Families' heartache as tragic disease robs kids of memories, skills before untimely death

When Noah Bevan passed away, aged 15, he could no longer walk or talk. Eventually he was unable to swallow. Now another Brisbane mother is facing the same heartbreaking scenario with two of her children.

Danielle O'Neal Follow

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The Koistinen family has launched this video in celebration of MPS Awareness Day. It tells the heartbreaking story of their son Jobe who is battling Sanfilippo Syndrome.

When Noah Bevan passed away at 15 years old, the teenager had regressed to a developmental stage of about a one-year-old.

The beloved son and brother from Warner, in the Moreton Bay region, had Sanfilippo Syndrome, a rare form of childhood dementia that causes progressive brain damage.

There is currently no cure or approved treatment and the life expectancy for children with the degenerative condition is 12 to 20 years.

Julie and Craig Bevan with children sabel, 11, Madilyn 5, Ella, 15, Jack 13, and Max, 9, who is holding a photo of Noah. Picture: Peter Wallis

Experts believe there are less than 100 cases in Australia.

Mum Julie Bevan said she had never heard of Sanfilippo before Noah was diagnosed at age six, after the family went looking for answers to explain his delayed speech and difficulties in toilet training.

He was the only child in the family of eight children to inherit a defective gene from each of his parents which resulted in the disease.

Noah's regression was rapid and dramatic. He quickly lost the few developmental skills he had developed during childhood and by the time he reached his teens, he could no longer walk and talk. Eventually, he could not swallow.

"It's heartbreaking watching your child lose skills that they've already had," Ms Bevan said.

"Noah was diagnosed and then we grieved right through his diagnosis up until his 15th birthday. That's nine years of knowing we were going to lose him to eventually lose them anyway, it was like a double whammy."

The O'Grady and Bevan families. Two of the O'Grady children suffer from Sanfilippo syndrome and face the same regression that Noah Bevan experienced. Picture: Peter Wallis

Ms Bevan described her son as a "gentle soul" who loved animals and was adored by his large family.

Despite his agonising pain and frustration due to his inability to communicate, Noah continued to smile and could still recognise his family when he passed.

"I hate the thought of other people having to go through this," she said.

The Bevan family gather each year to celebrate Noah's birthday and this year, when their smiley boy would have turned 17, they are hosting a fun run fundraiser to raise vital funds for research.

Brisbane mother Jillian O'Grady is desperate for a cure or treatment for Sanfilippo, which two of her children – Rory, 7, and Anna, 5 – have.

Rory, 7, and Anna, 5, O'Grady have been diagnosed with Sanfilippo. Picture: Peter Wallis

While the disease is still terminal, both children have an attenuated form of the disease, meaning their regression has been slower than usual.

"Without a treatment they will have the same outcome, it's just a much slower progression," Ms O'Grady said.

"They don't have very many symptoms at this stage, in fact Anna you would never know she is any different. She is keeping up with her peers quite well in prep.

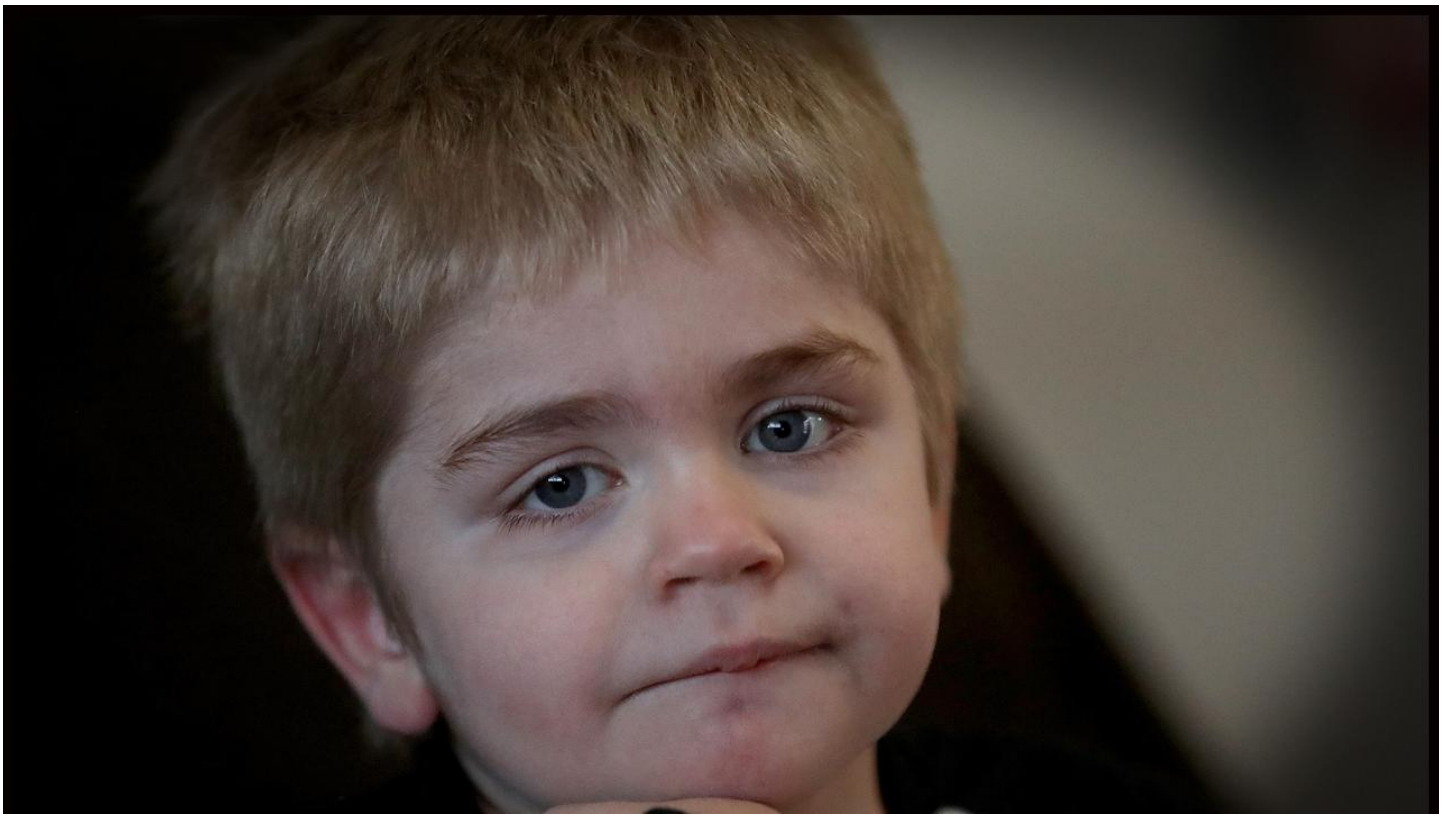
"It's so hard because I have these two kids who seemingly are normal to anyone who crosses them, but it's always there, constantly. One hundred per cent of the time it's in my mind what will happen without a treatment."

Brendan and Jillian O'Grady with Rory, 7, Anna, 5, and Juliet, 5 months. Picture: Peter Wallis

Ipswich boy Oliver McCoombes, 5, who was last year profiled by The Courier-Mail as a little boy likely to soon forget who his parents are, has regressed in the past 12 months.

“He has lost most of his speech now, and he’s also started to have a lot of behavioural issues, extremely hyperactive,” mum Catherine McCoombes said.

“No one we’ve told has ever heard of it and I know a lot of other parents have found with rare conditions like this it’s usually up to the parents and family to raise money for the research.”



Oliver McCoombes, from Ipswich, also has childhood dementia disease. Picture: Jamie Hanson

Ms O’Grady said she believes researchers are on the cusp of a treatment.

“I know families facing this diagnosis seven years ago probably felt the same, but I do truly feel we are on the cusp of treatment becoming available, but I don’t know if it’s just me desperately wishing that is the case,” she said.

“Hopefully it’s not too late for my kids or for others who have got it.”

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Rory and Anna O'Grady. Picture: Peter Wallis

On Saturday, Noah's K9 Fun Run at the Sandgate waterfront will raise vital research funds for the devastatingly cruel disease.

For more information visit https://www.sanfilippo.org.au/noahsfunrun

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