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How an insidious, untreatable disease broke the heart of a **Ballarat family**



Bree Pellow, Skye Robson and Teghan Henderson. Bree and Teghan are co-organisers of a fundraiser for Skye who has been diagnosed with a rare degenerative illness Picture: Kate Healy

WHEN she was barely out of nappies, it was thought that Skye Robson might have had a learning disability, the reality of what it was broke the heart of her loving family.

The bubbly youngster who talked "a lot" and loved to sing, had some struggles with learning, but that was seen as far from unusual.

"We just thought she had a bit of delayed learning," Dad Mark Robson said. "We met with pediatricians, we were looking at getting her into the specialist

school for a year, If she had to repeat prep, so be it, then she'll be the cool kid who's 18 in in year 12 driving to school." But the reality was much worse.

FROM 2015: The cruel disease that will rob Skye of a normal life



best described as childhood Alzheimer's or dementia, with a life expectancy unlikely to see her exceed her teenage years. "It's pretty catastrophic," Mr Robson said. "It starts with delayed

It was discovered that Skye had Sanfilippo Disease, a degenerative condition

development and will degenerate. She loses mobility, her speech, ability to walk. One day her brain will just stop. IN OTHER NEWS

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- "It's heartbreaking for any parent, it's understood there are less than 100

kids in the country with this." Since her diagnosis six years ago, carer Teghan Henderson has been a constant support, with her own family also offering respite at various times

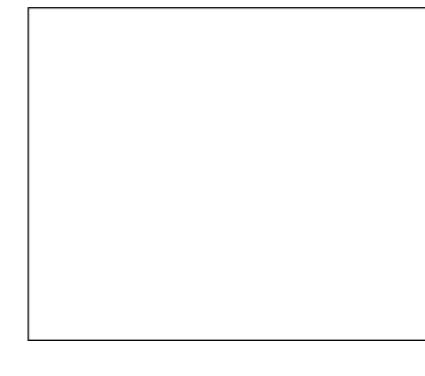
for the Robson's, who also have a son, Luke, who fortunately does not share

the condition. Ms Henderson said it had been heartbreaking watching a vibrant child deteriorate before her eyes.

"When I first started working with Skye she would talk so much, she would

"It's hereditary and both parents need to be a carrier of the gene, and then it's a one in four chance it will happen."

sing and dance, now she's not able to say much at all," Ms Henderson said.



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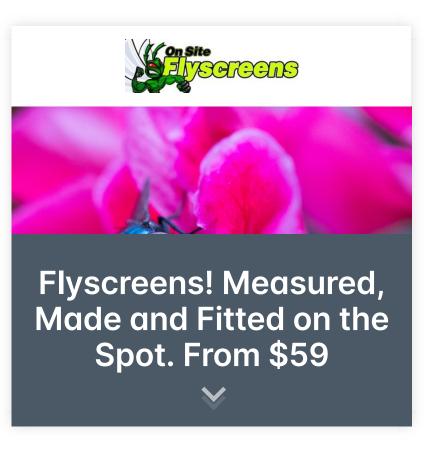
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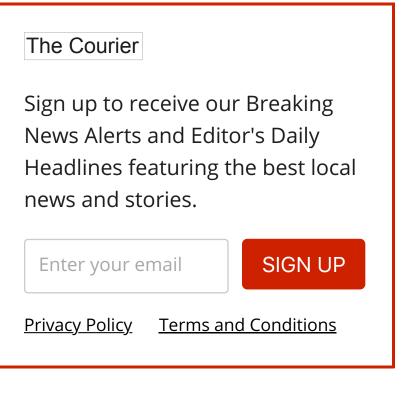
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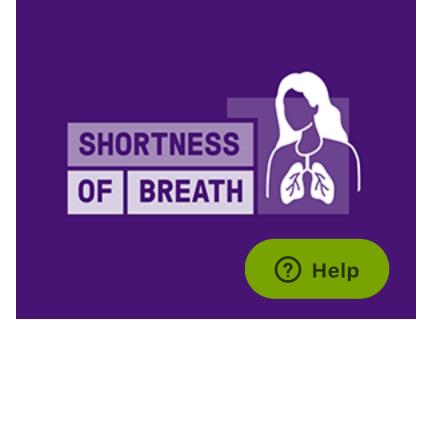
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that the body is unable to process. As the brain gets progressively damaged, children experience severe

Bree Pellow, Skye Robson and Teghan Henderson. Picture: Kate Healy

hyperactivity, disordered sleep, loss of speech, intellectual disability, cardiac issues, seizures, loss of mobility, and finally death, usually before adulthood.

Sanfilippo mostly affects the brain. Over time, brain cells fill up with waste

There is no treatment or cure available. Among the therapeutic avenues being explored, currently gene therapy is the most promising.

which is why a wide variety of approaches continue to be researched. It affects about 1 in 70,000 children and it is estimated that there are 75 to 100 children in Australia living with the condition.

However, a combination of treatments is likely to offer the best outcome

Ms Henderson and Bree Pellow, are raising money and awareness for Sanfilippo all throughout August by walking 15,000 steps a day. Right now they have a team of 18 ready to start pounding the pavement in support of

Skye. "We have always wanted to do some kind of fundraiser for Sanfilippo and

help raise as much awareness as possible," Ms Henderson said.

thought why not give ourselves a big step challenge for a whole month. Anyone can join in with us. "We know so many people who love Skye as much as we do and they are the ones who have signed up to do this with us. We are so grateful for the support we have already received."

"Due to COVID we were limited to the things we were able to do. At the

moment we are both enjoying getting out and walking or running so we

around. Our focus since the diagnosis has been quality of life of life. "For us a cure is most likely going to be too late, but it will be legacy for Skye."

"She's got more and more involved with Skye and Skye loves to have her

Mr Robson said he didn't know where the family would be without Ms

"Teghan has been involved in Skye's life since the diagnosis, she's just an

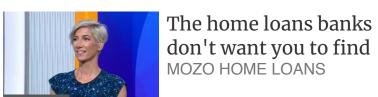
Show your support and make a donation at hopeforskye.com.au or join Ms Henderson's team and do the Steps for Skye challenge at sanfilippo.org.au/stepsforskye

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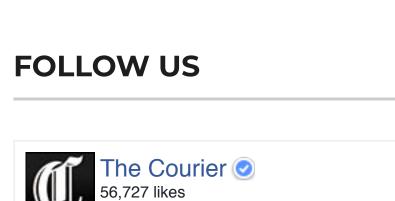
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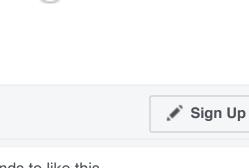
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Henderson.

amazing young lady," he said.





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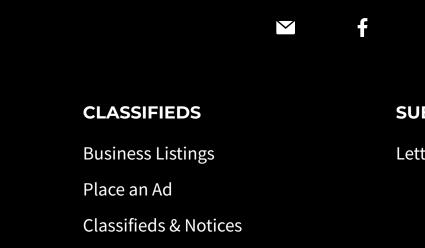
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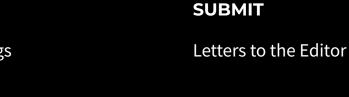
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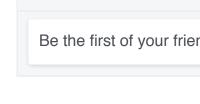
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