# Ataxia-Telangiectasia Society

## Fundraising and Relationship Manager

### Background information

This is an exciting time to join our small but ambitious charity and take responsibility for increasing our income, enabling us to grow and deliver the best possible support to people affected by A-T. The post will require you to develop strategies and to manage activities in a very hands-on way. You will be working both independently and in collaboration with the Chief Executive and trustees as part of a team committed to harnessing experience and innovation to meet the needs and aspirations of our people.

**The condition**
Ataxia-Telangiectasia, or A-T, is a neurodegenerative, genetic disease which affects many parts of the body, causing severe childhood disability and premature death. It is progressive; if affects the cerebellum, the body's motor-control centre, and in 70% of cases weakens the immune system, leading to respiratory disorders. It also significantly increases the chance of childhood leukaemia and other cancers. While the condition is relatively rare, it is estimated that in the UK more than 1 person in 200 people carries the faulty gene.

**The organisation**
The A-T Society is a national charity providing information and support to people affected by A-T and funding and promoting research. It has excellent relationships with those affected by A-T and with leading clinicians and researchers, in the UK and abroad. It is the only organisation in the UK doing this and one of the most active at international level. The information it provides is accessed world-wide.

Amongst other things the Society:

- provides information via a range of media (leaflets, website, phone contact, newsletters etc.) to families affected by A-T, professionals, schools and the public generally
- provides practical support, guidance and advocacy through a professional support worker, as well as support grants and access to a counsellor and specialist physiotherapist and occupational therapist
- organises information and support events, respite holidays and activity days
- in partnership with the NHS has established and supports national specialist clinics at Nottingham and Papworth
- funds research and supports researchers looking into the cause and cure of A-T

Set up 20 years ago, the charity has been run very effectively by the volunteers who founded it. Now, however, with the appointment of a Chief Executive, the trustees want the charity to step up to a new level. They want it to become a modern and professional organisation, with a higher profile, better able to meet the changing needs of people affected by A-T. They also want to increase the scale and effectiveness of its research funding, which will involve national and international collaboration.

The Society is in the process of carrying out a strategic review with the aim of agreeing a new Strategy by the end of the year.

**The role**

The Society's income in 2009 was just under £200k. The main sources of income are grant-giving trusts and locally organised community events, each of which accounts for approximately one third of the total. The rest comes from various sources, including a £29k grant from the NHS towards the cost of our national clinics and £16k from regular givers.

For the last 9 years the Society has employed a part time fundraiser, through whose efforts we have achieved a good record of successful applications to a wide range of trusts and are supporting an ever-increasing number of community events.

With this full-time appointment, the Society is looking to deliver a significant increase in income over the next few years. The key will be a more proactive approach to identifying and building constructive relationships, with trusts, with people willing to organise events and with other potentially significant donors. We will also be looking to do more to promote challenge events as well as legacy and in memoriam giving and to make better use of the possibilities afforded by the web and social networking.

The Society is a small organisation, withall the advantages that brings in being 'light on one's feet'. We are open to innovation and creativity, as long as it is effective in helping us deliver better support and outcomes for people affected by A-T. As part of a small team, the post-holder will be expected to contribute to the Society's planning and strategic development.

The Society has a Fundraising Committee, consisting of the fundraiser and a number of trustees and volunteers with experience in fundraising. The post-holder will be expected to lead and develop this.

**Terms and conditions**

**Hours of work:** the post is full time and working hours are 35 per week, normally 9am – 5pm. However we are prepared to give consideration to requests for flexible working.

**Location:** the job is based at the Society's offices in Harpenden and the post-holder will be expected to work from there regularly. However the Society is prepared to give consideration to requests for arrangements involving some work from home.

**Holidays:** all employees are entitled to 25 days' annual leave, (in addition to UK public holidays).

**Probation:** the appointment is subject to the satisfactory completion of a six month probationary period.

**Pension:** The Society does not currently operate a pension scheme but will be introducing one later this year. The post-holder will be eligible to join after 6 months in the role.

**To apply**
Please send a copy of your CV and a letter explaining why consider yourself to be suitable for the job either by e-mail to: angie@atsociety.org.uk or by post to:

Richard Daglish
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**Applications should be received by 5.00 pm on Wednesday 21 July 2010.**