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Cancer that killed dad won't get me

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EXCLUSIVE

Lisa Wachsmuth

Ryan Harding has no memories of his father Robert but has lived his life with the knowledge that he shares the same rare disease that took his life.

Yet now, thanks to a miracle drug that has just been listed on the Pharmaceutical Benefits Scheme, Mr Harding finally has hope that he will not suffer the same fate as his dad – and neither will any of his children.

The listing means that the life-changing medication Belzutifan will drop in price from \$12,000 a month to \$31.70 monthly or \$7.70 with a concession, making it accessible to the hundreds of Australians suffering with the rare neuroendocrine cancer, Von Hippel-Lindau (VHL) syndrome.

For Mr Harding, it means he can finally plan for a future.

“My dad died aged 32, when I was just 18 months old,” the Tamworth man said.

“I underwent genetic testing at 12 months along with my two brothers – me and my middle brother had the gene, but my oldest brother did not.

“VHL causes tumours to

grow in certain parts of the body – the spine, the brain, eyes, ears, kidneys, pancreas and more. I have had two laser eye surgeries and six spinal surgeries to remove multiple tumours in the last 15 years – the first when I was 13.”

It’s taken a physical and mental toll, weeks in hospital at a time, months in rehab learning to walk again, and again.

“The fear of the unknown – that’s the biggest killer,” he said. “I’m 28, not too far from the age that dad was when he died. And I’ve been having surgeries since my teens – it’s robbed me of so much.”

Mr Harding has worked hard to bring awareness to the condition to help others and has been instrumental in the massive effort to get access to Belzutifan, after it proved to not only shrink tumours in patients in the US but stop them from growing completely.

He was part of a patient-led lobbying campaign, supported by NeuroEndocrine Cancer Australia (NECA), which led to Belzutifan being listed on the

PBS in December.

NECA CEO Meredith Cummins said the listing was a “Christmas present”.

“Prior to this treatment for VHL has been limited,” she said. “It’s been approved by the TGA in Australia for a few years but only one patient could afford the cost – by remortgaging his house.”

Mr Harding said he was “speechless” when he heard the drug had been PBS-listed. He’s now planning an overseas trip for his 30th, something he could not have risked before.

“I still have several tumours, but my latest scan shows the majority of them have shrunk so hopefully it will mean less scans, and no more surgery,” he said.

“After every surgery I’ve had to do intensive rehabilitation – now I can put the effort into rehab without worrying about going backwards again.

“And if my efforts have stopped another 13-year-old going through what I did, then that means the world to me.”



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Ryan with his dad Robert.



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Ryan Hardings has had multiple tumours removed but now has hope. Picture: Andrew Pearson