AWARD ANNOUNCEMENT 2019-20

Tourettes Action delighted to announce research grants awarded

Improving the lives of those living with TS

The Tourettes Action research grants awards scheme supports research and seeks better treatment and management of TS to help 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 round of awards includes four grants detailed below.

Grant award 1: Professor Chris Hollis
Award amount: £42,688.82
Title: Smartwatch vibration therapy (SVT) for the self-management of tics in young people with Tourette Syndrome: A pilot randomised controlled clinical trial and feasibility study.
Many young people with Tourette Syndrome (TS) cannot access or benefit from behavioural treatments for tics while drug treatments can have unpleasant side effects. Hence, there is a need for safe and effective treatments that can be used by young people to self-manage their tics on a daily basis when at home or school. Our research team together with technology experts, clinicians and young people with TS, has developed a form of vibration-based therapy which has been shown to be effective in other conditions and could therefore be helpful in TS too. This therapy is delivered through a Smartwatch that emits gentle vibrations similar to those produced on mobile phones. We tested this Smartwatch Vibration Therapy (SVT) in a small group of young people with TS who wore the Smartwatch for 30 minutes in clinic and they found that it reduced their tics largely, while being comfortable for them without producing any unwanted effects. We are now proposing to carry out a larger study to test how feasible and acceptable it is for young people to wear the Smartwatch for a longer time, i.e. a week, when at home and school. The results will support a future larger controlled clinical trial to test whether SVT works over a longer period of time as compared to their usual treatment.

Grant award 2: Professor Penny Gowland (University of Nottingham)
Award amount: £16,500

Title: Developing novel brain imaging approaches to investigate the neural basis of premonitory urges in Tourette syndrome

Most individuals with Tourette syndrome (TS) report that their tics are preceded by 'premonitory urges' [PU] - uncomfortable bodily sensations that are experienced as a strong urge for motor discharge. Unfortunately, PU are particularly difficult to investigate using conventional brain imaging approaches, as they are spontaneous events that are not manifest as directly observable behaviour. PU are particularly important because individuals who experience PU often report that these experiences are more *bothersome* than their tics and that they *would not exhibit tics if they did not experience PU*. For this reason, it has been proposed that PU should be considered as the driving force behind the occurrence of tics, and it is timely and important to investigate the functional anatomy and pathophysiology of PU. To quantify brain activity associated with spontaneous events requires a model-free approach in which the timing of events is not known *in advance*. We propose to utilise a novel functional magnetic resonance imaging (fMRI) approach, developed at the University of Nottingham and that is termed '*Sparse Paradigm Free Mapping*' (SPFM), for this purpose. We aim to demonstrate that by using this approach, we can reliably obtain fMRI measurements associated with premonitory sensory phenomena in TS that are not in themselves directly observable as overt behaviour. To achieve this objective we will validate the SPFM approach by investigating the functional anatomy of several common urge phenomena, including PU in TS, and demonstrate that PU can be reliably measured in TS without the necessity for overt tic expression.

Grant award 3: Dr Sally Robinson (Evelina London Children's Hospital)

Award amount: £3551

Title: The impact of interoceptive awareness and attentional control on tics, anxiety and quality of life in young people with Tourette Syndrome/Chronic Tic Disorders (TS/CTD)

There is growing interest in how perceptions of internal body sensations (e.g. heartbeat, muscles), called interoception, may contribute to psychiatric symptoms (e.g. anxiety, mood). In children and adults with Tourette Syndrome/Chronic Tic Disorders (TS/CTD) lower ability to accurately perceive internal body sensations has been shown to be related to increased tics and anxiety and lower quality of life. Research also suggests that reduced attention to internal body sensations may be helpful to manage tics. This suggests that higher awareness of body sensations in TS/CTD may influence tic expression, whilst the ability to control attention and shift it away from internal sensations may be important for tic management. These aspects of interoception have not yet been explored in TS/CTD.

To inform future psychological therapies, this study will explore interoceptive accuracy, awareness and attentional control in young people with TS/CTD compared to controls, aged 11-17 years. The study will use experimental tasks and questionnaires. Exploring the role of interoception in TS/CTD is of importance to understand the factors that contribute to tics and comorbid psychiatric symptoms. A better understanding of these factors would help to inform the development of psychological treatments for young people with TS/CTD.

Grant award 4: Dr Sally Robinson (Evelina London Children's Hospital)

Award amount: £1,175

Title: Improving tics and quality of life in children with Tourette's syndrome (TS): A pilot investigation into an HRT workshop with TS mentor co-facilitation

Background: Group Habit Reversal Therapy (HRT) and Exposure Response Prevention (ERP) are both therapies that can help children manage their tics. Children tell us that one of the best things about such groups is meeting other people with tics. However, going to these groups on a weekly basis can also get in the way of everyday life. We would like to look at (a) whether a shorter HRT group would be as helpful as the longer course of sessions (b) whether it is helpful for these groups to also be led by a peer mentor (an older person who also has tics and has had the same therapy in the past).

Method: Ten children with Chronic Tic Disorder or TS will take part in three HRT workshops that are co-designed and led by peer mentors that also have TS. Another parent workshop will run alongside this. The children and parents will be given questionnaires before the workshop, and 3 and 6 months after the workshop. Children and parents will also be given an interview to see what they thought of the workshop.

Results: We will look at the results of the questionnaires to see if there is any improvement in tics, mood and quality of life after taking part in the workshops. We also plan to look in detail at the feedback given in the interviews to see how helpful the children found the workshop and any improvements they suggest.

Discussion: We hope to find out whether having shorter HRT therapy, as well as including peer mentors in the workshops, will be useful in managing tics and improving the patients' quality of life. These findings have to potential to further develop tic treatments for children.

Success rate:
For researchers interested in making future grant applications – here are some statistics about the success rate from this round of Tourettes Action research grant awards. In the initial contact 14 'Expressions of interest' were received, 9 of these were invited to make a full application (64%), with a final success rate of 28% with four 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 2019-2020. 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 this round:

Our sincere thanks to this year's external peer reviewers: Kevin Black, Mark Edwards, Andreas Hartmann, James Leckman and Yulia Worbe.

There will be another grant round in the Autumn of 2019. For any information about future applications, please contact research@tourettes-action.org.uk