Posted on:
16 February 2022

Williamstown NDIS participant, Luke Ogden has no shortage of drive and determination.

He is about to fulfil one of his biggest goals to create his first major event, the A-T Wheel-a-thon 2022.

Luke, 35, was born with a rare condition, called Ataxia-telangiectasia (A-T – pronounced ay-TACK-see-uh Tey-LAN-jick-TAY-sha), which heavily impacts his mobility and speech.

With NDIS funding for home mods, equipment and supports, he’s enjoying a full life.

He’s regularly out with family and friends, tackling all sorts of activities such as, hiking, campaigning for A-T and hosting events.

“Luke just amazes me. His organisational skills… he’s just so good at everything. He organised this entire event from home all on his iPad and laptop. It’s just been amazing to see it all come together,” his mum, Lee said.

“It wasn’t that hard,” Luke added with a smile. "The only thing concerning me was where I was going to source the wheelchairs from so people without disability could join in too.

Thankfully a Hoppers Crossing Independent Living service loaned us 12 manual and 10 powered wheelchairs for the event so now we’re all set for a fun-filled, action-packed day."

When Luke was born Lee said her and husband, John, were unaware of his condition.

“We thought everything was alright, then when Luke started to walk we noticed he got the wobbles, and they never left, eight months later he was diagnosed with A-T,” she said.

“We had never heard of it, and we didn’t know or meet anyone from the A-T world until we discovered the Johns Hopkins Hospital, in Baltimore, in the US, in 2005.

“We flew over there to meet with neurologists and immunologists who understood A-T.

“At the time Luke was still walking. They just marvelled at his ability, defying his condition, but as he aged it started to affect his mobility and speech more and more. In 2015, he stopped walking.”

The Roebig’s were the first family we knew of dealing with A-T so we jumped on board to support their foundation.

We wanted to help raise more awareness and provide more funding for medical research into A-T’s cause, its treatment and prevention, and now BrAshA-T (a not-for-profit charity) has

opened a clinic in Brisbane, which is wonderful.”

Luke said he really wanted to come up with something original to help support BrAshA-T so he settled on an A-T Wheel-a-thon.

“It’s going to be huge,” he said. “It’s also going to give participants a chance to see the world how a wheelchair user sees it.

Hopefully they’ll get a better understanding of the challenges we face every day, like accessibility. It’s a genuine issue.

“People don’t understand it until they experience it so I’m hoping the Wheel-a-thon will give participants a whole new perspective and appreciation for wheelchair users and for people with disability in general.

“I’m really looking forward to the event. It’s going be so much fun, and I hope people of all ages get behind our cause and join in,” he said.

The A-T Wheel-a-thon 2022 will start at 1 pm, at Hatt Reserve, Williamstown, on March 5. Participants and spectators can look forward to a sausage sizzle too.

Related Stories and videos

Wheelies, walkers and supporters to turn Williamstown purple and white

Luke sets sail on Wheelathon success

9 October 2023
International Day of People with Disability 2023 – We’re better together

Luke sails on through Wheelathon success

22 November 2023
Tom has set himself an epic endurance challenge to raise awareness for National Stroke Week.

Tom’s 9000km epic cycle to raise young stroke awareness

2 August 2021
More stories and videos