

# WHERE DOES THE MONEY GO?

**FUNDS RAISED FROM THE NF HERO CHALLENGE GO TOWARDS THE CHILDREN'S TUMOUR FOUNDATION AND ARE INVESTED IN TO THREE AREAS:**

## **SUPPORT SERVICES**

The Children's Tumour Foundation prioritises front line services. Money raised in our online campaigns contribute to funding support roles and clinical nurse specialists to help patients with NF navigate the complex hospital system, and aid decision making by providing vital access to key information and counselling through the stages of diagnoses, treatment options and the systemic monitoring of NF symptoms.

The CTF support team provide community days and family camps, so that families impacted by NF are able to meet and interact with other families who are on the same medical journey.

They provide peer support groups, counselling and are the link between the NF community and medical sector for many families.

## **RESEARCH**

The CTF has invested over \$1,000,000 in medical research to date. This includes the formation of the NF Research Centre at Westmead Children's Hospital, the Barney Fellowship through the Royal Melbourne Children's Hospital, the NF Centre for Translational Excellence and the NF skin clinic in Sydney through the Royal North Shore Hospital and research projects in to the links between autism and NF, NF and development, as well as a Repamycin Clinical Trial.

Our current funding focus is on funding Phase 2 and 3 clinical trials, such as Mek Inhibitors, which are the most promising treatment option for NF related tumours, having proven success in both shrinking and stabilising brain and Optic nerve tumours.

Our long term goal is to establish and fund an NF specialist clinic in every state of Australia, so that every family impacted by NF has access to advanced care within a multidisciplinary team of NF specialists.

## **EDUCATION**

The Children's Tumour Foundation works closely with Health Ministers and NF specialists from around the globe to provide educational resources to support and guide the NF community, medical professionals and Government bodies.

The CTF aims to improve awareness about NF within the broader community through education and as such host a series of seminars, conferences and webinars to regularly educate and update clinicians and medical professionals.

# STATS & FACTS

## WHAT IS NF?

NF is a genetic disorder that causes tumours to grow on the nerves, including the brain and spine.

Nf affects everyone differently- it causes tumours to grow anywhere IN or ON the body, at any time. There is NO way to predict how it will affect your child. It may lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain and cancer.

THERE ARE 3 TYPES OF NF - **NF1, NF2 & SCHWANNOMATOSIS**

THERE ARE OVER **10,000** PEOPLE LIVING WITH NF IN **AUSTRALIA** AND **2.5 MILLION** WORLDWIDE

EVERY **3 DAYS** A CHILD IS BORN WITH NF IN AUSTRALIA

**20%** OF PATIENTS WITH NF1 WILL DEVELOP ON **OPTIC GLIOMA**

**50-80%** OF CHILDREN WILL EXPERIENCE **LEARNING & BEHAVIOURAL DIFFICULTIES**

**50%** OF NEW NF CASES ARE CAUSED FROM A **SPONTANEOUS MUTATION**, MEANING THERE WAS NO FAMILY HISTORY

**30-50%** OF PEOPLE WITH NF1 WILL DEVELOP A **PLEXIFORM NEUROFIBROMA**, A MORE INTRICATE TUMOUR THAT INVADDES MULTIPLE NERVES

**MENTAL HEALTH ISSUES**, SUCH AS **ANXIETY** AND **DEPRESSION** ARE MORE COMMON WITHIN THE NF COMMUNITY THAN THE GENERAL POPULATION.

**10%** WILL DEVELOP **SCOLIOSIS**

THERE IS **NO CURE** AND EFFECTIVE TREATMENT OPTIONS ARE **LIMITED**

**90%** OF PEOPLE WITH NF2 WILL DEVELOP A **VESTIBULAR SCHWANNOMA**

**60-80%** OF PEOPLE WITH NF2 WILL DEVELOP A **SPINAL TUMOUR**

NF2 IS USUALLY **DIAGNOSED** IN TEENS OR EARLY ADULTHOOD