

Tourettes Action Research Strategy 2019-2022

This research strategy outlines Tourettes Action's continuing development of its research portfolio supporting the highest quality research programmes and initiatives over the next 3 years. We envisage continuing to attract grant applications from a broad audience to enrich the range of Tourette Syndrome (TS) research undertaken. This research strategy was approved by the Board of Trustees, who will review its implementation and progress on a regular and on-going basis.

Why Tourettes Action funds research

Tourettes Action (TA) is a charity for people suffering from the neurological disorder known as Tourette Syndrome. TS is a tic disorder characterized by involuntary, sudden, repetitive movements and sounds of varying severity. TS is commonly associated with other conditions such as obsessive compulsive disorder (OCD) and attention deficit hyperactivity disorder (ADHD). TS is usually diagnosed in childhood and often starts at the age of around 5-7. Whilst some people find they may have some improvement in their condition with better control over their tics from early adulthood, for many people with TS it will be a lifelong experience. Some 10% of the TS population suffers from coprolalia (involuntary swearing) and a similar number with echolalia (involuntary repetition of words or sounds). Approximately 1% of school age children have TS to some degree, and at least 300,000 children and adults have TS of sufficient severity to require support for their condition.

TS is perhaps the most publicly misunderstood of all neurological conditions and has considerable stigma attached. People with TS experience personal isolation and rejection, as well as significant disadvantages in education, employment and health care across a range of encounters with statutory agencies and services. Severe physical tics can not only cause individuals embarrassment but also pain and injury. There is currently no specific medication that will cure or fully control the symptoms of TS. Treatment uses a variety of drugs to reduce tics and other features with varying degrees of success. A few of the most seriously affected patients have undergone neurosurgical deep brain stimulation, a treatment that is established for other movement disorders such as Parkinson's disease, tremor and dystonia. For TS it is not yet considered a standard treatment. Although there have been positive results, not all patients have had a sustained benefit in the long-term. Psychological and/or behavioural treatments such as habit reversal therapy are evidence-based but often unavailable due to lack of specialised therapists.

TA is dedicated to providing information, support, services, and advocacy for and on behalf of those living with TS. We wish to help to improve their lives in the present with information, support and direct services; and in the future by promoting understanding and advocating policy change where necessary. One of the chief aims of TA is to support research and to seek better treatment and management of TS (via research into new therapies and potential cures) with a view to improving the lives of those living with TS. We will therefore continue to focus on these three areas: treatment, management of TS and improving the lives of those living with TS.

The unique role of Tourettes Action in the research landscape and how it adds value.

TA is the only UK based charity working with families and individuals living with TS and is therefore well placed to promote and evaluate research. It can add value above the purely financial by working with both the community and those living with TS to help identify individuals willing to take part in research and assisting researchers with the structure and approval of proposed research. We are

committed to ensuring that our research strategy will help us make a real difference to all people affected by TS.

The types of research and scientific areas Tourettes Action intends to support

Building on the success of the research awards scheme in the previous three years TA will continue to prioritise research into the treatment and management of TS. People affected by TS are mostly interested in treatment. We do not underrate the importance of research which examines the cause of TS and aims to eventually develop better treatments so do not exclude such work. As more funding becomes available TA will be able to widen the brief. The main aim is to fund research which has the potential to create significant new findings with a deliverable outcome to support people living with TS. We will also consider biological research areas using criteria relating to likely impact/implications. Some of the leading edge scientific research into the syndrome is beyond our current funding plans, for instance large scale multi-centre genetic studies and other areas requiring consortia of investigators e.g. deep brain stimulation. TA also considers seed-funding small 'pilot projects' in these areas as a precursor to future applications depending on TA's funding capabilities at that time. TA is interested in hearing from researchers about their ideas of innovative research projects that will advance our knowledge of TS, particularly for new hypotheses where initial pilot or supporting data is required prior to a full research project. As well as supporting scientific/medical research we will also consider applications from a wider scope than a purely scientific/medical nature (e.g. psychological in nature).

The types of grants, including times scales Tourettes Action supports, the extent of the support and what research expenses Tourettes Action can offer to cover

TA will fund this research through designated funds which will be in the region of £75,000.00 per annum. TA may also consider higher research investment on an exceptional basis. Please contact us to discuss further.

Funding rounds happen once every year with a **call for Expressions of Interest (EOI) being advertised in the Autumn** and money to be awarded by **early Summer the next year**. TA offers 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 or Europe**. 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 only support the directly incurred costs of research and will not pay indirect or directly allocated costs, in line with the Association of Medical Research Charities (AMRC) policy on [supporting research in universities](#).

You can find out more about the directly incurred costs of research TA will pay for and the directly allocated costs which TA will not pay for in the Assessment process of applications for Tourettes Action awards, please use this [LINK](#).

Partnerships that Tourettes Action has or wishes to develop.

TA already has a strategic partnership with both the Tourette Association of America and European Society for the Study of Tourette Syndrome. Such partnerships improve the impact and reach of cross-disciplinary research. TA is a member of the AMRC and membership is recognised as a quality mark demonstrating vigorous peer review processes are in place ensuring that only the highest quality of research is supported.

What types of people/institutions Tourettes Action will fund

TA will fund research applications from researchers and/or clinicians in a recognised research centre, university or hospital **in the UK or Europe**. Grants will be awarded to career level university researchers, or to more junior researchers with the support of a senior supervisor. Researchers will be required to have their research proposals accepted by either a university ethics committee or a NHS ethics committee if appropriate.

Any questions about this research strategy or the research awards application process please contact the Research Manager at Tourettes Action research@tourettes-action.org.uk

Tourette Syndrome (UK) Association,
The Meads Business Centre, 19 Kingsmead,
Farnborough, Hampshire, GU14 7SR
<https://www.tourettes-action.org.uk/>