

OUR VISION

A life without limitations for everyone living with Neurofibromatosis.

OUR MISSION

To provide hope for everyone impacted by Neurofibromatosis in Australia by advocating for change, advancing research and empowering this community with the knowledge, connections and support needed at every stage of their journey.

OUR COMMUNITY

Our community includes everyone living with Neurofibromatosis (NF) in Australia (diagnosed and/or undiagnosed) along with their family, carers and friends.

It also includes healthcare professionals, employers and educators.

NF can affect anyone regardless of age, ethnicity, gender or family history.



LEAD CHANGE

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



SUPPORT & INFORM

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



ADVANCE RESEARCH

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



LEAD CHANGE

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

Goals

1.1

Lead advocacy nationally for the NF community.

1.2

Collaborate with local and international partners, as well as the NF community to leverage and maximise impact.

1.3

Elevate NF in the national consciousness, ensuring every Australian impacted is supported and every Australian not impacted is made NF aware.

1.4

Identify and continue to evolve funding sources to support existing and future needs of the NF community.

What success looks like

- Be recognised as the charitable authority on Neurofibromatosis (NF) in Australia, ensuring the Children's Tumour Foundation becomes synonymous with NF.
- Improved collaboration within the sector that accelerates better health outcomes for everyone living with Neurofibromatosis (NF) in Australia.
- Financial sustainability and diversification of funds to enable the delivery of key support programs, dedicated NF clinics and research studies.





SUPPORT & INFORM

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

Goals

2.1

Provide access to free, personalised and confidential support services for people impacted by NF in Australia.

2.2

Continually improve access to quality information for the NF community.

2.3

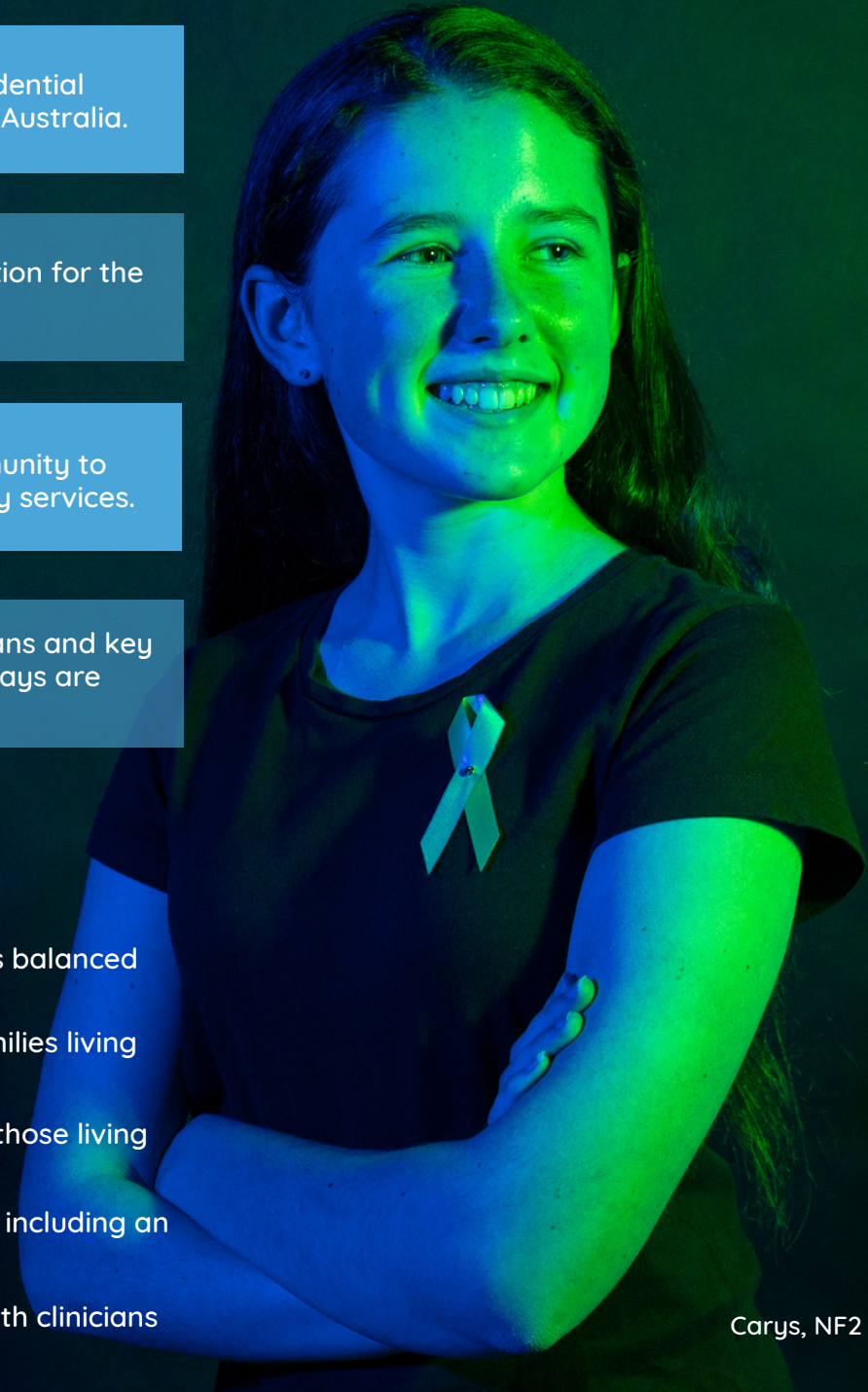
Create ongoing opportunities for the NF community to connect with us, each other and complimentary services.

2.4

Advocate alongside the community with clinicians and key decision-makers to ensure better health pathways are available nationally for people living with NF.

What success looks like

- Everyone impacted by NF, regardless of location, type or financial position can access balanced information and support when they need it.
- Identify and foster an increasing number of new relationships with individuals and families living with NF in Australia.
- Drive increased participation in programs or services that build connections between those living with NF, their support network and other service providers.
- Significantly increase the range of resources to meet the needs of the NF community, including an upgraded health kit.
- Enable the expansion of designated NF clinical services through active consultation with clinicians and key decision-makers in each state and territory.





ADVANCE RESEARCH

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

Goals

3.1

Actively engage with key clinician researchers to support studies and treatments into all types of NF.

3.2

Collate and disseminate research updates from within Australia and around the world.

3.3

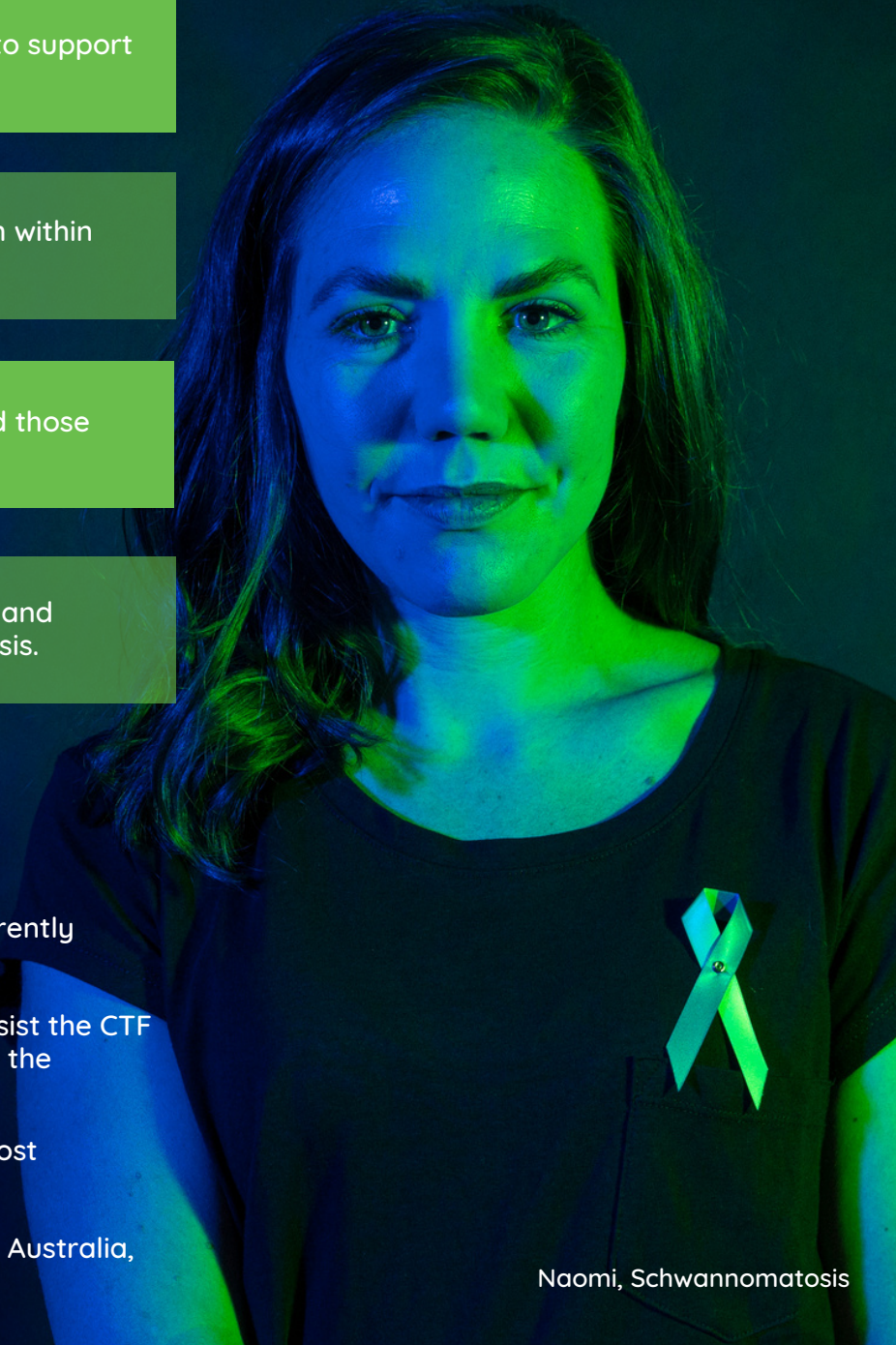
Facilitate connections between researchers and those with a lived experience of NF.

3.4

Bring together a panel of world leading clinical and scientific experts in the field of Neurofibromatosis.

What success looks like

- Development of a research roadmap that enables the CTF to sustainably and transparently contribute to future studies, clinical trials and treatments.
- Assemble a panel of key medical advisors in the field of NF within first 12 months to assist the CTF with specific, objective clinical and scientific expertise where the evidence is unclear, or the expertise is outside the scope of the CTF management and staff.
- Our communication channels are recognised by NF clinicians and community as the most comprehensive and up-to-date hub for NF-related research studies in Australia.
- Grow networks by cultivating an environment of trust with clinicians and researchers in Australia, the US and UK to allow more proactive and regular sharing of information



Naomi, Schwannomatosis