NEWS

A 'common' but unheard of condition

BY SOPHIE BOYD

THE thing Hannah Wilson wants more than anything is to be treated like everyone else.

The 11-year-old Wodonga girl, who wants to be a chef or digital illustrator when she grows up, was born with a genetic condition which causes tumours to form along nerves in her body.

Neurofibromatosis affects one in every 2500 Australians and is characterised by freckling on the skin, brown skin spots called café-au-lait marks and benign tumours.

Hannah and her brother Liam, 9, - who wants to be a gaming Youtuber - were both diagnosed with Neurofibromatosis type 1 before their second birthday.

The growths forming beneath Hannah's skin, including along her optic nerve, cause her constant pain and she's already had to undergo surgery to remove two tumours from her back.

But the most painful part of the condition for Hannah, is people's reactions.

"We're not that different to regular people," Hannah said.

"We can do the same things other people can do."

Their mother, Vanessa Engel, 29, said despite being more common than both Cystic Fibrosis and Multiple Sclerosis combined, few people have heard of Neurofibromatosis.

She believes the condition is less well-known because it doesn't present as what people think of as a 'traditional looking' disability.

The genetic condition can be invisible with tumours growing below the skin causing nerve pain, but it can also result in protruding tumours which often lead to unwanted comments.

"A lot of people question and judge and make their own assumptions," Ms Engel said.

"One of the reasons NF isn't as heard of is because we do live in the shadows, children and adults who have NF.

"I've heard a lot of cases of adults who don't like going outside, they don't like people looking at them, they wear a lot of baggy clothes."

Hannah said people have made comments in the past, which weren't nice.

"In year three and year four, people starting asking why I had so many spots," she said.

"You can't catch it...

LOVE: Hannah Wilson, 11, Vanessa Engel, and Liam Wilson, 9. Hannah and Liam both have a rare genetic condition, Neurofibromatosis, and want to raise awareness of the disease within the community. **Pictures: MARK JESSER**

"I didn't ask to have it."

Ms Engel said seeing her children learning to dislike something about themselves because of others' reaction was heartbreaking.

"That's the hardest part as a mum, she's starting to hate this condition," she said.

"She never asked to have it and people judge her because of it.

"I just want everyone to treat my children equally and I want awareness, just because they were born different doesn't mean they are different.

"I always tell them their condition doesn't define them and I make sure they grow up knowing that."

Unfortunately, there is no cure for the condition which can lead to cancer, deafness, blindness and physical difference.