

Northern beaches mum raises awareness of genetic condition after son is diagnosed with tumours

Julie Cross, Manly Daily
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UNKNOWN to his family, benign tumours were silently growing on 10-year-old Sydney boy Zion Poy's brain and in his kidneys.

It was only when he suffered a serious seizure last year — which his mother Angela van Boxtel initially mistook for a heart attack — that he was diagnosed with the genetic and incurable disorder tuberous sclerosis complex.

The doctors said white patches on Zion's skin, which Ms van Boxtel and his father Coben were told were just harmless when he was first born, are also skin tumours. Like many with TSC, he has developed epilepsy due to the tumours pressing on his brain.

“We were living this idyllic life on the northern beaches,” Ms van Boxtel said. “Zion is an active kid who liked to surf. We had no idea he was sick.”

Ms van Boxtel, from Freshwater, said she has been to hell and back since discovering her son had an incurable disease, but was now in a more positive place.

However, it has affected the family — there are three other boys aged, 21, 19 and 12 — as Zion has to attend constant hospital appointments and check-ups with multiple specialists.

“Doctors said it would have been better if he had been diagnosed at birth so they could have monitored when the tumours started to grow,” Ms van Boxtel said.

“But they also said he had nine years of not having to worry about being sick and we are very happy he had that time.”

Ms van Boxtel said she was keen to raise awareness of the genetic disorder, which in Zion’s case was by spontaneous mutation at conception, rather than passed directly from parents to child.

“That is a relief to know that it doesn’t affect our other children,” she said.

While Zion has coped well with his diagnosis, Ms van Boxtel, an artist and environmentalist, said he is concerned about his epilepsy and how others view him now.

“I told him there were amazing people in the world with epilepsy including a rapper he likes, Prince and lots of sports people,” she said.

“He has talked about his epilepsy at school and it’s important to him that he feels accepted and not like a stranger.”

Ms van Boxtel has started creating a rug from recycled jeans which she will eventually donate to a children’s hospital or facility to help raise awareness and funds for Jeans for Genes day, which was held on August 4.

She needs 100 pairs of jeans and hopes people will donate \$10 along with their jeans. The funds will go to the Children’s Medical Research Institute.

Read the original story here <http://www.couriermail.com.au/news/mum-raises-awareness-of-genetic-condition-after-son-is-diagnosed-with-tumours/news-story/6290310682347790447d1179c92b0ec9?cspt=1509578724%7Cdd582e444d27d6972df106860d95944e>