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Max shares his story to raise awareness of Neurofibromatosis



Rochelle Kirkham

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Max Rego will be on crutches for the next few weeks while his leg is in plaster. But no, he did not break his leg.



SUPPORT: Danielle Rego with sons Max (middle) and Jacob. Max was diagnosed with Neurofibromatosis when he was seven and is sharing his story to raise awareness. Picture: Adam Trafford

The 11-year-old from Bacchus Marsh underwent surgery last week to transfer a tendon from his working leg to his leg that is not working so well with the aim to hold his foot in a better position for walking.

Max was diagnosed with Neurofibromatosis Type 2, also known as NF2, when he was seven-years-old.

At the time, his family had never heard of the genetic condition and did not know anything about it.

"We were in a bit of shock that our son had this genetic disorder that was lifelong, no cure, very little treatment and we had never even heard of it," Max's mum Danielle Rego told *The Courier*.

"We didn't know where to go for help and we had to try to explain it to family and friends, his school, everyone."

"We were in a bit of shock that our son had this genetic disorder that was lifelong, no cure, very little treatment and we had never even heard of it."

Danielle Rego, Max's mum

Max and his mum Danielle are sharing their family's story for World Neurofibromatosis Day on Monday to raise awareness of the condition and signs and symptoms.

"It is important to start getting the message out there and making people aware of what is something that impacts these people for life, that they struggle with and there is so little awareness about," Ms Rego said.

"People assume because Max is on crutches in plaster he has broken his leg and he gets a little bit of help from having to correct people

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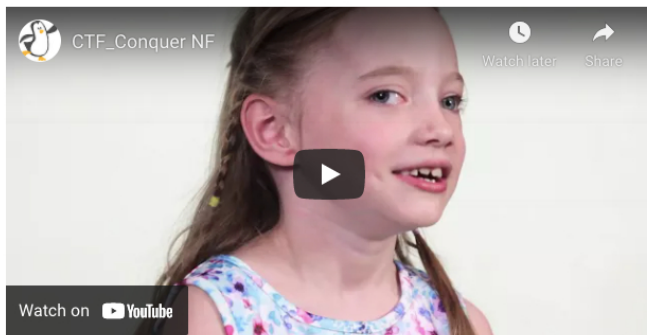
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and he gets a little bit sick of having to correct people.

"It is great if we can get some awareness out there and make people understand a little more what it means when he says NF."

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



NF1 is the most common of the three conditions and is characterised by brown skin spots, freckling in the groin and armpits and benign tumours.

The majority of people with NF1 will never be impacted by major medical complications but for others the condition can be severe, debilitating and life-threatening.

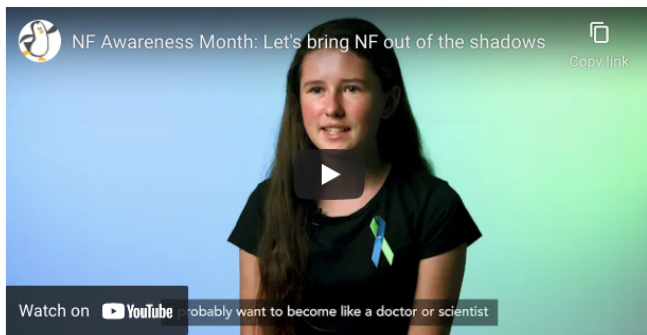
NF2 is the second most common type and is characterised by the development of tumours on the nerve that carries sound and balance information to the brain.

It is also a variable condition and people may develop other benign tumours in the brain and spine.

Cataracts may appear in young children and other eye abnormalities are likely to become an issue for people with this condition.

Schwannomatosis is the rarest form of NF and causes tumours to form on nerves on the spine and other peripheral nerve and occasionally may form on the brain.

Most tumours are not cancerous but are often slow-growing, causing chronic and debilitating pain and may compromise function.



Max's journey to an NF diagnosis began when he had a cataract removed at five-years-old.

His parents took him to a podiatrist with concerns about a persistent limp, which did not go away after initially thinking he had hurt himself at school.

Ms Rego said Max's limp turned into a severe drop foot and he would walk on the side of his foot, which lead to referrals to neurologists, neurosurgeons and to the Royal Children's Hospital NF clinic.

A large tumour was found in Max's thigh, impacting his ability to walk. Since, he has undergone multiple surgeries and countless medical appointments.

When he was nine-years-old he spent three months with an external fixator on his leg to correct his drop foot.

Ms Rego said more widespread awareness about NF would help Max at school, particularly with his upcoming transition to high school, and everyday life.

"As far as Max, you can see he has a disability with his leg, but other than that it is not a really visible thing on him. People just aren't aware when you say he has got NF2," she said.

"Max's school is quite good now, we have done a lot of talks at the school.

"The Children's Tumour Foundation are great and very helpful and they have provided us pamphlets and packs he can take to school so he doesn't have to explain it to his teacher every year.

"But he starts secondary school next year and that is a whole new complexity to it."

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Max will be in plaster and on crutches for the next four weeks, before he begins physiotherapy to relearn how to use his foot.

"We're hoping this might be the last surgery on that leg. His walking has been the biggest impact for him so far, but NF impacts people in so many different ways," Ms Rego said.

"For him, he will continue to have hearing tests and MRIs every year. We have to hope it comes back saying there has been no change each time.

"That is the best you can hope for because there is no cure, so you hope that things haven't changed because if they have changed you just have to look into what has to be done with that.

"We take it year by year and appointment by appointment and see what happens."

Visit the [Children's Tumour Foundation](#) for more information about NF. May is NF Awareness month and World Neurofibromatosis Day is Monday May 17.

The Ballarat Town Hall clock face will be lit up in blue and green on Monday and Tuesday night.

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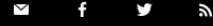
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