



**FUNDING
RESEARCH,
FINDING HOPE**

“Together we are stronger”
Patient associations joining forces
To fund rare disease research

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What is A-T?



Ataxia Telangiectasia





About Action for A-T?



was established in 2012
by parents whose
daughter
was diagnosed with
the condition





Deciding whether partnership working is right for your association requires careful consideration





What are the possible Challenges?

- Often lack of contact between organisations with similar objectives**
- Potential loss of control and ownership of research projects**
- Complex funding and reporting structures**
- Ability and desire to work with others**
- Issues over the allocation of funds**
- Concerns that supporters and beneficiaries won't approve of the partnership**
- Lack of day to day time and resources**
- Could slow the funding process down**



What are the possible opportunities?

Could help to bring new treatments and therapies to patients sooner

Each party can bring their unique strengths and perspectives to the partnership

Project costs and resources can be shared

Non duplication of effort

Projects can get underway more quickly

Can help to leverage future donations

Generally, partnerships are well received by beneficiaries and supporters

Opportunity to learn and develop



Action for A-T rationale



Action for A-T believe there are many opportunities to further the search for a treatment or a cure for A-T through working with third party organisations that may have overlapping aims or objectives to our own

Working in partnership with other organisations is key theme of our strategy

Some of our existing partnerships were established soon after Action for A-T was founded

Initial partnerships with the A-T Children's Project in the USA and Sparks in the UK were initiated due to a lack of resources

Early partnerships were varied in their nature



RELAXED



FORMAL



Funding partnerships overview



Since it was founded in 2012, Action for A-T has grown exponentially and are now the leading funders of A-T research in the United Kingdom. Our funding partnerships have contributed significantly to this growth as well as the following:

- **Adopting a flexible approach to collaborative funding. We are happy to lead or follow**
- **Appointment of a part time research manager**
- **Recruitment of a volunteer research advisory committee (RAC) which includes patient representation and a broad range of scientific expertise in all areas of A-T**
- **Working closely with the A-T research community to create interest in the condition**
- **Establishment of an award winning peer review and project management process**
- **Creation of a comprehensive research strategy and partnership funding policy**

Working in this way has enabled us to create collaborative funding partnerships with a variety of organisations around the globe



Case study 1 – BrAshA-T





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- Australian based volunteer led patient organisation with limited resources
- We approached them asking if they wanted to Co-fund any of our latest research projects
- Projects were already peer reviewed and passed for funding. Details had not been publicly announced
- Agreed to contribute a total of £50,000 towards two projects. £25,000 each
- Full project management and associated reporting undertaken by Action for A-T *AMRC Guidelines
- Comprehensive funding agreement in place to specify all areas of partnership arrangement
- Support acknowledged on all associated media as “funded in partnership with”
- Stage payments made to Action for A-T rather than institution, invoiced in arrears
- Open dialogue throughout the entire process to keep all parties up to speed



Case study 2 – Action Medical Research





Case study 2 – Action Medical Research



- **Large UK based paediatric medical research charity who fund in all areas of child health**
- **Provide joint funding opportunities for other medical research charities and patient associations**
- **Agreement in place with Action for A-T to co-fund up to £500,000 of research in 2018**
- **Action Medical Research (AMR) to manage the application process and call for applications**
- **Full peer review, project management and associated reporting undertaken by AMR**
- **Outline applications agreed with us and representation from our RAC at the final peer review meeting**
- **Final funding decision with Action for A-T trustees**
- **Stage payments made to AMR rather than institution. Initial payment when project agreed and future payments invoiced in arrears**
- **Slower process from start to finish but significant additional investment in A-T research**



Key considerations



- Understand what you want to achieve
- Find the right partner
- Set roles and objectives
- Put in place policies, systems and processes
- Communicate, communicate, communicate
- Operate with integrity
- Maintain your independence
- Be transparent at all times





Closing remarks



By building relationships where integrity, independence and transparency are central, patient associations should feel comfortable in pursuing collaborative funding partnerships to further their aims and objectives

Always discuss the principles for partnerships with trustees, supporters and stakeholders before beginning discussions with potential funding partners

It is important to have a clearly defined research strategy that sets out what you want to achieve and with whom

Be open and transparent about the partnerships you form

Aim to have an established point of contact with the person who leads on managing the relationship



Closing remarks cont-



"It is the long history of humankind (and animal kind, too) that those who learned to collaborate and improvise most effectively have prevailed."

Charles Darwin

Thank you