

## **Tourettes Action is delighted to announce Research grants awarded.**

### **Improving the lives of those living with TS**

Tourettes Action research grants awards scheme supports research and better treatment and management of TS, with an aim to improve the lives of those living with TS.

After selection by the **Tourettes Action Scientific Advisory board** and via an external peer review process the winners of this first round of awards includes two grants detailed below.

**Grant award 1:** Professor Georgina Jackson (University of Nottingham)

**Award amount:** £22,675.79

**Title:** Evaluating the efficacy and tolerability of peripheral nerve stimulation as a potential therapy for Tourette syndrome

Individuals with TS and their families state that developing safe and effective, non-drug, therapies for TS should be a high priority for researchers, and that such therapies should ideally be suitable for home administration.

Safe and effective forms of non-invasive brain stimulation have been shown to alter motor excitability and reduce tics in TS, However, these techniques are often not suitable for treatment outside of the clinic, or for use with young children.

We propose instead to investigate whether safe and effective methods of peripheral somatosensory stimulation – specifically, transcutaneous electrical nerve stimulation (TENS) - can be used to effectively reduce tics in TS.

TENS involves delivering mild electrical signals to a targeted peripheral nerve, and is frequently used to provide pain relief. It is used widely within the NHS (e.g., to provide pain relief during childbirth or for chronic pain conditions), is non-invasive, and has no serious side effects. TENS machines can even be purchased 'over the counter' in many countries, including the UK.

We will investigate: (a) whether TENS - delivered to the wrist - can alter cortical motor activity and thereby contribute to the suppression of tics, and (b) whether such stimulation is well-tolerated by young adults with TS.

**Grant award 2:** Dutch Knowledge Centre for Child and Adolescent Psychiatry

**Award amount:** £28, 933

**Title:** Tackle your Tics: feasibility of a brief, intensive group-based exposure therapy programme for children with Tourette Syndrome

Behavioural treatment is considered a first-line intervention for tic disorders. However, patients still reach an average tic reduction of only 30 % and many patients do not have access to adequate behavioural treatment at all. Behavioural treatment for tics is only

available to a very limited extent. Due to a lack of trained specialists, families often have to travel long distances for weekly therapy sessions. The therapy and daily exercises at home are experienced by children as tough, and can cause fatigue and concentration problems in school. Patient associations advocate that families urgently need treatments that are easier to undergo and which also support children to cope with their Tourettes.

Purpose of this pilot study is to overcome the barriers described, make therapy more accessible and improve tic reduction, quality of life and treatment satisfaction. In a marathon-period of three days, small groups of children with TS will follow a brief intensive programme consisting of ERP treatment, psycho-education, relaxation activities, group support, a training app and parent meetings.

First, the feasibility of this programme will be studied in the Netherlands. The results will provide guidelines for further development of the programme, to the benefit of a lot of children as well as adults who deal with the impact of TS in their daily lives.

**Grant award 3:** Melina Malli, Tizard Centre (SSPSSR), University of Kent

**Award amount:** £ 18,600

**Title:** The Stigma of Tourette Syndrome

Our study will provide information about whether or not people with TS experience stigma; how stigma affects their quality of life, how individuals with TS access support, services, and advocacy; how good these services are; and in the absence of support, how people with TS cope with and get help for their condition. Through a national online survey, online focus groups, and in-depth interviews with adults and youths with TS, our aim is to understand the meaning and nature of stigma in relation to this population of people.

The objective of our study is to show how prevalent stigma is amongst people with TS. By allowing people with TS to tell their own stories about how stigma affects their quality of life we will gain knowledge about how stigma is felt and experienced. We will also find out how good current care and support systems are for people with TS and ways in which services could be improved. It is also our objective to facilitate wider conversations among policymakers and practitioners about how best to provide support to people with TS.

### **Success rate:**

For researchers interested in making future grant applications – here are some statistics about the success rate from this first round of Tourettes Action research grant awards. In the initial contact 17 ‘Expressions of interest’ were received, 10 of these were invited to make a full application (59%), with a final success rate of 12% with 2 projects being awarded research grant money.

**Thank you!**

Thank you to all the applicants and to all the experts who were involved in the external peer review process. Please find below the names of all peer reviewers who were involved in the Tourettes Action grant awards scheme for 2017-2018. These peer reviewers from numerous countries around the world, provide high-quality, insightful, and rigorous critiques of submitted applications. We extend our appreciation to all peer reviewers for providing their clinical, scientific, and methodological expertise and by doing so, for being instrumental in maintaining and enhancing the clinical relevance and scientific quality research funded by Tourettes Action. Although peer review is often considered a relatively unsung academic responsibility, we hope that by publishing the names of all Tourettes Action grant awards scheme peer reviewers they will receive the recognition they greatly deserve for their indispensable contributions.

**External peer reviewers for 2017-2018:**

Alan Apter, Robert Dykes, Davide Martino, Huw Morris, Michael Morton, Tara Murphy, Bob Peckitt, Hugh Rickards, John Walkup and Douglas Woods.