WHAT IS NF? – IT'S A WARRIOR'S LEGACY

Neurofibromatosis (NF) is a set of three complex genetic conditions that cause tumours to form on nerve cells throughout the body and affects more than 10,000 people in Australia.

- Neurofibromatosis Type 1
- Neurofibromatosis Type 2
- Schwannomatosis

The signs, symptoms, and management of each condition are different, as is the treatment for every individual.

Rhys Burnet, a student at Shalom College from Year 8 to half-way through Year 11 had Neurofibromatosis Type 1 (NF1)

He wasn't diagnosed at infancy but was in Year 4 in 2010.

NF1 is the most common of the three genetic conditions, affecting 1 in every 2,500 people in Australia.

Previously known as Von Recklinghausen Disease, around 50% of people affected will have inherited it from one of their parents. Rhys was a mutant gene with roughly half of all cases arising in families have no history of NF.

Neither of his parents (Maria and Andy) have an NF history.

It is most often diagnosed in childhood and characterised by brown skin spots called café-au-lait marks, freckling in the groin and armpits and on the skin, and benign tumours (lumps under the surface of the skin) known as neurofibromas.

NF1 is an extremely variable condition. The majority of people with NF1 will never be impacted by major medical complications and will live a long, fulfilling life.

For others, like Rhys experienced, the condition can be severe, debilitating, and life-threatening – even causing death. Particularly if a tumour develops in the brain as did with Rhys.

In some cases, signs of NF1 may not appear until later in life, often around puberty.

<u>There is no known cure, and treatment options are limited.</u>

EVERY 3 DAYS A CHILD IS BORN WITH NF IN AUSTRALIA

NF can lead to a range of significant health issues including deafness, blindness, paralysis, physical differences, bone abnormalities (Rhys had scoliosis), learning difficulties and chronic pain and cancer (which Rhys passed away as a result).

NF can affect anyone regardless of age, ethnicity, gender, or family history and causes tumours (known as neurofibromas) to grow around the body's nerve cells, including the spine and brain, under the surface of the skin or deep in the body.
It is impossible to predict how mildly or severely someone with NF will be affected.

The **Children's Tumour Foundation of Australia** raises awareness of NF and supports families experiencing this condition. Their support team was a great resource for Maria when Rhys was diagnosed with his brain tumour in June.

Rhys' mum Maria has become involved by sharing the NF message to raise awareness and assist where possible with fundraising. Money raised goes to funding research and much is now happening in this area. When Rhys was diagnosed not much and still not much is known. But there are new discoveries every day.

Maria has a number of NF ribbons as pictured available for sale for $5.