

GENERAL TRUSTEE JOB DESCRIPTION AND PERSON SPECIFICATION

September 2026

Tourettes Action
Registered Charity No: 1003317



WELCOME FROM THE CHAIR

Thank you for your interest in being a trustee for Tourettes Action (TA). We are the only UK-wide charity dedicated to supporting individuals with Tourette syndrome and their families. Our staff, volunteers and supporters are engaged and energised in driving forward our mission. Everything we do is grounded in our community's needs and informed by both the voices of our community and research-based evidence. Our vision is a world where people with Tourette syndrome are **accepted, supported and embraced** and a world which enables people with the condition to reach their full potential.

Tourettes Action is a charity regulated by the Charities Commission for England and Wales. The TA Board, comprising up to 12 trustees, are responsible for providing leadership and strategic oversight of the charity.

Together, the Board sets the strategic direction of the charity, decides priorities and discusses and approves the activities and plans put forward by the Chief Executive. In addition, the Board is responsible for managing the finances of the charity, overseeing what is budgeted and spent and that sufficient money is kept in reserves to meet any unforeseen costs.

The Board is a supportive team of trustees who bring insights from diverse and varied backgrounds, comprising individuals with Tourette syndrome, parents or family members of someone with Tourette syndrome and expert clinicians and academics working in the field of Tourette's. Each member of the Board brings different professional knowledge, skills and experiences that are needed to oversee the charity effectively. This includes expertise in functional business and finance skills, IT, as well as experience or skills working in the public, health, education and charitable sectors. Trustees are selected to ensure that there are sufficient and varied skills and perspectives to enable a good level of support and challenge to the TA team. Alongside other trustees you will ensure Tourettes Action is carrying out its purpose for the public benefit and provide oversight of the Chief Executive in order to ensure that the charity is being run efficiently and effectively in accordance with its charitable purpose and values.

Current Vice chair Ed Palmer says;

"Being a trustee of TA has been a truly enjoyable experience. As well as contributing to the bright and creative Tourette's community, and ultimately trying to improve the lives of those who, like me, live with Tourette's, it has been a brilliant opportunity for my own personal growth. I have learned about finance, management, staff appointments, fundraising and project management,

all while being supported by and learning from the diverse experiences and skills of the other board members."

We are looking for trustees who are committed to the cause of supporting people with TS and their families and reducing health and social inequalities. Although lived or professional experience is beneficial, we also encourage applications from those with a genuine interest in the condition and a willingness to learn more and who share our goals and values.

We hope that this recruitment pack will help you understand our organisation and the trustee role. Should you have any questions, please feel free to contact pippa@tourettes-action.org.uk.

*Marc Lewis
Chair of Trustees, Tourettes Action*

Application Deadline

Interested candidates are asked to submit a CV and letter of application using our [application form](#) by **Monday 12th October**, identifying relevant professional experience and stating why you think you have the skills and experience to be a trustee, as well as highlighting things you have done that may help the cause of Tourettes awareness and support.

Interviews

We aim for shortlisting and interviews to take place in the second half of October or early November.

Interviews will be held on Teams/Zoom with a panel of trustees and scheduled on a weekend morning or weekday evening.

We want to make all stages of our recruitment process as inclusive as possible. If you require any reasonable adjustments in the process, we will be happy to discuss this.

About Tourettes Action

Tourettes Action is the only UK-wide charity dedicated to supporting individuals with Tourette syndrome and their families. Our staff, volunteers and supporters are engaged and energised in driving forward our mission. Everything we do is grounded in our community's needs and informed by the voices of our community and research-based evidence.

Our Impact

Our service users are at the heart of everything we do. The services provided by TA have the potential to be life-changing. Our helpdesk team offers vital information, advice, and support during the most challenging times. Our education team ensures that children and young people are accepted, understood, and able to thrive in school, college, and university. Our advocacy support assists adults with navigating life with Tourette syndrome, offering guidance on areas such as benefits, employment, and healthcare. Additionally, we create numerous opportunities for individuals with Tourette syndrome to connect with others who share the condition in a supportive and accepting environment where people can simply be themselves, fostering resilience and building lasting friendships along the way

Trustees are responsible for oversight of TA's activities, and provide strategic direction, guidance, and support to the Chief Executive who is responsible for running the charity and executing on TA's strategic priorities as follows:

1. To enable people with Tourette syndrome to thrive by providing accessible support, advice and training, to individuals and their families, and professionals, helping people living with the condition to flourish at home, in education and in employment.

2. To raise awareness of Tourette syndrome and reduce the stigma associated with it by increasing public awareness and understanding about the reality of Tourette syndrome, and what it means to live with it.

3. To reduce health inequalities for people living with Tourette syndrome. We campaign so that everyone with Tourette syndrome can have access to an appropriate NHS healthcare provision, regardless of their location, ethical or cultural background or social status.

4. To ensure that no-one with Tourette syndrome feels alone by building a network of support for people with Tourette syndrome and their families.

5. To support research into Tourette syndrome. Informed by the views of our community, we assist and promote research that examines the causes, the treatments, and the impact of Tourette syndrome, with a view to improving the lives of people with the condition.



You can find out more about our Mission, Vision, Values and Goals on our website by clicking this [link](#).

BECOMING A TRUSTEE – JOB DESCRIPTION AND PERSON SPECIFICATION

Who we are looking for

Due to the retirements of a number of trustees reaching the end of their permitted terms of office, we currently have up to two vacancies.

We particularly encourage applications from i) individuals with Tourette syndrome AND / OR ii) individuals with skills or experience in the following areas: education, safeguarding, or political, healthcare, or disability campaigning and advocacy.

Key information

- Voluntary role (unpaid), reasonable travel expenses for Board activities reimbursed
- Successful applicants will have their appointment confirmed at the next AGM in December 2026
- Trustees may serve for a 3-year term from the next AGM, with an opportunity for renewal for up to a further two terms of 3 years

Attendance requirements

- We ask that trustees, as a minimum, commit to attending four Board meetings per year, including allocating time to read the Board papers that are sent out ahead of meetings. Meetings of the full Board take place on a Saturday or Sunday. Meetings take place either virtually (e.g. Zoom/Teams) or in person, and last approximately 3 hours. The Board aims to meet in person twice a year with the location varying taking into account travel requirements of trustees.
- Subject to relevant experience, most trustees also serve as members of a sub-committee which requires attendance at 4 additional meetings per year. Sub-committee meetings usually take place prior to the main Board meeting on a weekday evening via Zoom/Teams and last for approximately 1 hour. The Board has several sub-committees, including a Finance and General Purposes sub-committee, a Safeguarding and Services subcommittee, and a Research subcommittee.
- In addition, trustees may be requested to participate in ad-hoc discussions or activities with other trustees, or provide advice or support to the Chief Executive, between meetings.

What you will do

The statutory duties of a trustee are to:

- Ensure that TA complies with its governing document, charity law, company law and any other relevant legislation or regulations

- Ensure that TA pursues its objects for the public benefit as defined in its governing document and uses its resources exclusively for this purpose. This means that the charity must not spend money on activities which are not included in its own objects, no matter how worthwhile or charitable those activities are.
- Contribute actively to the Board in giving firm strategic direction to TA, setting overall policy, defining goals and setting targets and evaluating performance against agreed targets
- Participate in the appointment of the CEO and monitor her/his performance
- Ensure the financial stability of the charity and ensure the proper investment and protection of the charity's assets and funds.
- Ensure the effective and efficient administration of TA
- Safeguard the reputation and values of TA

Other duties

In addition to the above statutory duties, each trustee should use any specific skills, knowledge or experience they have to help the Board reach sound decisions. Typical responsibilities include;

- Reviewing Board and subcommittee papers in advance of meetings and being prepared to ask questions and contribute to discussions at Board meetings
- Providing advice or guidance on issues in which the trustee has special expertise
- On an ad-hoc basis, or on the basis of an individual's experience and skills, contributing to Board activities and the development of Board reports/proposals.
- Leading discussions in areas of expertise at Board meetings or in other ad-hoc discussions
- Providing guidance to the CEO on new initiatives

Trustee person specification

- Commitment to and willingness to work in accordance with TA's principles and values
- Willingness to devote the necessary time and effort to the charity
- Strategic vision
- Good, independent judgement
- Ability to think creatively
- Willingness to speak their mind in a constructive and collaborative manner
- Able to work effectively as a member of a team
- Skills and experience in one or more of the following areas:
 - Education sector
 - Political, healthcare, health policy, or disability advocacy or campaigning

- Safeguarding knowledge and experience
- Business and management skills to advise and assist the charity in its work. In particular, we are looking for people with business acumen, marketing skills, an understanding of digital fundraising and strategy, and corporate fundraising partnerships.
- Research skills and experience in designing and conducting studies of Tourette syndrome.
- Knowledge and understanding of Tourette syndrome from lived experience, family/ friends or from a professional interest is desirable but not essential. All applicants are nonetheless expected to have either an understanding of the condition and / or a clear commitment to developing this.
- Understanding and acceptance of the legal duties, responsibilities and liabilities of trusteeship
- Abide by Nolan's seven principles of public life as outlined in the Trustee Code of Conduct: selflessness, integrity, objectivity, accountability, openness, honesty and leadership

Training will be provided to support new trustees in their role.

Inclusion and accessibility

We welcome applications from people of all backgrounds and life experiences. If you need adjustments at any stage of the process, please tell us what would help.

Safer recruitment, eligibility and declarations

We're committed to safeguarding and to taking reasonable steps to protect everyone who comes into contact with the charity. Appointments will be subject to proportionate safer recruitment checks and declarations, which may include references and verification of identity.

This includes confirmation that you are not disqualified from acting as a charity trustee under the Charity Commission's automatic disqualification rules, and a conflict of interest declaration with agreement on how any conflicts will be managed.

[APPLY HERE](#)