



Assessment process of research awards

Expressions of interest are invited and are initially assessed according to general scientific quality and in terms of the Tourettes Action's research strategy. In the first instance, please email your expression of interest form to us research@tourettes-action.org.uk

What can Tourettes Action pay for?

Funding rounds will happen once every year with a call being advertised in the Autumn every year and money to be awarded Spring/Summer the next year. TA will initially offer individual project grants which may be too small to cover significant employment costs. Grants are only available for research where the principal investigator is based in a recognised research centre, university or hospital in the UK. The following types of grant are available:

- Pilot and feasibility studies which will lead to applications to major funders for large-scale research trials;
- Other small projects
- Postgraduate studentships (awarded to supervisors - project based assessment)

TA will pay the directly incurred costs of research:

- research staff (e.g. research assistant salaries, junior researchers at post-doctoral level). Charities paying salaries of staff working part time should check that their total FTE doesn't exceed 100% (i.e. if a researcher is already employed on a 75% contract, the maximum a charity should pay under a new grant would be 25% FTE)
- Consumables and other costs directly attributable to the project
- Cost of equipment specific to the needs of the project
- Travel and subsistence

TA will not pay the directly allocated costs:

- research investigators: the proportion of time spent by the senior researchers such as the principal investigator and co-investigators on a research project. Some charities specify that 'senior staff' are those who completed their PhD more than 10 years ago, and as such expect them to be employed by the university or fully funded from elsewhere so do not require funding for their own salaries.
- costs of shared resources such as clerical and administrative staff, nurses, lab technicians, supervisors and collaborators who are already employed.
- Equipment not specific to the research such as lab supplies and lab equipment are also classed as directly allocated costs: the space used by researchers

How the strategic fit will be assessed during peer review?

As a member of the Association of Medical Research Charities (AMRC), TA abides by the guiding principles of peer review to assess expressions of interest and full grant applications.

In order to further TA's research aims, TA uses a Scientific Advisory Board (SAB). Comprising both scientific and lay members.

Expressions of interest are invited and are examined by the Scientific Advisory Board (SAB) and if successful at this stage are invited to make a full application. There will be two types of peer review depending on the amount of money to be awarded. In the case of grants under £25,000 the SAB will screen initial expressions of interest and invite those to make a full application, considering both the strategic fit and the likelihood of achieving a meaningful outcome. The SAB will coordinate the initial review of full applications and review these applications if they are under £25,000. If the award amounts are over £25,000 then the SAB will instigate external peer review by specialists throughout the UK, Europe and the United States. The outcomes of peer reviews of applications will be assessed by the SAB.

The SAB peer-review process is conducted by practicing scientists or clinicians, who are expert in the area as well as lay reviewers. The SAB will consider the TA research strategy prior to instigating a research call. The peer review process is to be used to assess the quality of scientific ideas by subjecting them to independent scrutiny by qualified experts. Peer review enables charity trustees to seek appropriate, independent, expert advice and remains widely accepted, both within the research community and outside it. Properly conducted, peer review provides an unbiased view of which research projects should be supported.

Applicants unsuccessful at this stage will be notified promptly. If after the peer review process the full application is not successful then the applicants will have the opportunity to respond to points raised by reviewers.

TA's membership of the AMRC also ensures that such rigorous standards are maintained as TA will be subject to audit by the AMRC every five years. The next one being in 2020. As a member of AMRC, TA adheres to their policy on supporting research in universities (which focuses on the role of a charitable funder to support the direct costs of research) and the AMRC's policy on animals in research which outlines the role of medical research funders in supporting the principle of using animals in research when it is necessary to advance understanding of serious health conditions to develop better treatments and there is no alternative.

The Scientific Advisory Board

The SAB will report to the charity Board of Trustees who will review the strategy on a twice-annual basis.

Overview of roles of the RSC and SAB

The Research Sub-committee:

- Is to act as a research subcommittee of the main board of trustees. The RSC has been appointed primarily to establish research procedure and policy including advising/seeking potential candidates for the Scientific Advisory Board.
- To act as an intermediary between the Scientific Advisory Board (SAB) and the Board.
- To work up the structure / regulations for grant-giving
- To have an oversight function over the SAB
- To have an oversight function over internal and external research projects

The Scientific Advisory Board:

- Tourettes Action aims to have balanced SAB membership which, comprising of scientific, clinical and academic expertise, can give the appropriate level of scrutiny to research applications
- If the research call for a round requires specific expertise, additional members can be co-opted to ensure the SAB has the appropriate level of expertise to review applications and contribute to the funding discussion.
- The SAB is an independent body within Tourettes Action; only SAB members are involved in the decision-making over recommendation of research applications. Tourettes Action staff are present to provide a secretariat function and ensure Governance around decision making and conflict of interest is managed within the meeting.
- To encourage, stimulate and support research related to Tourette syndrome;
- To assist and advise in the formulation and the funding of research proposals;
- To receive and consider applications for funding in addition to the peer reviewers;
- To approve applications and fund appropriate research projects after recommendations from the peer review panel;
- To monitor the progress and outcomes of research activities funded by Tourettes Action;
- To seek funds to support research and development and to provide a database on funding bodies.
- In line with the Association of Medical Research Charity (AMRC) best practice guidance, Tourettes Action aims to select committee members across a breadth of experience, expertise, institutions, age and gender to provide a balanced view.
- The SAB's recommendations will be presented to the board of trustees via the RSC.
- Following board approval of recommendations grants will be awarded. Go to the TA website page 'Our role with research' to see 'who's who' in the Tourettes Action boards and committees and how peer review sits in the grant award system.

- There you will also find Tourettes Action's policy on how to deal with conflicts of interest in scientific advisory panels. This policy identifies potential conflicts of interest, and sets out how to record and manage them in any committees, trustees, staff and volunteers.

When will research grants be awarded?

Funding rounds will happen once every year with a call being advertised in Sept/Oct and the award announcement will be at April/May.

How will Tourettes Action support researchers beyond the award of the grant?

TA is in a position to help with lay involvement in research design, the initial and ongoing recruitment of research subjects and the dissemination of results. This will be done through various channels such as the TA website, newsletter, Facebook, twitter, Health Unlocked, TA forum, via the support groups network and making use of the contacts database TA maintains. Professionals would be supported by the TA research manager from start to finish of the research and encouraged to publish papers and/or conference presentations/posters. Any successful grant will be monitored through annual reports and contact with the research manager and the researchers. Outcomes of the research are expected to include publications in journals as well as conference presentations to comply with research dissemination to the rest of the research community. There will be follow-up after the end of the grant. This will ensure that as many outcomes of the research can be captured as possible allowing us to fully evaluate the impact of our research funding.

Publication, conferences and dissemination

Tourettes Action expects the researchers in receipt of the TA research award to disseminate your findings within the scientific community, to allied professionals, to individuals affected by the condition, and also to the public community at large. Many professions have membership organisations which regularly communicate with their membership, and are very keen to receive articles about relevant science. We strongly encourage you to disseminate your work in this way. We expect to see information about such activities and events involved in monitoring reports, and expect to hear about conference papers and presentations you will be making. How effective you have been, and intend to be in this, can influence our funding decisions. We encourage open access publishing and would like you to consider publishing in open access publications. Where possible, we will consider paying for one such article per project.

If you have any questions about any part of this process please contact Dr Seonaid Anderson TA research manager Seonaid@tourettes-action.org.uk