

ACTION FOR A-T IMPACT REPORT

2013-2025

Action for A-T
Driving change in A-T
research since 2013

**ACTION
FOR A-T**

**FUNDING
RESEARCH
FINDING HOPE**



'As we celebrate the past 12 years, I am humbled and inspired by the incredible journey we've shared. Twelve years ago, we set out with a singular vision: to transform the lives of those affected by ataxia telangiectasia (A-T) through groundbreaking research and unwavering community support. Today, that vision has turned into tangible progress, made possible by the tireless efforts of our supporters, researchers and partners worldwide. None of this would have been possible without you, our donors, fundraisers, and advocates. Your commitment fuels our mission and ensures that every step we take brings us closer to treatments and, one day, a cure for A-T. Thank you for being part of our story.'

SEAN KELLY

Chief Executive of Action for A-T



'We are so grateful to each and every person who has supported Action for A-T during the last 12 years. The dedication, commitment and generosity of our supporters has been incredible for us to witness as a family and also more broadly as part of the wider A-T community. The charity has already made a lasting impact thanks to every single fundraising activity, large or small, undertaken by you, our amazing supporters. As a result, with every project we fund, we move closer to fulfilling our mission to find a treatment or cure for this rare condition. Action for A-T simply could not have come this far without you. Thank you for believing that together, we can all make a difference!'

EMILY AND TOBY READ

Founders of Action for A-T



FUNDING RESEARCH

Building foundations in research innovation

We are proud to have funded pioneering research in A-T, exploring disease progression and preparing for new treatments:

- Defining the course and pattern of A-T's natural history
- Generating novel tools to screen for potential therapies (e.g. by creating mini brains)
- Investigating methods that could allow researchers to detect the benefit of a new treatment (e.g. biomarker research)
- Seed funding early ideas or proof-of-concept studies. Many of these projects have produced the data needed to secure larger-scale funding. This funding is crucial for translating research into viable solutions that will impact the development of A-T treatments.

How our progress has impacted patients today

Action for A-T has transformed the landscape of A-T research, directly impacting patient treatment and wellbeing. By investing over £5.7 million in 60 groundbreaking studies, we have accelerated the development of potential treatments, including drug repurposing trials and genetic therapy exploration. Our research has improved symptom management strategies, leading to better clinical care and support for families. Additionally, we have strengthened global collaboration, ensuring that those affected receive the best possible medical advice, therapies and hope for future breakthroughs.



OUR HIGHLIGHTS:

- AMRC Excellence in Peer Review Audit winners
- Founding member of the Global A-T Alliance
- 158 London Marathon runners raising **£482,000** since 2015
- Our ongoing partnership with Constellation Automotive Group, which has raised **£910,000** since 2017

FUNDING RESEARCH - (2013-2025) 12 YEARS OF ACTION FOR A-T IN NUMBERS

 **£5.7 MILLION TOTAL INVESTED IN RESEARCH**

TOTAL RESEARCH SPEND SINCE 2013

Development of treatments and interventions, **£2,058,716**

Aetiology, **£1,863,276**

Detection, screening and diagnosis, **£981,051**

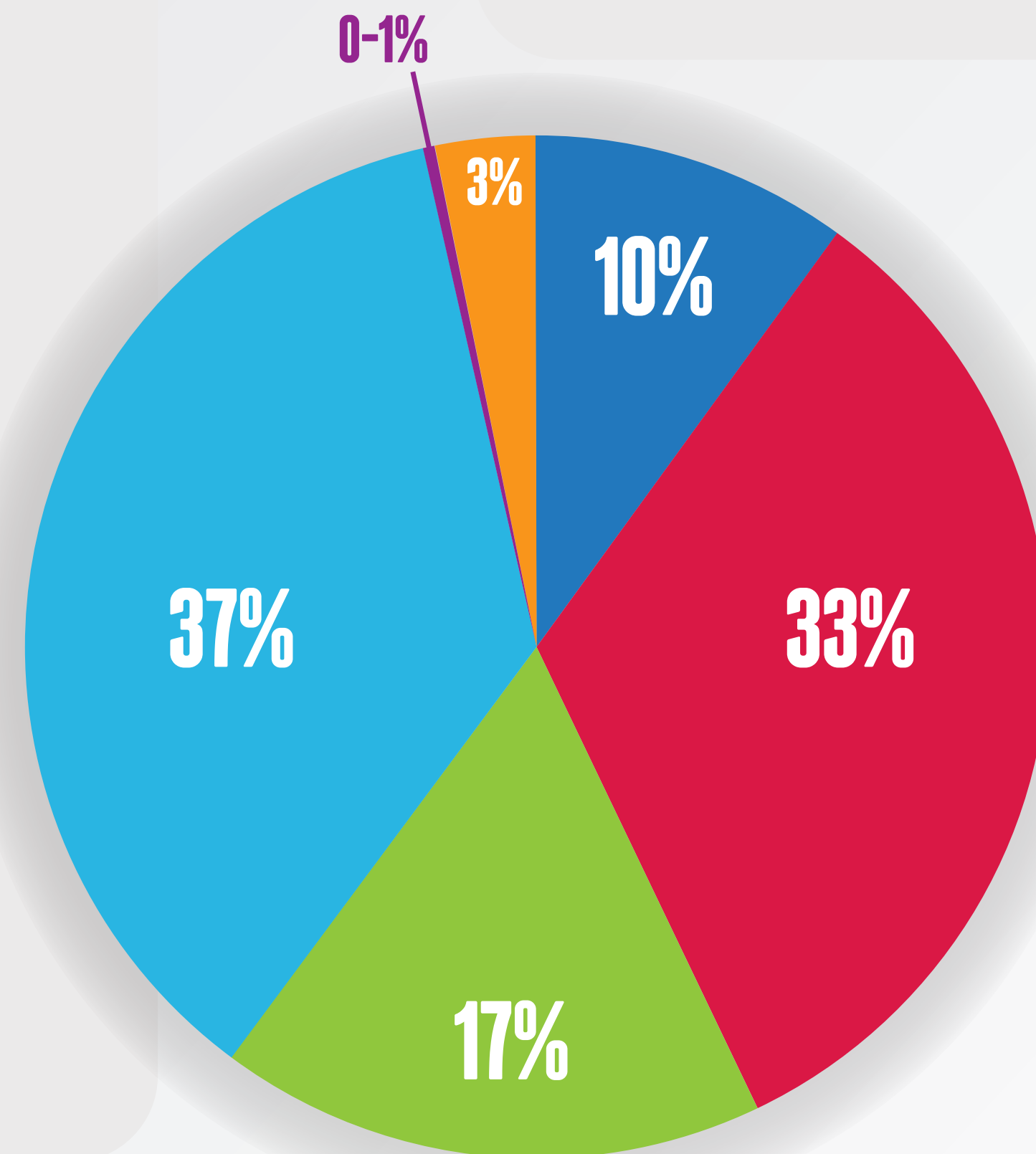
Underpinning research, **£555,431**

Management of diseases and conditions, **£176,285**

Evaluation of treatments and interventions, **£17,656**

Driving research

Our first grant round in 2014 received **5** research grant applications. By 2023, the number of applications increased to **17**, representing a **340%** increase



FINDING HOPE



In 2018, 44 supporters helped two boys with A-T reach the summit of Mount Snowdon, raising over **£24,000**.

'Events such as this are vital in our quest to find a cure or treatment for A-T.'

TOBY READ
Action for A-T Chairman



37 supporters took part in the 2017 Cotswolds Way 100-km endurance walk, raising **£51,000** towards A-T research.

'One of the toughest but most rewarding challenges I have ever completed.'

SUSIE SHILLINGFORD
Action for A-T Supporter

The Mollie's Miracle team have supported Action for A-T since 2021, when Mollie was diagnosed with A-T. Since then, they have staged and participated in various events, raising over **£30,000**.



'Funding from the Action for A-T and BrAshA-T has made it possible for us to make mini brains from British and Australian A-T patients and perform ultra high-resolution gene sequencing. This provides us with an extremely detailed analysis of the cells that make up these mini brains, giving us important clues about how the disease progresses and, importantly, providing a platform to test drugs on.'

DR SAM NAYLER
QIMR Berghofer Medical Research Institute,
Queensland, Australia



'In 2020, BrAshA-T and our counterpart in the UK, Action for A-T, were the driving force in the establishment of the A-T Global Alliance. Along with A-T charities from around the world, our intention was to pool our funds for a greater impact and to leverage the specialist skills of each of the alliance organisations.'

MIKE CLAHSN
President of BrAshA-T, Australia





What's next for Action for A-T?

1. **Fund projects** with an emphasis on improving quality of life
2. **Continue to support** projects to quicker diagnose, better manage and treat the problems faced by patients living with A-T, improving their duration of life
3. **Invest** in the rapidly evolving field of gene therapy to find treatments and potentially a cure

'In 2019, we applied to Action for A-T to fund a research study looking into cancer screening for people with A-T. The grant awarded to us by Action for A-T of around £100,000 allowed us to demonstrate that using whole-body magnetic resonance imaging (MRI) scanning for cancer screening in children and young people with A-T was feasible and well tolerated.'

PROF ROB DINEEN
University of Nottingham,
Nottinghamshire, United Kingdom

'We travelled to Nottingham for Mollie to take part in the MRI research trial for A-T. It was not the first time Mollie had an MRI, but it was her first full body scan, and she was awake for the whole procedure. She was super brave and so well behaved, shining like the star she is. Knowing this research could lead to earlier cancer detection for children with A-T means the world to us and so many families.'

EMILY BARKER
Mollie's mother

'Thanks to the founders of Action for A-T, we managed to identify and diagnose what was wrong with our beautiful little girl. We are also grateful to have more time to understand the condition and make every moment for Lilly count.'

JOE DAY
Kent

'We are so thankful for everyone who is working on A-T research and donating money. Further research is the only thing that can help A-T families like us.'

ANONYMOUS
A-T Family

'As a patron for Action for A-T, I am committed to raising awareness and much needed funds to support the hugely positive goal of trying to make life better for those affected by A-T.'

JONNY WILKINSON
Lead Patron

'I've met families who are living with A-T. They're all determined to make sure that those living with this condition live as well as possible. Their determination has inspired me to push myself and try to make a difference.'

NAGA MUNCHETTY
Patron

ACTION FOR A-T



If you would like to support us, please visit www.actionforat.org or contact us at

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Thank you

We are hugely grateful to everyone who has partnered with us over the last 12 years, leading pioneering research and supporting us in all our fundraising efforts. We would like to pay special thanks to the following organisations and individuals for their exceptional support:

- **Constellation Automotive Group – £910,000**
- **Medical Research Council – £392,464**
- **Chris Herring – £117,382**
- **Simon Toon - £85,625**
- **Chris Sheasby – £72,088**
- **BGC Partners – £72,000**
- **James Osborne – £67,635**
- **WASPS Legends Charitable Foundation – £64,540**
- **Aviva Investors – £63,738**
- **Naga Munchetty – £54,159**
- **Monica Seccombe – £43,110**



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