



TS 2000 Study

Annual Newsletter 2012-13

Hello to All

It's been about a year since we were last in touch, so we've written this newsletter in time for Christmas and the TSA Annual Family Conference. We will have a presence at the conference and we're hoping to meet some of you there. We want to let you know how the research is progressing and tell you about some exciting new developments in the study, including new funding to carry out Phase 2.

Research Update

In a few families in the study, TS was identified before seizures began and, with Ayla Humphrey in Cambridge, we have been following children to look at how their development has progressed before and after the onset of epilepsy. This has indicated that children who develop a form of epilepsy called infantile spasms are likely to have problems in intellectual development, particularly if infantile spasms are not treated quickly and effectively.

Phase 2

Last year, we started on Phase 2 of the TS 2000 study. Phase 2 aims to follow-up all the children in TS 2000 to see how they have been progressing since they were originally assessed. We hope to learn more about the types of problems that develop as children grow up. We are very keen to find out about the development of each and every child in the TS 2000 study, because we want to get as accurate a picture as possible about the 'natural history' of Tuberous Sclerosis.

We have been contacting families and inviting them to complete questionnaires by post and 'online' regarding their cognitive & behaviour development. We are also asking for details about seizures, medical investigations and other medical updates. As part of this survey, we are also asking teachers to provide information about the child's progress and behaviour at school. The findings will help us further understand areas of strengths & difficulty. So far, we have received a large number of responses and we are very delighted that so many teachers have helped by successfully completing the questionnaires. Please send them our thanks.

The added information we now have on the children is providing us with a much better understanding of the factors that lead to some children with TS having developmental and behavioural problems whilst others do not. If you haven't received information from us about the questionnaires, or if you did but have lost it, then please get in touch and we will send it out to you.

New funding

New funding has recently been awarded which will provide support for a new team of researchers to work on Phase 2. The US charity Autism Speaks has awarded a grant that



will fund a postdoctoral researcher (Dr Fiona McEwen) and a research worker (Mrs Emma Woodhouse) to look at what influences the development of Autism Spectrum Disorder in some individuals with TS. The Tuberous Sclerosis Association has awarded a Research Training Fellowship to fund a clinical research fellow (Dr Kishan Sharma), who will focus on to what extent there is overlap in the factors that lead to Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder (ADHD) in TS. The Baily Thomas Charitable Fund has awarded a grant that will fund a postdoctoral researcher (Dr Charlotte Tye) to look at the factors that influence intellectual functioning in TS.

Home based assessments

During 2013 the research team will be offering to visit families at home or at a local clinic to carry out in depth assessments of behaviour and cognition. We will ask parents to complete an interview about how their child's behaviour, communication and play has developed, and complete some questionnaires that ask about specific aspects of communication, social interaction, activity levels and attention. We will also ask children or young people with TS to take part in some assessments, which will include a range of tasks designed to assess intellectual ability, social understanding, planning, attention, and thinking style. This will involve a mix of conversation, paper and pencil tasks, simple social games, and computer based tasks (such as watching short video clips). Some of these assessments are used in clinics that specialise in Autism and related disorders and ADHD. If children are found to be experiencing these types of difficulties then we will offer to send a report to children's doctors.

We will also offer certain assessments to some siblings who are *unaffected* by TS. It is important to have a comparison group who are closely matched to children with TS in terms of family and social factors and siblings provide an ideal group.

Families who take part in these assessments will be given gift vouchers as a token of our appreciation.

The Research Team

A few colleagues have joined the research team to help with Phase 2.

Dr Fiona McEwen will be the London based study coordinator. Fiona is a postdoctoral researcher, based at the Institute of Psychiatry (King's College London) who has previously worked on research in areas such as imitation and social development in children and adults with and without Autism, and testing new diagnostic tools for Autism and for common co-occurring mental health conditions, such as anxiety and depression. Fiona will be one of a team of researchers contacting families, carrying out home assessments, liaising with clinics, and analysing data and publishing findings.

Dr Charlotte Tye is a postdoctoral researcher who will be part of Phase 2 team. Charlotte studied Experimental Psychology at the University of Bristol before moving to the Institute of Psychiatry in London. Her PhD thesis focused on the similarities and differences in brain activity between Autism and ADHD and children that are diagnosed with both disorders and the genes underlying this. Within the TS2000 study, Charlotte is interested in how we can use these genetic and brain markers to predict learning difficulties and developmental disorders in TS.

Dr Kishan Sharma is a child psychiatrist who will be part of the Phase 2 team. Kishan completed his Child Psychiatry training in Manchester and worked as a Consultant Child Psychiatrist before joining the TS 2000 study. He has an interest in child and adolescent neuropsychiatric disorders and their influence on child development. He is also a wildlife enthusiast and supports Arsenal..!

Mrs Emma Woodhouse is a researcher who will be part of the Phase 2 team. Emma completed her degree in psychology at the University of Bath. She has worked as a researcher in Autism, ADHD and mental health at the Institute of Psychiatry since 2006,

and is currently completing counselling training alongside her job.

Ms Hannah Boardman is a 22 year old graduate who will be assisting the TS 2000 team during Phase 2. She studied Biological Sciences at the University of Birmingham before completing an MSc psychology conversion degree at the University of Hertfordshire. She has been working on a research project for the past 18 months at University College London looking into the prevalence of Dementia in those with and without Downs Syndrome and other learning difficulties.

Contact details

If any of your contact details have changed we'd really appreciate it if you could let us know.

Thank You!

We would like to take this opportunity to thank you again for participating in this study. The data we collect from this study is a very important way to learn more about the natural history of Tuberous Sclerosis.

With Best Wishes,

A handwritten signature in blue ink that reads "P.F. Bolton". The signature is written in a cursive style and is followed by a long, thin, upward-sloping line that extends to the right.

Professor Patrick Bolton
Professor of Child & Adolescent
Psychiatry and Honorary
Consultant, Institute of
Psychiatry, London

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If you need to Contact us:

TS 2000 (Fiona McEwen)
PO80
Institute of Psychiatry
16 De Crespigny Park
London
SE5 8AF

Tel: 020 7848 5272

Email: ts2000@kcl.ac.uk

Website: www.tuberoussclerosis2000.co.uk