NEUROFIBROMATOSIS FACT SHEET

Children's Tumour Foundation
CONQUERING NF

Neurofibromatosis (NF) is a genetic condition that causes tumours to grow on nerves throughout the body, including the brain and spine.

NF is classified into three different disorders; NF1, NF2 and Schwannomatosis.

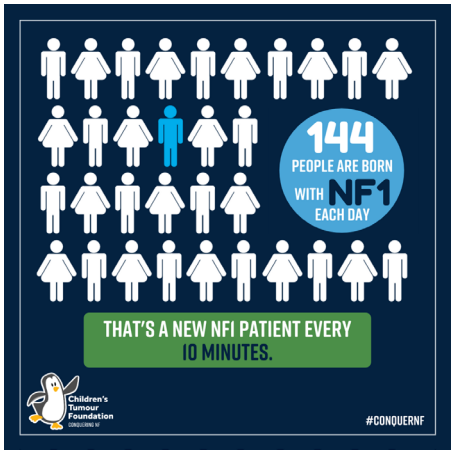
There is currently no cure & treatment options are limited.

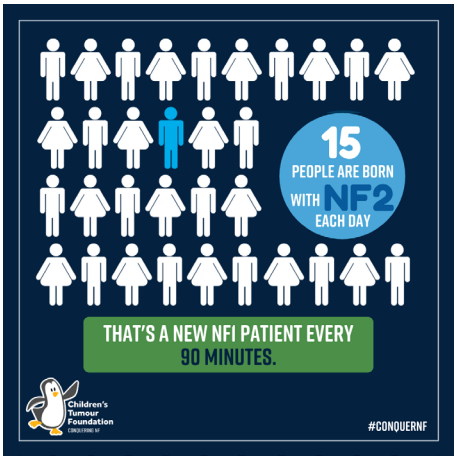
NF STATISTICS IN AUSTRALIA

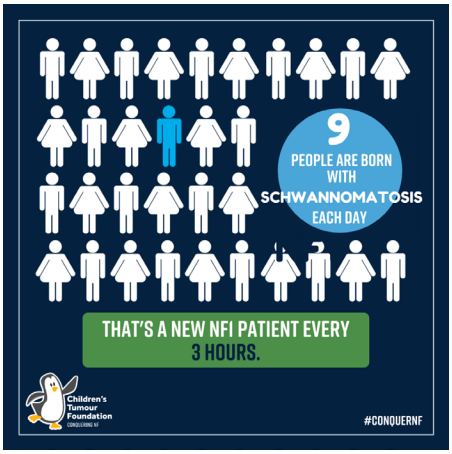
- NF affects **1 in every 2,500** people in Australia.
- **Every 3 days**, an Australian child will be diagnosed with NF.
- There are approximately **10,000 people** living with this condition in Australia.

THE OVERALL PICTURE

- There are over 2.5 million people living with NF worldwide.
- Although NF is a genetic condition, almost half of all cases are as a result of a spontaneous mutation, meaning there was no family history of the condition.
- Each type of NF varies in its incidence.
  - NF1 is the most commonly inherited neurological condition. Each day, approximately 120 people are born with NF1.
  - NF2 is rarer, affecting 1 in every 25,000 - 40,000 people. This equates to 15 people born with NF2 each day.
  - Schwannomatosis is the rarest of the three, with 9 people born with the condition each day.







DIAGNOSIS

- Reaching a diagnosis of NF can be a long and painful journey for many.
- Awareness of NF and its signs and symptoms are lacking within the medical community. Many GPs lack the knowledge to identify early warning signs or indicators of NF.
- The diagnostic criteria is complex, and patients must display numerous symptoms in order to reach a diagnosis of NF, unless they undergo genetic testing.

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LIVING WITH A TICKING TIME BOMB

- Many people describe living with NF like a "ticking time bomb". The condition is so unpredictable, there is no way to determine where a tumour will appear next.
- For children and adults living with NF, tumours are their normal. For many, their lives are spent going to and from doctors appointments, long hospital stays, major surgery to remove tumours, or living in an agonising limbo of "watch and wait".

ADDITIONAL HEALTH BURDENS

- Neurofibromatosis is an extremely variable condition. No two cases are the same. Some people living with NF1 will live a long and fulfilling life, for others the condition can be severe, debilitating and life threatening.
- Health issues related to NF1 include learning and behavioural difficulties, softening and curving of bones and curvature of the spine (scoliosis). Tumours may also grow on nerves in the brain, such as the optic or cranial nerves, as well as along the spinal cord nerves.
- People living with NF2 will often experience hearing loss, ringing in the ears, headaches and balance problems. They may also experience vision loss or other visual abnormalities. Along with this, people with NF2 may also develop tumours in the brain and spine.

TREATMENT

- Treatment options are extremely and are aimed at alleviating symptoms and the burden of the condition. ***Currently, there is no cure to NF.***
- For many people living with NF, they are often told that there is nothing to do but "watch and wait", leaving them with an overwhelming sense of uncertainty.
- For many, surgery is the only option to manage these tumours. Most surgeries will aim to "debulk" the tumour, which allows the tumour to regrow. The removal of plexiform neurofibromas is especially challenging as they involve more than one nerve root, leaving people at a high risk of nerve damage.
- Chemotherapy is another treatment option that is sometimes used in the treatment of NF. The aim of this treatment is to shrink neurofibromas and alleviate an individuals symptoms. However, not all tumours will respond to chemotherapy.
- Promising research has emerged from the US in the treatment of NF1. MEK Inhibitor drugs Selumetinib and Trametinib have shown positive results in the treatment of plexiform neurofibromas - either reducing in size or remaining stable.
- The Children's Tumour Foundation is co-funding a similar trial in Australia led by senior paediatric oncologist Dr Geoff McCowage. The trial will run for 5 years and is expected to commence in late 2020.

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THE CHILDREN'S TUMOUR FOUNDATION OF AUSTRALIA

HISTORY

- The Children's Tumour Foundation of Australia, previously known as the Neurofibromatosis Association of Australia, was founded by a group of families impact by NF and existed to provide support amongst the group.
- In 2010, the organisation saw an increasing need and demand to connect with NF families across Australia, and saw the organisation shift its focus nationally.
- NF Australia limited began trading as the Children's Tumour Foundation of Australia (CTF).

OUR PURPOSE & MISSION

- ***We exist to help families navigate a pathway from fear to hope.***
- This pathway is established by empowering those impacted by NF. We do this by providing balanced information, connections to appropriate health services along with connections to each other. We support emotional wellbeing as people face the many challenges that comes with a diagnosis of NF.

WHAT WE DO

- We will do whatever it takes, for as long as it takes until a cure for NF is found.
- At the CTF, we focus on improving life outcomes in three ways:
    1. *Providing access to critical support-related services*
    2. *Investing in promising research and more effective treatments*
    3. *Advocating for improved access to care and awareness of the condition*

CONTACT US

Interviews & Media Enquiries:

For any interview enquiries or media enquiries, please contact our Marketing & Acquisition Manager Renee Anschau on renee.anschau@ctf.org.au | 0478 344 330

Visit www.ctf.org.au to find out more.