

PRESS RELEASE [date]

Title of your event Subtitle – what your event is trying to achieve e.g. Cycling 100km to support those with ataxia. [Location]

Para 1: What is happening / what happened and when?

Example points to include:

- What you are going to be doing / what you did
- Why you are doing the event what's the story behind your event?
- When it is / was
- How much raised
- Add the hashtag #CaptainTom100 #AtaxiaUK100

For example:

As part of Captain Tom's 100 challenge, Joe Bloggs is cycling 100km on 1 May 2021 to raise funds and awareness for the charity, Ataxia UK. Joe is cycling for his sister, Sarah, who has Friedreich's ataxia (FA), and hopes to raise £1,000 to support thousands of other people affected by the ataxias, too.

Sarah was diagnosed with FA at 5 years old and has used a wheelchair ever since. Joe said: "It's been really difficult to watch Sarah's condition progress, but despite her challenges, she's so positive every day. Her spirit, just like Captain Tom's is why I want to cycle 100km for her and others suffering with an ataxia."

Captain Tom was in the spirit of hope, motivation and positivity which reflects in Joe's 100km cycle as he hopes to help Ataxia UK find treatment and cures for the ataxias.

Para 2: What is ataxia and what is its affect (Feel free to add more or edit the text below. If your event is for someone close to you, you can talk about how ataxia affects / affected them.)

The ataxias are a group of rare, neurological conditions. They disrupt the messages sent from our brains to our muscles, which makes communicating and moving a daily

challenge. They are progressive and currently there are no cures for the majority of ataxias. Around 10,000 adults and 500 children have ataxia in the UK.

According to a GOV.UK study, only 13% of the UK population have heard of ataxia. The lack of knowledge around ataxia leads to a low diagnosis rate, which means there are many other people battling with ataxia and who receive no support.

Para 3: How your fundraising event will change things e.g. where will the money go (Feel free to add more or edit the text below.)

Ataxia UK is the only charity in the UK that funds research into all of the ataxias, and supports those affected until they find them. Research into treatments and cures for the ataxias is happening all the time, but it takes time and money. By donating to a fundraiser, your money will help those affected by ataxia by providing support via a helpline, crucial research into cures, useful publications, branches and support groups across the country, and much more.

Para 4: Quote

Sue Millman, CEO of Ataxia UK said: "We are very grateful to see the ataxia community coming together in memory of Captain Sir Tom Moore, and emulating his spirit to raise vital funds and awareness of ataxia. It is the support from fundraisers like ours that help to keep Ataxia UK afloat and enable us to work on your behalf. Thank you."

Ataxia UK funds research to find treatments and cures. They offer support to families affected, and look to improve treatment and care for patients.

For more information visit ataxia.org.uk or facebook.com/ataxiauk

- Ends -

Notes to Editors About ataxia:

- The Captain Tom 100 challenge was set up in memory of Captain Tom Moore for people to raise money for charities around the number 100, as it would be his 101th birthday.
- The challenge takes place from Friday 30th April-30th May 2021.
- #CaptainTom100 #AtaxiaUK100
- Ataxia is a group of neurological disorders that affect balance, coordination and speech. There are many different types of ataxia that can affect people in a variety of different ways.

- 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 and 500 children 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 cure.

About Ataxia UK:

- Ataxia UK funds research into treatments for the condition and our ultimate aim is to find a cure for all of the ataxias. 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 @AtaxiaUK and Instagram @ataxiauk

For more information or to arrange an interview with a case study, please contact Leanna Coleman at Ataxia UK on 020 7582 1444 or <u>communications@ataxia.org.uk</u>.