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Cheers as Fox G1 syndrome child Kush celebrates five years

Lawrence Machado, Rouse Hill Times



A BIRTHDAY for young Kush Singha and his family is not your average event — every day the Glenwood family counts its blessings.

Kush was the first person in Australia diagnosed with FOX G1 syndrome.

The syndrome affects most aspects of development and impairs brain development, speech and sight.



Kush spent his first three birthdays in hospital which is why the family always makes a big deal of it.

Last month, Kush celebrated a milestone — he turned 5 and blew out his candles with dozens of people from the community.

His dad, Vivek Singha, who stood for the Greenway electorate as member of the Science Party in the 2016 federal elections to raise awareness for the Fox G1 syndrome, said he was proud to be celebrating such a milestone with his son.

The family is also raising money for ongoing research into genetic conditions done by Children's Medical Research Institute and is planning to fund a PhD student to research the rare genetic condition.



Kush when he was two years old. Picture: Peter Kelly

“Kush can’t speak or walk but we see that joy in his face,” Mr Singha said.

“We always have a big celebration for Kush’s birthdays.

“We really missed those first few. He was in hospital, having seizures.

“Then doctors didn’t know what was wrong with him so they put him on medication which knocked him out.

“He was on about six medications and all puffed up. It was very sad and very scary.”

Kush was finally diagnosed with the condition after genetic testing and his doctors and parents have been able to manage his medication and improve his quality of life.

He attends The Ponds School for children with special needs and spends time with his three siblings.

Full story: <https://www.dailytelegraph.com.au/newslocal/rouse-hill-times/cheers-as-fox-g1-syndrome-child-kush-celebrates-five-years/news-story/b49eb85a20c54d44a59438a6a1a19b71>