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Ben Spencer, a man with ataxia, a degenerative neurological condition has taken on climbing Mount Snowdon and conquered it to raise awareness and funds for Ataxia UK.

Wednesday 21 June, 2023

Where: Snowdonia National Park [Yr Wyddfa]

When: 14th June 2023

How: Snowdon Climb - Wheelchair and rollator walking device for the main climb and then the final push on two adapted walking sticks. - Travel to Snowdonia on accessible public transport to highlight travel providers who take disability travel seriously.

Support team: 5 Volunteers

Climb time: 16 Hours. With travel and rest days this will be a 5-day marathon.

Ben Spencer, aka the Tube Snapper is known for his extraordinary challenge of visiting and photographing every single one of the 272 stations on the London Underground network. This was a 4-month challenge against the time, as Ben wanted to make sure he does this before *ataxia* takes away his ability to walk. Following this endeavour, Ben received significant air time from organisations such as BBC and ITV and multiple other news outlets, in addition to having grown his social media following which now includes the likes of: TFL, The London Transport Museum, BBC TV and Radio, Euronews Travel and Transport.

This challenge has gained Ben international news coverage, which he used to raise awareness of his condition, ataxia, as well as the need for improvements in accessible travel within the capital and beyond. But Ben felt he needed to do more to raise awareness and funds for others affected by ataxia.

Which is why on 14th June 2023, Ben has faced his toughest challenge yet. After several months of training, he decided to climb up as far Mount Snowdon as possible [Yr Wyddfa]. Ben has also decided to document his journey to raise awareness of accessibility in London and beyond. Ben said that he: "will be using wheelchair accessible transport including a London Bus, The London Underground, the Elizabeth Line, Mainline Trains and the Snowdon Sherpa bus service to get to base camp in Wales."

The climb day was long and exhausting. Starting at 6am and finishing just shortly before midnight, Ben and a support team of 5 took the Llanberis path, leading them to the peak of Mount Snowdon. To do this, Ben used a range of mobility aids including sticks, a rollator and a wheelchair. Ben said about the day that: *It took 16.5 hours and a support team of 5. Using my wheelchair, Veloped walking machine and adapted walking sticks I got to the top of Yr Wyddfa, Mount Snowdon. To all the people who have donated so far, your money will make a huge difference to the 500 children and 10,000 adults in the UK with Ataxia. Let's get a cure for Ataxia.*

Ataxia is a progressive neurological condition that disrupts the messages sent from our brains to our muscles. Not just the muscles we use to move, but those we use to speak, listen and see. Over time, people with Ataxia are slowly imprisoned in their own bodies, losing the tools they once had to communicate with loved ones. In some cases, it affects the heart muscle, making it difficult for the heart to pump blood around the body which can lead to heart failure. More than 10,000 adults and 500 children in the UK live with Ataxia. It is hereditary, it is progressive. There is no cure. Yet.

For his awareness and fundraising journey, Ben has received support from Ataxia UK. Ataxia UK CEO, Sue Millman, said that: *"most people can't conceive the access problems for disabled people when using public transport, unless they're disabled themselves or they have had close contact with somebody who is disabled. The simplest journeys can become complicated by one or two steps, or the lack of dropped curb."*

Ataxia UK funds research to find treatments and cures and until one is found they offer support to families affected, and looks to improve treatment and care for patients.

Ben's story is not just that of 10,000+ people in the UK with ataxia, but all of those that face issues while

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using public transport on a daily basis. As Sue Millman put it: "We should create an accessible world for everybody."

You can watch the video explaining Ben's fund and awareness raising efforts here: https://www.youtube.com/watch?v=gYntt-a6GHA

For more information on Ben and his journey visit <u>www.snowdon4ataxia.com</u>, for more information about ataxia, see <u>www.ataxia.org.uk</u>, and with any press-related queries, or requests for video and stills content from the climb day, please contact Viktor Elzer 020 7582 1444 or email Ataxia UK's communications team at: <u>communications@ataxia.org.uk</u>.

About ataxia:

- Ataxia is a group of neurological disorders that disrupt the communication between the brain and the body; the cerebellum and our muscles. There are many different types of ataxia that can affect people in a variety of different ways.
- Ataxia disrupts someone's ability to communicate: it erodes speech, vision and hearing, isolating them from loved ones, friends and society.
- Ataxia disrupts someone's ability to move their body in the way they wish.
- Ataxia disrupts someone's agency; their ability to work; their independence; their choice; their control.
- Ataxia disrupts every aspect of a person's life. Then their life itself.
- Ataxia disrupts the heart's ability to beat.
- Ataxia disrupts how the public perceive people. People with ataxia are often misinterpreted as drunk because of their wobbly walk. When they try to explain why, they are misunderstood again because of their slurred speech.
- Anyone of any age can get ataxia, but certain types are more common in certain age groups. For example, people with Friedreich's ataxia are usually diagnosed in childhood or adolescence.
- Around 10,000 adults in the UK currently live with a form of the condition. Ataxia UK is currently funding research to find out how many children have the condition, but it is thought there are several thousand.
- Some forms of ataxia are treatable, but in most cases there is still no

About Ataxia UK:

- Ataxia UK funds research into treatments for the condition and our ultimate aim is to find a cure. The charity also supports those with ataxia through a range of services - from providing a helpline and other information resources, to organising events and local support groups.
- For more information on the charity's work and its other events go to <u>www.ataxia.org.uk</u> or visit the Ataxia UK Facebook page <u>www.facebook.com/ataxiauk</u>.
- Please connect with us on twitter <u>@AtaxiaUK</u>
- Many people with ataxia have their own websites and blogs links can be found at <u>http://www.ataxia.org.uk/pages/local-support.html</u>

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