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Turning the streets of historic Williamstown purple and white for the annual A-T Wheelathon marks 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 raises awareness and funds for the Brash A-T Foundation, would be even bigger than the first.

“For this year’s event, there’s a different kind of circuit and it’s going to be huge,” Luke said.

“It’s open to everybody. On the Wheelathon page, people can register to enter and get sponsored, sponsor someone else or donate.”
Kicking off on 14 October, ‘wheelies’, walkers and supporters will 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, Luke said the Wheelathon would offer a rare insight into the world of wheelchair users.

“Everybody can get involved and can register to walk or use one of the wheelchairs that we provide. Or you can bring your own,” he said.

“It’s going to give people 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.”

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 has already raised over $11500. Monies raised will go towards funding research into a cure for AT, supporting Australian families affected by it, and supporting clinical and medical trials.

White long-sleeve, or purple t-shirts will be available for purchase on the day, and a sausage sizzle will be available through Rotary.

A colourful, fun and fulfilling day awaits all those who attend.

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

The A-T Wheelathon will start at 1pm, at the Royal Yacht Club of Victoria, Nelson Place, Williamstown, on 14 October.

For more information on AT and the A-T Wheelathon, or to register or donate, visit www.brashat.org.au

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