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Twins Jobe (right) and Tate. Picture: Caroline Bowen

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Children's Alzheimer's heartbreak for Essendon family

Rachel Clayton, Moonee Valley Leader

May 15, 2019 3:30am

Subscriber only



The parents of a young boy dying of a rare and frightening genetic disease are calling on people to support a campaign to help prolong their son's life.

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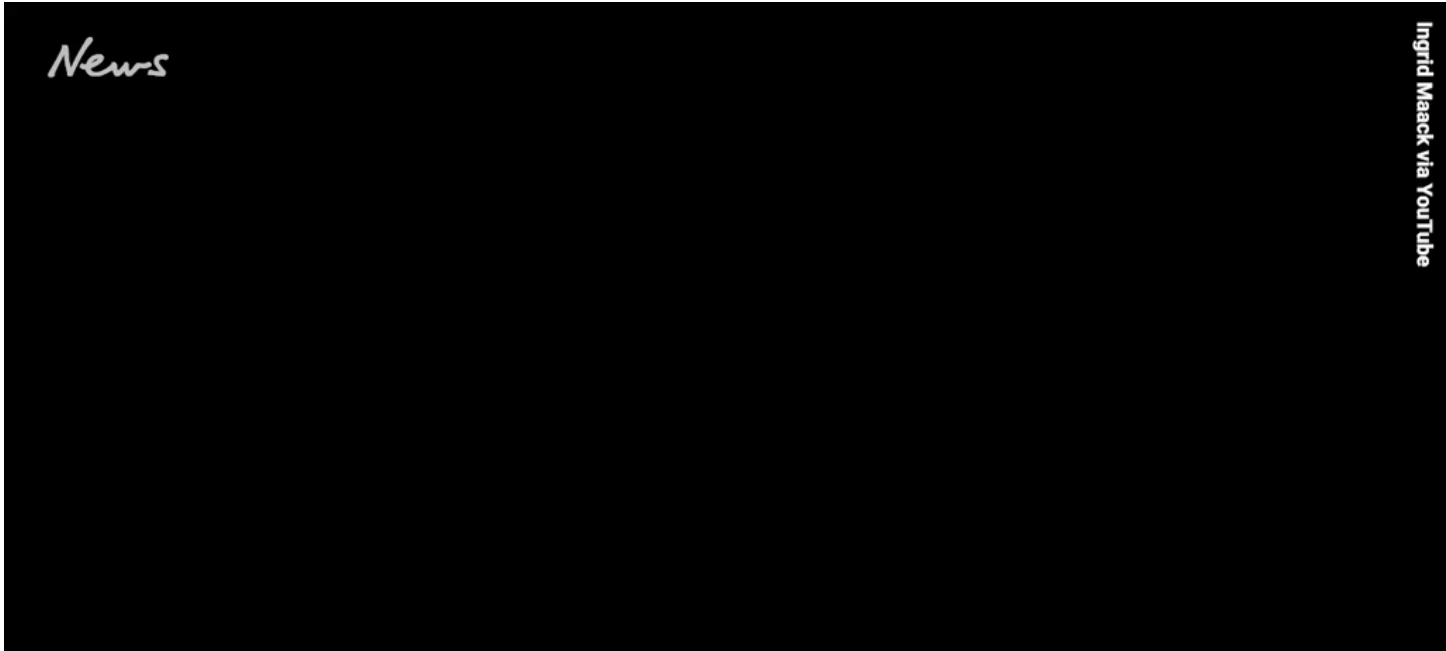
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It is a rapidly degenerative condition that causes fatal brain damage.

There is no effective treatment or cure and the life expectancy for children with the condition is just 12 to 20 years. There are about 70 to 100 patients with Sanfilippo in Australia.

Today is Mucopolysaccharidosis (MPS) Awareness Day and children's Alzheimer's is one form of the MPS group of diseases.



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Ingrid Maack via YouTube

Mrs Koistinen said because the boys were born premature at just 29 weeks, she was always on the lookout for any developmental delays.



 Tenille and Tim Koistinen with Jobe (left) and Tate. Picture: Caroline Bowen

“By the time he was two years old, Jobe’s fontanelle — the soft spot on head — had not closed and his head size had grown quickly in a short space of time,” she said.

An MRI showed large spaces in Jobe’s brain.

Mrs Koistinen Googled Jobe’s clinical notes and found what the doctors were testing for.

“I thought, that’s worst-case scenario, it can’t be us, it won’t be Jobe,” she said.



 Tenille Koistinen with Jobe. Picture: Caroline Bowen

“We are grieving for our son’s life and yet he’s still this sweet, thriving three-year-old boy, and isn’t showing symptoms at this stage.”

There are clinical trials under way around the world but there’s no approved treatment for the condition.

Earlier this year, Jobe underwent screening for an experimental clinical trial in Spain but did not qualify.

Mr and Mrs Koistinen hope a future treatment or experimental trial will improve Jobe’s chances of living beyond his life expectancy.

“As a parent all we hope to do is protect our children, fight for them and do everything in

our power to rid them of pain,” she said.

“We appreciate any support people can give whether donating funds, sharing Jobe’s story, or letting us know about potential fundraising opportunities,” Mrs Koistinen said.

HOW YOU CAN HELP

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