

PBS
LISTING

'MY BOYS SECOND CHANC

**AMELIA IS
RELIEVED HER
SONS WON'T
GO THROUGH
WHAT SHE HAS**

Amelia Ramsay was just eight years old when she found out she, along with her two sisters, Melinda and Greta, and their mother, Toni Freudenstein, all had a rare and life-limiting cancer.

The neuroendocrine cancer, which is called Von Hippel-Lindau (VHL) syndrome, causes tumours and cysts to grow throughout the body. At the time of her diagnosis, there was no cure and the only treatment available involved operations to remove tumours when they arose.

Amelia, now 38, has had more than 50 surgeries in the last 30 years, including eight brain surgeries and a kidney transplant.

However, now thanks to a new drug which has just been listed on the Pharmaceutical Benefits Scheme (PBS), Amelia's children – Xavier, 18, and Leo, 12 – will not have to face a similar fate, having both been diagnosed with VHL.

"I cried when I heard," Amelia, who lives in Brisbane, tells New Idea.

Amelia says she and husband Isaac knew there was a 50 per cent chance of the boys having VHL.

HAVE A Eat life'



Multiple surgeries have taken a huge toll on Amelia's body.

"I can't use the medication as my transplanted kidney can't process it, but the boys can.

"It changes the way they can look at the future. They can go to university and do things without thinking about it."

The listing of the drug belzutifan, which can shrink tumours without the need for invasive surgery, will see the cost drop from \$12,000 per month to just \$31.70 per month.

The PBS approval comes after a dedicated campaign by patients who were struggling to access the extremely expensive medication.

"We showed that in the long run all the surgeries needed cost more than the drug," Amelia says.

The family were diagnosed with VHL after her older sister Melinda, then 19, lost vision at the beach. Tumours were discovered on her retina. She sadly passed away aged 33.

Their mum, Toni, who'd lost sight in one eye giving birth, was later diagnosed with the same condition. She later died aged 69.

"The doctors started asking questions," Amelia says. "My grandmother died aged 34 from kidney

"I think we were both pretty accepting. I missed most of Grade 4 because

drug became necessary for her young son Kingston, who's had his first eye surgery.

Greta has also already started on it and MRIs show that her tumours are shrinking.

While Amelia can't take it herself, she's happy knowing her boys will have no problems accessing the miracle drug.

"I'm quite unwell these days but that's OK," Amelia adds. "I'm relieved for my family knowing the boys' future will be better than mine."

By Emma Levett

'I'm relieved for my family'

cancer and I had been quite sick recently. Greta and I had genetic testing and we both had it too.

I was in hospital. Life changed quickly but it made us resilient."

The entire ordeal made

Amelia keen to live life to the fullest. She married her teenage sweetheart, Isaac, at 21 and they soon welcomed their sons.

Amelia's sister Greta also has two children who have been diagnosed with VHL.

The belzutifan



Amelia and Greta were thrilled to know their children can access the drug.

"Mum (centre) never let us think we were different," Amelia says.

FOR MORE INFORMATION ON THIS AND OTHER NEUROENDOCRINE TUMOURS (NETS), VISIT NEUROENDOCRINE.ORG.AU