



 **FAMILY TIES:** Timothy and Tenille Koistinen, with their sons, Jobe and Tate, 3, are trying to raise money for research on childhood dementia, Sanfilippo Syndrome, which has afflicted Jobe.

YOUNG Jobe Koistinen wants to be a fireman when he grows up.

But diagnosed with a rare form of childhood dementia in March last year, Jobe, now 3, is already racing the clock.

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Sanfilippo Syndrome, also known as Mucopolysaccharidosis (MPS) III, is a rapidly degenerative condition that which there is no treatment or cure.

Life expectancy for children with the condition is just 12 to 20 years.

Parents to twins Jobe and Tate, Timothy and Tenille Koistinen were devastated to learn their son had a rare gene 75 children Australia-wide.

Having grown up in Albury, Mrs Koistinen said they felt disbelief, fear and helplessness after the diagnosis, wh birthday.

"The impact has been one of utter devastation," she said.

"We are grieving for our son's life and yet he is still this sweet, thriving three-year-old boy, asymptomatic at this



Tim and Tenille want hope for their son, Jobe

There are clinical trials under way around the world, but still no approved treatment for the condition. Earlier this year Jobe underwent screening for an experimental clinical trial in Barcelona in Spain, but unfortun

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Mrs Koistinen said clinical trials in gene therapy and enzyme replacement therapy overseas were showing posit
But she said time was not on their side.

"Between the ages of three and five, these children start to lose their skills," she said.

"We're basically trying to prolong the onset of that degeneration.

"By raising awareness and much needed funds we can help progress clinical research in hope towards an effecti

"We're not just doing it for the children with Sanfilippo now but for the ones who haven't been born yet too."

On Friday night Wodonga restaurant Miss Amelie will host a fundraiser for Sanfilippo and #hopeforjobe.

Tickets include fine dining canapes, local wine, beers and cocktails with DJ Luke Merriman. Tickets are via: ev
charity-night-tickets

Alternatively, donate at: hopeforjobe.com.

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