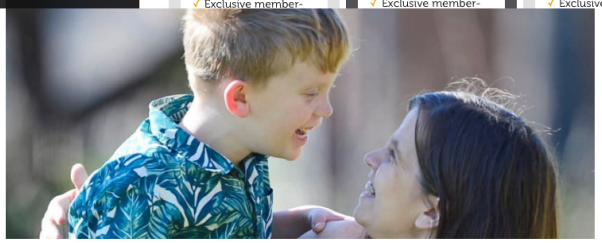


Shepparton's Xavier Wynn, 7, with mum Karla Williams.

Shepparton's Xavier Wynn has a dream.

When he grows up, he wants to play for the Richmond Tigers, like his hero, Jack Riewoldt.

Bouncing around the park with his family, the seven-year-old evidently has the energy, passion and joy to see this dream come true.

But sadly, his mum Karla Williams knows his body will never allow it.

His bright smile doesn't betray it, but for Xavier, each day is constant, excruciating pain.

He's living with neurofibromatosis (NF), a genetic condition that causes tumours to grow on nerve cells throughout the body.

Most are only mildly affected by NF – but for some, like Xavier, the symptoms are severe.

A large tumour has grown along his spine and down his left leg, squeezing his spine to the point the bones are crumbling.

The only solution is a spinal fusion, which will freeze his lumbar region in place – but forever limit the growth and movement of those bones.

But Karla knows it will all be worth it in the end.

"I just want Xavier to have a normal life," she said.

Zalia, 3, Danny and Xavier Wynn, 7, and Karla Williams.

This Neurofibromatosis Awareness Month, Karla is sharing Xavier's story to highlight the largely unknown – but highly prevalent – condition.

"It occurs in one in every 2500 births," she said.

"It's the most common condition you've never heard of."

There are three different types of NF.

Karla and her children live with type one (NF1), which can cause bone deformities, learning difficulties and high blood pressure.

The most frequent features of NF1 include coffee-coloured birthmarks, freckles in areas not usually exposed to sunlight and tiny lumps on the irises and skin – all of these harmless.

People with NF1 can also experience learning difficulties, with around half struggling in the areas of reading, mathematics or spelling.

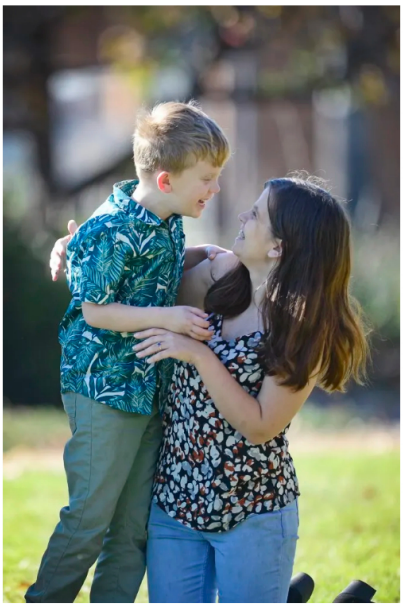
Less frequent symptoms include bone problems.

About 15 per cent of children with the condition develop a noticeable curve in their spine, known as scoliosis, with a small number requiring surgery to straighten it.

Born with NF1, Karla knew there was a 50 per cent chance her children would have it too.

But the only symptoms Karla had experienced were a few little skin bumps – nothing to cause alarm.

While her daughter Chantelle, 13, was born with the condition – and it looks likely her other daughter Zalia, 3, will be diagnosed with it too – their symptoms are also mild.



Shepparton's Xavier Wynn, 7, with mum Karla Williams.

Born in 2013, Karla's son Xavier started showing slight symptoms early on, including small birthmarks and developmental delays.

But it was never enough for a diagnosis.

Until, at age two, Xavier's gait started to change.

"He was in-toeing his left foot, and had very little control over that leg," Karla said.

After an X-ray revealed nothing, Xavier was referred to a neurologist, who ordered an MRI.

That's when they discovered the large tumour spreading throughout his body.

"That instantly gave him the diagnosis of NF1," Karla said.

"If anything I felt relief. I knew something was going on with him, I wasn't crazy."

Known as a plexiform neurofibroma, the tumour was devouring Xavier's body like a weed, infiltrating his nerves, vessels and muscles.

But there were minimal treatment options.

"Surgery is usually high-risk," Karla said.

"(The tumours) are involved in a lot of major nerves and vessels, and they're usually very vascular in nature, so they have their own blood supply."

While the tumour is benign, it can still be very dangerous.

In Xavier's case, it's caused his spine to curve severely to the point he needs surgery.

"But what complicates that even further is that the tumour has broken down his bones, so they're a lot weaker than what they should be," Karla said.

Before the end of this year, Xavier is set to undergo a spinal fusion.

It's a surgery usually reserved for teenagers – because once bones are fused, they can't grow any more.

"And with Xavier being only seven, he has a lot more growing to do," Karla said.

Shepparton's Xavier Wynn, 7, lives with debilitating genetic condition neurofibromatosis.

The surgery will fuse together the bones of the lumbar region of Xavier's spine, which is responsible for the most movement, including bending over.

But it's also their only option.

"At first it was devastating to hear he had to go through this, and hearing all the risk factors involved," Karla said.

"But he's deteriorating so fast before our very eyes, it's going to be a relief when it's over."

Due to Xavier's developmental delays, he still doesn't quite understand what's going on.

But while he's battling pain every day, he remains a happy, energetic little boy.

"I've showed him what a normal spine looks like and what his looks like to explain why he needs a back brace to straighten it out," Karla said.

"But he just says, 'Okay Mum', and off he goes playing again."

It's been a challenging few years for Karla and her partner Danny Wynn, as they support Xavier through his health battles.

But they're continuously grateful he's such a happy kid.

"It would be a lot harder if the pain was making him very obviously miserable," Karla said.

Karla encouraged other parents to learn the signs of NF – a condition that has been invisible for far too long.

"But it's important to remember, Xavier is on the severe end," she said.

"Be reassured, kids with NF can go on to live a relatively normal life.

"It's important to see the light on the other side of this condition."

On May 17, buildings and landmarks throughout Australia will light up blue and green to mark NF Awareness Month.

This will include Shepparton's Riverlinks Eastbank, the Monash Park tree and Mooroopna Water Tower.

For more information, visit ctf.org.au

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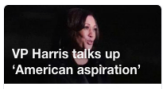

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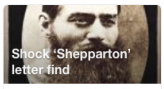

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Shepparton seven-year-old Xavier Wynn lives with genetic condition neurofibromatosis

By Charmayne Allison