Posted on:
22 November 2023

Turning the streets of historic Williamstown purple and white for the annual A-T Wheelathon marked a double delight for founder and local, Luke Ogden.

Luke, who was who was born with a rare condition called Ataxia-telangiectasia (AT), created the event in 2022 to shine a light of support on the disease.

The NDIS participant said the event, which raised awareness and funds for the Brash A-T Foundation, was even bigger than the first.

“For this year’s event, there was a different kind of circuit,” Luke said.
“It was open to everybody. On the Wheelathon page, people registered to enter and got sponsored, sponsored someone else or donated.”

The Wheelathon on 14 October, saw ‘wheelies’, walkers and supporters head off from the Royal Yacht Club of Victoria along a 5 km course.

Complete with an array of manual and power wheelchairs, provided by NDIS provider Independent Living Services, the Wheelathon offered a rare insight into the world of wheelchair users.

“Everybody got involved and registered to walk or use one of the wheelchairs that we provided, or brought their own,” he said.

“It gave people a chance to see the world how a wheelchair user sees it.

“Hopefully, they got a better understanding of the challenges we face every day, like accessibility.”

When he’s not busy planning the Wheelathon, Luke’s no stranger to achieving his goals.

While AT heavily impacts his mobility and speech, NDIS funding for home modifications, assistive technology, equipment and supports, ensures he’s enjoying a full life.

“Luke was able bodied until 12 years ago. He hadn’t really had any assistance until he began to deteriorate,” Luke’s mother Lee said.

“He got an early transition to the NDIS in 2017. It’s been amazing.

“Luke has accessed 3 chairs, and as he uses a chair permanently. We’ve had our doorways widened and automated, and our hallway widened through the NDIS.

“He accesses carers and support workers who take him in to the city or away. That’s been fantastic for Luke and great for his independence.”

Luke enjoys the outdoors and hiking the rugged creeks, lakes and waterfalls of Tasmania. He loves days out in the city, going to concerts, hosting events, campaigning for AT, and making the most of the things he loves.

“I’ve got a chair for indoors, and an outdoor chair suitable for grass which I can also take into shopping centres,” Luke said.

“I’ve also got a 4-wheel-drive chair that goes anywhere, which I’ve taken to Tasmania to hike through the snow.

“I go to the gym once a week, go on trips to the city, go to the movies, out to dinner or just hang out. I also love going to concerts or seeing comedians.”

AT is a rare, neurodegenerative, autosomal recessive disease which causes severe disability. Luke is one of only 50 confirmed cases in Australia.

Setting his sights on a successful second AT-Wheelathon, Luke raised funds for funding research into a cure for AT, supporting Australian families affected by it, and supporting clinical and medical trials.

Exceeding all expectations, Luke raised over $31,000 for the cause.

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