



PARTNER FOR PURPOSE

AND GIVE HOPE TO FAMILIES IMPACTED BY
NEUROFIBROMATOSIS IN AUSTRALIA

ABOUT US

OUR PURPOSE

The Children's Tumour Foundation is the only dedicated support service for people impacted by neurofibromatosis (NF) in Australia.

Our vision is a life without limitations for everyone living with NF in Australia.

The NF journey from diagnosis to treatment is challenging and most of what people will experience is unknown.

We provide personalised, accessible support and resources free of charge to every person impacted by NF, while also advocating for change and raising funds to advance promising research.



OUR STRATEGIC PRIORITIES



LEAD CHANGE

We advocate and work collaboratively to make NF a national priority.



SUPPORT & INFORM

We provide personalised, accessible support and resources free of charge to every person impacted by NF in Australia.



ADVANCE RESEARCH

We collaborate to progress promising Australian NF research by investing in new technologies, studies and clinical trials.

WHAT IS NF?

Neurofibromatosis (NF) refers to a group of rare and complex genetic conditions that cause tumours to form in the body, including the brain and spine.

NF can lead to a range of significant health issues such as deafness, blindness, physical differences, bone abnormalities, learning difficulties, chronic pain and in 10 per cent of cases, cancer.

EVERY 3 DAYS A CHILD IS BORN WITH NF IN AUSTRALIA

NF is present from birth, but one of the first indicators of the condition are coffee coloured marks (café-au-lait spots), that appear on the skin.

Its impact is felt throughout a lifetime and by the whole family.

NF can affect anyone regardless of ethnicity or gender, and roughly half of all cases arise in families with no history of the condition.

A SINGLE GENE CHANGE CAN LEAD TO A LIFETIME OF TUMOURS

In terms of prevalence, it stands with other genetic conditions like cystic fibrosis, yet receives minimal funding for support and research.

NF affects 1 in every 2,500 people in Australia, with millions impacted globally.

NF is unpredictable, progressive and there is no cure, but there is hope.



“For close to three decades, I kept my genetic condition a secret. Even as lumps and bumps began to appear over my entire body, I remained silent.”

With the support of the Children's Tumour Foundation, I have become a more confident, resilient and empowered version of myself.”

Janu Dhayanathan
NF Ambassador for the Children's Tumour Foundation

UNDERSTANDING THE NF JOURNEY



The first signs of NF often appear in childhood, but it is a progressive and lifelong condition.



Diagnosis can be difficult due to a lack of knowledge by health professionals and the variability of symptoms.



Isolation, bullying and feelings of exclusion are common due to physical and social limitations.



Up to 80% of people with NF experience learning difficulties.

Studying and accessing employment can be challenging.



Transitioning to adulthood and navigating healthcare systems can be complicated.



NF can cause physical changes, which can lead to feelings of anxiety and depression.



High healthcare costs and a lack of services impacts on quality of life.



There is a 50% chance of passing NF onto your child without costly interventions.



Managing multiple hospital and specialist appointments has a huge impact on people's lives.

THE IMPACT OF NF CHANGES WITH EACH STAGE OF LIFE.

The condition can often create multiple health issues that impact a person physically, mentally, academically, and socially.

Lives are often disrupted by numerous specialist appointments, surgeries and ongoing health surveillance, which extends well beyond the person living with it to include parents, carers and siblings.

DELAYS IN DIAGNOSIS CREATE ADDITIONAL CHALLENGES FOR FAMILIES.

Awareness of NF, along with a lack of understanding of the signs and symptoms, even amongst healthcare professionals, is far too common and has the potential to be life-threatening.

Delays in diagnosis mean that critical health checks and monitoring of new or existing tumours is not happening or not happening regularly enough. This can have a significant long-term impact on a person's health and wellbeing.

1 IN 5 CHILDREN WITH NF WILL DEVELOP A BRAIN TUMOUR.

Without careful monitoring, these children could become vision impaired, blind or something far worse.

UP TO 80% OF CHILDREN WITH NF WILL EXPERIENCE LEARNING OR BEHAVIOURAL DIFFICULTIES.

Without early intervention, it becomes increasingly difficult for these children to fully participate in school or play; creating a life-long ripple effect.

Unfortunately, no two cases of NF are the same, which is why we take a personalised approach to our care.

GREATER AWARENESS OF THE SIGNS AND SYMPTOMS OF NF WILL LEAD TO EARLIER DIAGNOSIS, INTERVENTIONS & TREATMENT.

WHAT WE DO

We are a patient advocacy and support organisation. We empower individuals and their families impacted by NF with the knowledge, connections and support needed at every stage of their journey, working to improve life outcomes in three ways:



SUPPORT SERVICES

Beyond the need to treat the physical symptoms of NF, living with NF can also take an emotional toll on both the patients and their families.

To combat the feelings of isolation and anxiety, we create opportunities for people to come together in safe, supportive spaces, connecting them with balanced information, treatment options and each other.

We fill the gap that clinical care is unable to meet.

PERSONALISED SUPPORT

FREE NATIONAL
HELPLINE

RESOURCES

NDIS SUPPORT

WEBINARS

INFORMATION DAYS

COURSE-BASED
SUPPORT

COMMUNITY CONNECTION

NF CAMPS

NF CONNECT

COMMUNITY DAYS

NAVIGATING CARE: MULTI-DISCIPLINARY NF CLINICS

CHILDREN'S HOSPITAL
WEST MEAD, SYDNEY

ROYAL CHILDREN'S HOSPITAL,
MELBOURNE

NF is a complex condition and requires the care of multiple clinicians.

Coordinated multi-disciplinary care reduces the stress on children and their families.



ADVOCACY

Living with a lifelong, chronic and progressive health condition is complex.

As the leading, national organisation working alongside Australians impacted by NF, we advocate for improved access to healthcare, education supports and economic position.

Our goal is to make life more equitable for those living with this rare condition.

SYSTEMIC ADVOCACY

GOVERNMENT
LOBBYING

THERAPEUTIC
LOBBYING

INDIVIDUAL
ADVOCACY



RESEARCH

We are one of Australia's leading charitable contributors to NF research with millions of dollars invested into key projects through on-going advocacy efforts and direct funding.

In addition to our own contribution of more than \$1.3million, in 2021, we advocated for more government funded research and the outcome was \$7 million in dedicated NF research funding through the Medical Research Future Fund.

With \$4.6million already awarded, this remains the most significant government funding and acknowledgement of those living with NF in Australia's history.

ADVANCING AND ENABLING

INVESTIGATIVE
STUDIES

TREATMENTS &
TRIALS

NF CLINICAL
SYMPOSIUM

WE HELP TO EXPAND PATIENT SUPPORT NETWORKS WHILE ALSO PROVIDING ACCESS TO INFORMATION & RESOURCES THAT CANNOT BE ACCESSED ANYWHERE ELSE.

INVEST IN SOCIAL INCLUSION

NF CAMPS AROUND AUSTRALIA

Connecting the NF community with information, services and each other is a huge part of what we do. Events like camps are designed to empower, educate and create critical points of connection. Most importantly, they are free and accessible to all.

But they do more than just connect families with each other, they also enable new friendships to form (sometimes for the first time) and create a space for peer support opportunities to form naturally.

These moments of connection would not happen without the Children's Tumour Foundation.



NF camps enable children with NF and their siblings to bond with other kids in similar circumstances and play in a safe environment, free from bullying and discrimination.

This supports the wellbeing of the whole family.

The focused psychosocial support provided by the team plays an important role in protecting against negative outcomes, while also promoting positive social behaviours.

A SAFE SPACE WHERE KIDS AND ADULTS WITH NF DON'T HAVE TO FEEL SELF-CONSCIOUS.

"It was so good to be able to do something that was connected to my child's NF that wasn't an appointment, forms, or additional worries and burden."

"It was so lovely to finally be able to do something FUN that we could only do because he has NFI."

"NF Camp is the single best thing to happen this year. It's a place where young and old can relax and share stories, and an explanation isn't needed. No hassle. No judgement."

IMPROVE HEALTH OUTCOMES

NF CLINICAL NURSE SPECIALISTS

NF is a complex condition and requires input from many different medical specialties.

Access to a centralised hub where patients and their families can see multiple doctors and receive coordinated care via the NF Clinical Nurse Specialist, has a huge impact on their lives.

We currently fund two positions. One at the Children's Hospital Westmead, Sydney and another at The Royal Children's Hospital, Melbourne.

On average, each of these vital multi-disciplinary clinic will support close to 500 patient visits a year and is critical in reducing the significant anxiety caused by the condition.

Our objective is to establish similar clinical hubs in each state and territory around the country.



BUILDING CONNECTIONS TO SUPPORT MENTAL HEALTH

NF CONNECT is a facilitated, online chat session where different groups within the NF community come together in a safe and supported space.

For many people, this may be the only point of contact with another person experiencing many of the same challenges; helping to validate their feelings and reduce social isolation.

These sessions are run monthly in support of three different target groups, including teens and young adults, adults with NF, and parents & carers of children with NF.



"I made my own family with the most amazing group of people who I originally met on NF Connect."

NF CONNECT HAS HELPED CREATE SOME INCREDIBLE FRIENDSHIPS

Featured (left) is a group who met online during COVID in our NF Connect Teen and Young Adults sessions. The Victorian camp in November 2022 was their first chance to connect in real life

WHY SUPPORT KIDS WITH TUMOURS?

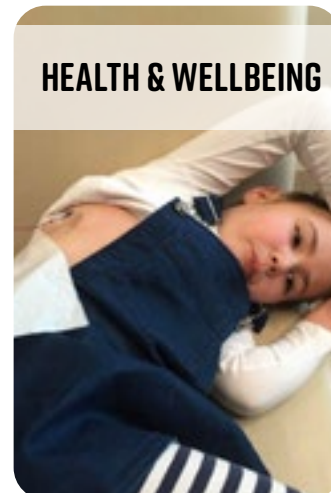
NO ONE SHOULD FACE A LIFETIME OF UNCERTAINTY ALONE

Imagine finding out your child's cute birthmarks were a sign of a lifelong genetic condition with few treatment options and no cure.

From navigating the early stages of diagnosis to managing treatments and care, we are the only dedicated support service for families in Australia. But, we can't do it without YOU.

Your support will ensure there is a dedicated NF service available for every family that needs it, now and in the future.

OUR SERVICE PROVISION COVERS A NUMBER OF INTEREST CATEGORIES



A condition that can affect any part of the nervous system and cause significant disability (or even death) in both children and adults should be a national priority. Sadly it isn't - yet. With your help, we can move a step closer to our goal to #CONQUERNF

DOING GOOD IS NO LONGER JUST GOOD FOR BUSINESS – IT'S CRUCIAL FOR SURVIVAL

The pandemic has afforded the opportunity for deep reflection on what's important, and for many it's been profoundly clarifying. COVID has accelerated the "Conscious Consumer" movement and a new kind of consumer has emerged from lockdown.

Just under two thirds of people agree that during COVID they've re-evaluated priorities and are more likely to buy products and services from companies doing good.*

Three quarters of Australian consumers agree it's time Corporate Australia stepped up and showed leadership in solving social issues.*

* Mintel, Global Consumer Trends, 2021

WAYS TO GET INVOLVED

COLLABORATE TO CREATE CHANGE

From experience, we know that when you combine a donation with active involvement from your team, a genuine connection to the cause and charity is developed.

We also know that every partnership is unique and our strength lies in our ability to adapt quickly and effectively to meet a specific need or capitalise on an innovative idea.

Here are just a few ways of how you can work with us.

GIVE

PARTNER DONATION

Leverage our brand to improve customer and employee loyalty

SPONSORSHIP

Become a sponsor of one of our major events or nominate us as a beneficiary of your own event

WORKPLACE GIVING

A simple and effective way for employees to give regularly

CAPACITY BUILDING

Invest in our people and growth so that we can increase our impact

GRANTS

We can direct 100% of your grant towards an agreed project.

ENGAGE

EVENTS & CAMPAIGNS

Attend or host meaningful experiences that connect audiences with the cause

SPEAKING ENGAGEMENTS

Inspire your employees through lunch and learn events

CSR ALIGNMENT

Identify opportunities for us to align with and support strategic CSR goals

SKILLED VOLUNTEERING

Put your time and talents to work on specific projects or idea generation

VOLUNTEERING

We have plenty of opportunities across Australia for your teams to get involved on the day or to prepare for our major events



OUR EVENTS IN ACTION

MAY IS NF AWARENESS MONTH

Every year in May, we run a number of initiatives to bring NF "Out of the Shadows" to help start a national conversation about NF. Some of these initiatives include:

- **Shine a Light on NF:** part of a global initiative to light up buildings and monuments blue and green around the country on May 17.
- **Steps Towards a Cure:** national fundraising event to raise funds for NF research.
- **Wear a Ribbon:** blue and green awareness ribbons are worn as a statement of support for every person living with, or impacted by neurofibromatosis.

Our priorities are to **educate, advocate and elevate the condition** to help improve understanding of the signs and symptoms, share the stories of real people affected by the condition and to educate Australians on the diagnosis and treatment.

CTF.ORG.AU/OUTOFTHESHADOWS



ROUND UP IN MAY

Ask customers to round up their total at point of purchase to support the Children's Tumour Foundation.

COMMIT A PERCENTAGE OF SALE

on selected items, potentially focussing on products that are blue and green.

DONATE MEDIA SPACE

to help us extend our reach and promote our campaign by donating three days of an existing ad buy from May 17 (World NF Awareness Day).

SELL RIBBONS & OTHER MERCH

at your POS to support greater fundraising efforts and awareness raising, including ribbons and socks.

MATCHED GIVING PARTNER

We are looking for a matched giving partner to encourage donations from May 17.

SPONSOR STEPS TOWARDS A CURE

Connect with a national fundraising event asking participants to step, stride or ride for NF Research.



MOVING TOWARDS A FUTURE FREE FROM TUMOURS

Steps Towards a Cure is a virtual challenge during NF Awareness Month - in May. It's FREE to register and you can participate from anywhere in Australia. All it takes is what you've got - step, stride or ride a distance of your choice and collect donations and rewards along the way.

The perfect way to get moving, bring a team together and fundraise to help fund new research discoveries.

STEPSTOWARDSACURE.COM.AU



A COLOUR RUN THAT IS BOLDLY BLUE AND GREEN

Runners will chalk it up over 2km, 4km or 10km in an explosive event that has everything from coloured powder, soaking stations, live music and more!

Once the race is over, the fun continues at the NF Village.

Runners and their support crew can rock it out to music and refuel with on-site food and drink vendors.

A perfect space for sponsors to showcase their products and connect with hundreds of participants and onlookers.

**HELD IN OCTOBER / NOVEMBER
IN SYDNEY, MELBOURNE & BRISBANE**

WATCH THE VIDEO



OUR BOARD & GOVERNANCE

We are privileged to receive the support of so many executives and professionals committed to our strategic growth, giving their time voluntarily to support the work we do. We are governed by a Board of Directors and supported by two expert sub-committees.

In addition to this, we have a **Medical Advisory Panel** made up of eight respected scientists, clinicians and researchers actively working with NF patients.



Peter Dowding
Board Chair
Co-Founder and Chairman of Propel Investments



Wes Lambert
Director and Audit & Risk Committee Chair
Senior District Sales Manager at Open Table



Donna Player
Director and Marketing & Fundraising Committee Chair
Merchandise Director at Camilla Australia



John Bishop
Director
Head of Employee Experience at 7Eleven



Peter Krideras
Director and Marketing & Fundraising Committee
Co-Founder of Releaseit and Green Friday



Laurence Dell
Director and Audit & Risk Committee
Partner at PwC



Hugo Dudley-Smith
Director and Audit & Risk Committee
Managing Partner at Gresham



Brooke Smith
Director and Audit & Risk Committee
Former General Manager of Insitu Group Pty Ltd



Luke Goldsworthy
Director and Marketing & Fundraising Committee
CEO and Owner of The Playhouse Group Pty Ltd

MEDICAL ADVISORY PANEL

We have established a Medical Advisory Panel to provide professional guidance and advice on the medical and scientific aspects of the information services provided, as well as any research grants made by the CTF.

The Medical Advisory Panel consists of eight health care professionals and scientific community members from hospitals and medical institutions across Australia.

- A/Prof Mimi Berman | Royal North Shore Hospital
- Dr Geoff McCowage | Westmead Children's Hosp. Syd
- Dr Katrina Morris | Royal North Shore Hospital
- A/Prof Jonathan Payne | Royal Children's Hosp. Melb
- Dr Kate Drummond (AM) | Royal Melbourne Hospital
- Dr Tim Hassall | Queensland Children's Hospital
- Dr Colin Derrick | Royal Perth Hospital
- Dr Gargi Pathak | Royal Perth Hospital

CLOSE TO 1000 FAMILIES
ACROSS AUSTRALIA CALL ON OUR
SUPPORT EVERY YEAR.



THIS IS WHY YOUR SUPPORT IS SO IMPORTANT

At five weeks, Danika's Mum Natasha noticed the first birthmark on her youngest daughter's body. The same birthmarks that Natasha's father has and that her eldest daughter, Matilda, also carry.

While Danika and Matilda were meeting all of their milestones, towards the beginning of 2020 Danika began to randomly vomit but appeared fine afterwards.

Knowing in her gut it was more than abdominal migraines, a brain MRI revealed a 5cm mass on Danika's cerebellum. Danika underwent an 8-hour surgery to debulk some of the tumour.

Devastatingly, within 7 weeks her symptoms reappeared and another MRI revealed the worst possible outcome. The tumour had grown back. Danika was rushed back into a second lengthy surgery.

She bounced back with her usual determination and cheekiness, but the biopsy results from her original surgery were not good.

She had a very rare stage 3 brain cancer.

A 6-years of age, she is on a "miracle drug" that has so far kept her tumour stable, but must now have a brain MRI every 8 weeks to watch for changes.

A diagnosis of NF is rarely straightforward and many people come to the CTF at breaking point, while others need help to navigate a next stage of life (school, transitioning to adult care or thinking about starting a family). Others just like to feel connected to the outside world and want a chat.

When Danika's health news became a living reality, the CTF support team was the friendly voice on the other end of the phone validating every emotion and giving guidance when needed. It was wonderful to be able to meet Natasha and her family in person at the very first WA Camp in March 2023.



IF YOU HAVE ANY QUESTIONS OR WOULD LIKE MORE
INFORMATION PLEASE CONTACT:

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SOCIAL:
  
[@ctfaustralia](https://www.instagram.com/ctfaustralia)



**GREATER AWARENESS LEADS TO EARLY
DIAGNOSIS AND INTERVENTION, LEADING
TO BETTER HEALTH OUTCOMES.**

