one of our NF Heros.

THANKS JANU

We want to extend a huge thank you to our ambassador, Janu, for her incredible support throughout FY2025. Janu has been a tireless advocate for people with NF, sharing her story and raising awareness of CTF across her social media platforms, participating in multiple webinars and podcasts, joining events like the Canberra meet up and the Colour Run, volunteering at the 50/50 raffle, and even attending meetings with government officials.

Earlier this year, Janu launched her personal NF story through a video generously produced pro-bono by **VidZero.** Her courage, openness, and dedication continue to inspire the NF community and beyond.

We are so grateful for Janu's ongoing commitment, energy, and advocacy — thank you for everything you do to help raise awareness and support for CTF.

A COMMUNITY INSPIRED

From movie nights to line dancing fundraisers, our NF community went above and beyond in FY2025 to raise both awareness and vital funds for those impacted by NF. These creative and spirited initiatives demonstrate the generosity, passion, and resilience of our supporters, and the incredible ways they champion the cause. We sincerely thank everyone who contributed their time, energy, and creativity to make a difference.

ST. GEORGE DRAGONS RAFFLE

The annual 50-50 Charity Raffle with the St. George Dragons raised over $5,000, supported by over 20 volunteers, including many from the University of Wollongong's Volunteer Program and our very own NF Community.

FUN RUN PARTICIPATION

Participation in fun runs continues to grow, offering a popular way for people to support CTF while connecting with the wider NF community. These events provide a space for families, friends, and supporters to come together, stay active, and raise awareness for NF.

In FY2025, over 90 people from across Australia took part in a variety of fun runs, **raising a remarkable $18,000 in total**. Highlights from the year included:

- Sydney City 2 Surf - 13 participants
- Central Queensland Rocky River Run- 17 participants
- Perth HBF Run for a Reason - 55 participants
- Port Macquarie running festival - 1 participant - Peter Kirkpatrick - raising $2,000!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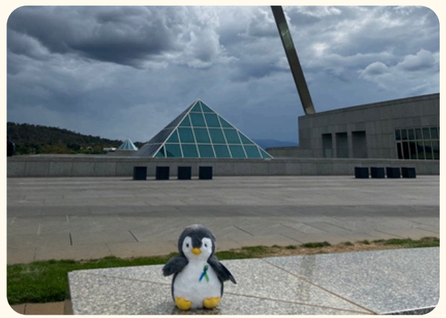
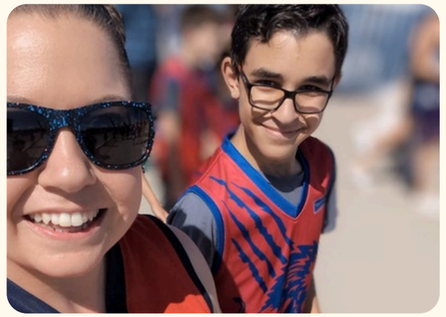
NO ONE SHOULD FACE
BRAIN TUMOURS
ALONE
Beacon


2876




Children's
Tumour
Foundation


Alex
FOR CTF
FUNDRAISER



THE POWER OF PARTNERSHIPS

We are incredibly grateful to all our partners and corporate supporters. From those who generously fund our events, camps, and vital services, to those who provide pro bono goods and services, your contributions make a real difference to the NF community. Your support helps us deliver programs, resources, and experiences that simply wouldn't be possible without you — thank you for being part of our journey.

We are deeply grateful to DLL and their employees for their ongoing support in funding our Nurses at the NF clinics.

Thank you to Yoghurt Digital who have provided pro bono long term support and management of our Google Ad account.

We thank Kidstuff for their ongoing NF Awareness Month Partnership, selling merchandise all year round, as well as donation matching during May to support the NF community.

We sincerely thank Nature Research for providing invaluable annual brand research pro bono, as well as their generous donation match during last year's Conquer NF In Colour Run.

We are incredibly grateful to the Stan Perron Charitable Foundation for their generous three-year funding of our Western Australia Camp.

We sincerely thank Berkley Insurance for generously doubling donations during the Conquer NF In Colour Run.

We thank PSI Cycling for their generous support, providing incredible prizes for Conquer NF in Colour and Step Up for NF participants and inspiring everyone to give their best.

We sincerely thank Community Bank Darling Square for their generous support in matching donations for our End of Financial Year appeal.

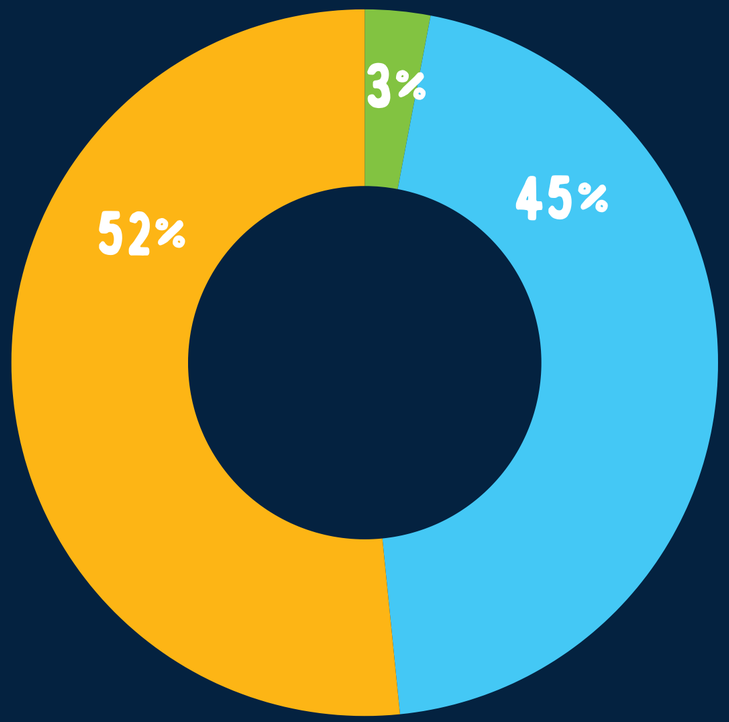
Thank you to Whiteley for kindly supporting our Model of Care Workshop which is a huge step towards releasing our National Standards of Care Guidelines for NF.

FINANCIALS

REVENUE

In FY25 revenue was
$1.28 million

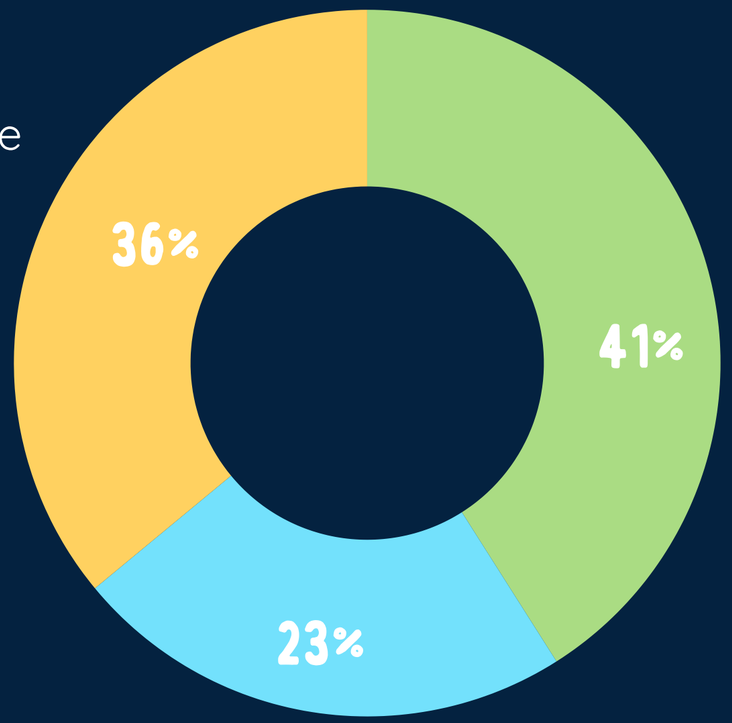
- FUNDRAISING & DONATIONS
- INVESTMENT REVENUE
- GOVERNMENT & GRANTS



EXPENSES

In FY25 expenses were
$1.37 million

- SUPPORT PROGRAMS
- EMPLOYEE EXPENSES
- ALL OTHER EXPENSES



THANK YOU TO OUR SUPPORTERS

From community champions and grassroots fundraisers to corporate partners, philanthropic foundations, and individual donors — every act of support this year has driven the mission of CTF forward.

Whether you hosted an event, donated, joined a campaign, or simply helped share our message, your generosity has made a tangible difference for people living with neurofibromatosis across Australia.

We are grateful to stand alongside such a committed and compassionate community. Thank you for helping create a future where no one faces NF alone — your support powers every step we take.

WE BELIEVE

that tumours should never be a child's normal.

WE EXIST

to provide hope for everyone impacted by Neurofibromatosis.

WE WORK

to advance research, advocate for change and provide support and connection.

Children's Tumour Foundation
CONQUERING NF