



TS 2000 Study

Annual Newsletter 2013-14

Hello everyone!

It's been a year since we were last in touch, so we want to update you about our progress in Phase 2 of the study as well as tell you about our exciting plans for future research. Thank you for your ongoing participation.

What we have been doing in Phase 2

We are coming to the end of Phase 2 of the TS 2000 study. Phase 2 aimed to follow-up all the children in TS 2000 to see how they have been progressing since they were originally assessed. We hoped to learn more about the types of problems that develop as children grow up. We were keen to find out about the development of each and every child in the TS 2000 study, because we wanted to get as accurate a picture as possible about the 'natural history' of Tuberous Sclerosis, and in particular whether children were at increased risk of neurodevelopmental disorders such as Attention Deficit Hyperactivity Disorder and autism.

We started visiting families in the summer of 2013 to carry out in-depth assessments of behaviour and cognition. We asked parents to complete an interview about their child's behaviour, communication and play, and complete some questionnaires that ask about specific questions of communication, social interaction 'adaptive' abilities for day-to-day life, activity levels and attention. In 2014 we were also given ethical approval to investigate obstetric risks, early infant environment and sleep problems and we have been contacting families to obtain this data.

We have also been asking children or young people with TS to take part in a range of assessments, tasks and games. These are designed to assess intellectual ability, social understanding, language, planning, memory, attention and thinking style. Over summer 2014 we started seeing a sample of families to assess siblings who are *unaffected* by TS. They will serve as a comparison group of children closely matched to children with TS in terms of family and social factors. We asked parents to complete online and paper-based questionnaires, and the sibling to complete some tasks to measure intellectual ability.

As well as questionnaire and interview data we have been working on collecting genetic and clinical data. We left/ sent out to some families home saliva kits and/ or cheek swab kits. We have also been contacting clinicians to obtain recent clinic reports, scan reports and digital images of brain and kidney scans.

Our progress in phase 2

We have seen almost 90 of the original 125 TS 2000 families, assessed 30 siblings and had contact with over 70 clinicians accessing over 40 digital brain scans. We are very grateful for your time and all of your hard work! Loss to follow-up is inevitable in a long-term follow-up study but every family that we see makes a really valuable contribution to the quality of the research that we are able to produce. In rare disease research we rely on small sample sizes, meaning that every family lost to follow-up and piece of missing data really counts. If you have not been seen by our team, but are now happy to participate, please get in touch! We will be happy to see you in the next few months. If you have any outstanding questionnaires or genetic samples to send us, please complete them and send them back to us.

Over the next few weeks we are making a last push to collect outstanding data on the families that we have seen. This includes paper-questionnaires, telephone interviews, computer based questionnaires and genetic samples. We enclose with this newsletter any questionnaires and genetic samples that we would be really keen to get from you as well as a telephone contact availability form for telephone interviewing over the next few

weeks. **If you get a spare moment over the Christmas holidays to complete these and send them back to us, you will be giving us the best Christmas present ever!**

New funding for EEG study

We have recently received funding from Action Medical Research to gather more in-depth information on brain processes using EEG and how they relate to intellectual and developmental outcome in TS. EEG is a non-invasive technique using a special form of hairnet that contains lots of small sensors. The hairnet can measure the naturally occurring 'brain waves' of people from all ages from infancy to adulthood, in the same way a thermometer measures temperature. The sensor hairnet is connected to a computer that records the activity of the brain while you or your child complete tasks on the computer. The tasks are very simple and are often used with infants and children to see what our brains are doing whilst they are at work.

Next year we will invite the TS 2000 participants to visit our research centre in London to take part in this project. We will reimburse participants for their travel, meals and other expenses during their trip, and can offer accommodation for long-distance travel.

We are interested to see whether different brain processes are associated with different outcomes in TS. Identifying these brain processes will help us to develop tests to predict outcome from an early age. If you'd like more information on this project or to register your interest, please contact Dr Charlotte Tye (charlotte.tye@kcl.ac.uk).

Our Research Team

As we reach the final stages of our data collection, we will be recruiting several new team members to help us with telephone interviewing, these will be MSc students within our department who will be helping us conduct research into Tuberous Sclerosis. We have recently bade a fond farewell to some of our old team members, Mrs Emma Woodhouse who has moved next door to conduct clinical work for the Adult Autism Team at The Maudsley Hospital, and to Dr Lisa Underwood who has moved to conduct clinical research in New Zealand. We wish them well and we have remained in touch.

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. Please **contact us** if you are having any problems completing the saliva kit (or need a new kit), cheek swabs, online or paper-based questionnaires, or would like to go through the questions in-person over the phone. **We are closing data collection in February 2015 so this is your last chance to get any information to us!**

With Best Wishes,



**Professor Patrick Bolton
Professor of Child & Adolescent
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& the TS 2000 Study Team

If you need to Contact us:

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