



## **-PRESS RELEASE-**

### **Two carers step up to shine light on childhood dementia, Sanfilippo syndrome**

STEPS FOR SKYE is a community fitness and fundraising challenge for Sanfilippo Children's Foundation.

It was started in 2020 when two amazing carers set themselves a challenge. Teghan Henderson and Bree Pellow, who care for 12 year old Skye Robson, rallied 15 walkers to each walk 15,000 steps per day for the entire month of August.

They are back at it again for the third year and they are calling on friends and family, as well as the wider community to step up to the challenge to help make it bigger and better than ever. Last year Steps for Skye raised \$25,000. They have doubled their fundraising goal this year to \$50,000.

Skye was diagnosed with the rare childhood dementia, Sanfilippo Syndrome when she was 4 years old. It is a serious degenerative condition that causes fatal brain damage, and for which there is currently no approved treatment or cure. Life expectancy for children with the condition is just 12-20 years.

Children with Sanfilippo Syndrome experience extreme hyperactivity in the early stages of the disease in which some children walk thousands of steps a day. As the disease progresses – and they experience neurological decline – they typically lose the ability to walk.

Skye's mum and dad, Daeng & Mark Robson, are so grateful for the support they have already received and would love to have more team members walking alongside them.

"We promised her love, happiness and quality of life when learning of her diagnosis, and that we would never give up on the hunt for a cure. We join in on the "Steps for Skye" campaign because we know every step takes us closer to a cure and fulfilling our promise to our beautiful little girl". Mr Robson said.

Since inception in 2013, the Sanfilippo Children's Foundation has committed \$5.4 million to medical research across 33 research projects including a clinical gene therapy trial currently underway at the Women's and Children's Hospital in Adelaide.

Register to join in the challenge or donate at [www.sanfilippo.org.au/stepsforskye](http://www.sanfilippo.org.au/stepsforskye)

**To learn more about the Sanfilippo Children's Foundation, or to donate visit:**

[www.sanfilippo.org.au](http://www.sanfilippo.org.au). Follow us on Facebook [www.facebook.com/sanfilippochildrensfoundation](https://www.facebook.com/sanfilippochildrensfoundation) and Twitter [www.twitter.com/SFCFoundtn](https://www.twitter.com/SFCFoundtn)

**For all media enquiries please contact Emma Kirkman [emma@sanfilippo.org.au](mailto:emma@sanfilippo.org.au) 0414 657 607 or Campaign Organiser Teghan Henderson [teghan96@hotmail.com](mailto:teghan96@hotmail.com) 0428 842 714**

