



# MOVING TOWARDS A FUTURE FREE FROM TUMOURS

The Children's Tumour Foundation is the only dedicated support service for those impacted by neurofibromatosis (NF), a rare and complex genetic condition that causes tumours to form on nerves in the body, including the brain and spine.

EVERY  
3 DAYS

a child is born with NF in Australia

50%

have no family history of the condition

MORE THAN  
13,000

people are living with NF in Australia

Those living with NF **face significant health issues**, struggle to find the right diagnosis, get access to the right treatments, and sometimes face **discrimination, stigma or even exclusion**.

Living with a lifelong, chronic and progressive health condition is difficult, but conquering NF is about more than just a cure. The Children's Tumour Foundation **advocate for change, advance research** and **empower and connect** this community.

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## SUPPORT SERVICES

Beyond the need to treat the physical symptoms of NF, we create opportunities to learn and to come together in safe and supportive spaces.

We provide non-clinical support and guidance via telephone, email and video call consultations, to discuss individual needs and solutions. We run camps, community days and NF information days, to enhance connection and well-being.

We provide a wide range of resources, including fact sheets, specialised toolkits and health management kits to empower individuals. We help navigate health systems to relieve the personal burden of living with a complex condition.



### THE IMMEDIATE OUTCOMES

For individuals and their support network

Increased health interventions from support navigating support systems

Improved wellbeing from connecting with others on the same journey

Increased health literacy and personal advocacy skills

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## ADVOCACY

No one should face a lifetime of uncertainty alone. Our goal is to make life more equitable for those living with this complex genetic condition.

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

We advocate and work collaboratively to make NF a national priority, working with local, state and federal government, health systems, therapeutic organisations, as well as education institutions.

### THE INTERMEDIATE OUTCOMES

For individuals, health systems and communities

Earlier diagnosis through increased awareness among health professionals

Increased access to other supports, such as learning and financial supports

Reduced burden of disease through earlier access to treatments and therapeutics



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## 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.

The Children's Tumour Foundation invests in research that investigates NF and its many complications, advances access to effective treatments and progresses the search for a cure.

The Symposium connects clinicians and researchers to stimulate new collaborations, showcase progress and fuel new ideas to conquer NF.



### THE LONG TERM OUTCOMES

For individuals and health systems

Improve predictability of symptom development

Reduce disease severity through effective treatments

Support discovery about NF and eventually a cure

The impact of NF changes with each stage of life and no two cases are the same. Our vision is a life without limitations for everyone living with NF.

**GREATER AWARENESS LEADS TO EARLIER DIAGNOSIS AND ACCESS TO INTERVENTIONS, LEADING TO BETTER HEALTH OUTCOMES.**

