

What is Ataxia Telangiectasia?

Ataxia –Telangiectasia (“A-T”) is a degenerative brain condition that causes many of the same disabling effects as ALS/Motor Neurone’s disease only it affects young children. Kids are born seemingly normal but peak physically around the age of 5 before slowly losing their physical abilities including the ability to walk, talk and even to feed themselves. Mentally they remain unaffected and so they effectively become trapped in a deteriorating body.

On top of the severe physical disabilities children with A-T must face, the condition also attacks their immune system. 1 in 3 children with A-T will develop cancer and many will die from lung disease. More than half will die before they are out of their teens and there is currently no cure and nothing that can slow the condition’s progression.

About Action for A-T

Action for A-T was established in 2012 by parents whose daughter was diagnosed with the condition. Our mission is simple, we aim to speed up the process of identifying a cure for A-T or treatments that delay or prevent the disabling effects of the condition. We do this by seeking and funding high quality peer-reviewed medical research both in the UK and around the world.

We have established a highly qualified multi-disciplinary medical advisory and peer review panel and a grant process which has led to us achieving certification with the national Association of Medical



Research Charities (AMRC). Since 2012, we have funded or co-funded a variety of A-T related research projects around the world (see www.actionforAT.org for more details) and are constantly on the lookout for new and innovative research funding opportunities.

Like many rare diseases, A-T related medical research receives little or no funding from the government and we are therefore heavily reliant on public support. We are committed to achieving our mission as quickly as possible but cannot do this without your help so urge you to lend your support in any way you can. Please join us in our mission to help the children and families living with A-T as your support offers them much needed hope.

In the words of one of the world’s most respected A-T researchers, finding a cure for A-T is:

“...just a matter of time and money...and more money means less time”

Professor Richard Gatti (2013)

How can you help?

Make a donation

You can make a one off or regular donation to help fund vital A-T research. Visit our website www.actionforAT.org and click on the donate button.

Take part in an organised event

You could do a sponsored walk, swim or triathlon, run a full or half marathon or get on your bike for Action for A-T. We have guaranteed places at a variety of flagship events and also run our own activities such as clay pigeon shoots and golf days. The sky is literally the limit as we can even arrange for you to abseil down a building, wing walk or skydive. Alternatively, if there’s a challenge you’ve always dreamt of taking on, lets us know and we will do our best to accommodate you? Check our website for a full list of our events, www.actionforAT.org/events.





We also have two fundraising campaigns which you can take part in.

- “Razor Free for A-T” – In February we encourage the men to go “Razor Free for A-T” and grow a full beard. Take part by yourself or encourage your club/society/community to take part too. The “Razor Free” campaign culminates on the 28th February which is National Rare Diseases Day and at this point we’ll be encouraging you to pimp your beard and send us the photos!
- “Take Tea for A-T” – Why not host your own tea party this summer and encourage your friends, work colleagues and neighbours to “take tea for A-T”. Our “Take Tea for A-T” pack is full of tips and ideas to enhance your party plus exclusive recipes for yummy cakes to sell at your tea party.



Organise your own event

You could organise a quiz night, coffee morning, raffle, car boot sale, music gig, tennis tournament, golf day, comedy night or even a family fun day to raise funds and awareness for Action for A-T. We love to hear what you’re up to so please do let us know what you’re planning and we’ll offer assistance where we can. We also love to feature pictures of events on our gallery so be sure to send us your photos to include on the website.

Become a corporate partner

Working with Action for A-T will help you motivate your staff and contribute to team-building, achieve your corporate social responsibility objectives, strategically promote your company as a responsible organisation, raise your profile and build your brand from PR opportunities, attract new custom and most importantly make a tangible difference to the future of A-T children and their families.

Volunteer for us

Whether it’s raising awareness, fundraising, joining our cheer team at one of our major events or offering your services on a pro-bono basis, we need you to help us achieve our mission!

Get in touch with us today for more details of how to support Action for A-T. www.actionforAT.org
E-mail info@actionforAT.org or call 01428 853313.

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RESEARCH,
FINDING HOPE**



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