



**TS 2000 Study**  
Annual Newsletter 2018-2019

**Hello everyone!**

It's been just over a year since we were last in touch, so we would like to update you on our progress on the TS2000 study and associated projects. Thank you for your ongoing participation in the study!

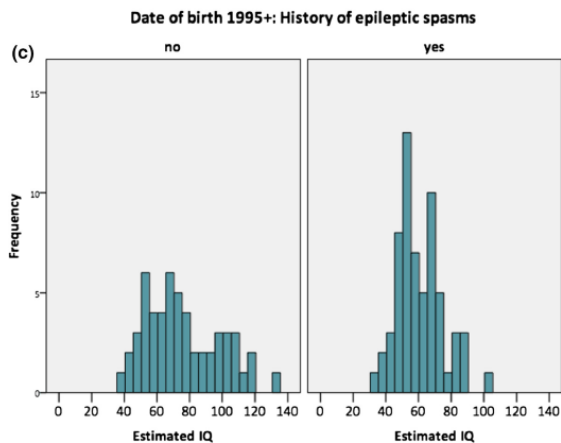
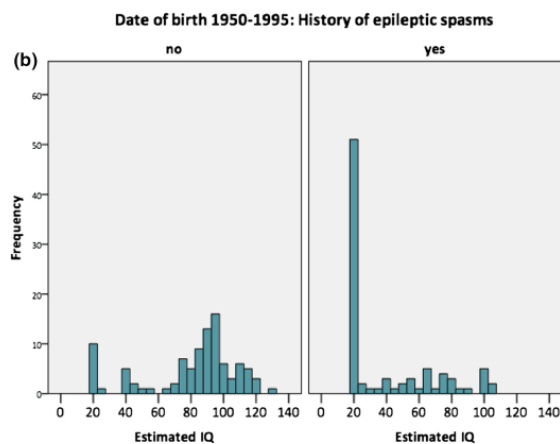
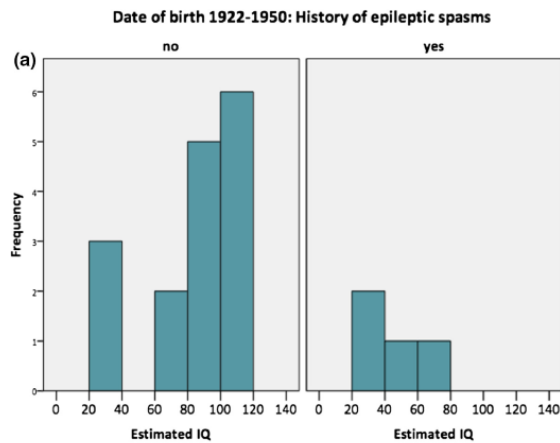
**Phase 3 is now complete!**

We have now finished phase 3 of the study, which we started in early 2016. The aim of Phase 3 was to investigate brain activity patterns associated with different outcomes in TS, such as autism spectrum disorder (ASD), epilepsy, attention-deficit/hyperactivity disorder (ADHD), and intellectual difficulties. We used EEG to record electrical brain activity ('brain waves') from electrodes on the head. We also used eye-tracking, computer tasks, puzzles, and play/conversation-based tasks to investigate cognition and behaviour associated with the brain activity we recorded.

**Recent publications**

The TS2000 team recently published a paper that used EEG data to investigate differences in individuals with autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). The researchers found that neurophysiological activity (brain-wave activity) was different within each group. Researchers hope that in the future data like this can be used to help clinicians in the diagnosis and treatment of conditions such as ASD and ADHD.

Further to this, researchers have published a paper comparing manifestations of TSC over time. They found that individuals born later were more likely to report having infantile spasms and more likely to be taking a medication called vigabatrin. Further to this, they were less likely to have profound, intellectual impairment, compared to earlier-born individuals. This data suggests that epileptic spasms were less likely to be detected in older patients and were therefore not treated. Whereas the later born cohort had better access to treatment and this has been reflected in differences in intellectual ability.



### We need your help!

We are hoping to collect some information on the TSC-Associated Neuropsychiatric Disorders (TAND) checklist. The TAND checklist is a screening tool that is used by health professionals in conjunction with the person with TSC and/or their carers in order to ensure that all needs are made aware of and to aid the clinician in

supporting the families. If you wouldn't mind completing the form attached to this newsletter and sending it back to us that would be greatly appreciated. We may get in contact with you for a more in-depth discussion regarding the checklist if you are happy to do but will provide more information over email closer to the time.

### Our research team

Abigail Runicles is a medical student at St. Georges University and research assistant here at Kings College. Abigail has joined the team in order to investigate the TSC-Associated Neuropsychiatric Disorders (TAND) checklist.

### Contact details

If any of your contact details have changes we would appreciate if you could drop us an email on [ts2000@kcl.ac.uk](mailto:ts2000@kcl.ac.uk) to let us know so that we can update our database.

### Thank you!

Once again, we would like to thank you for all of your hard work taking part in the TS2000 study. We wish you a very Merry Christmas and a Happy New Year.

With best wishes,

**Professor Patrick Bolton & the TS2000 Study Team**

**Professor of Child and Adolescent Psychiatry and Honorary Consultant, Institute of Psychiatry, Psychology, & Neuroscience, King's College London.**

Recent publications: Shephard, E., Tye, C., Ashwood, K. L., Azadi, B., Asherson, P., Bolton, P. F., & McLoughlin, G. (2018). Resting-state neurophysiological activity patterns in young people with ASD, ADHD, and ASD+ ADHD. *Journal of autism and developmental disorders*, 48(1), 110-122.

Tye, C., Thomas, L. E., Sampson, J. R., Lewis, J., O'Callaghan, F., Yates, J. R., & Bolton, P. F. (2018). Secular changes in severity of intellectual disability in tuberous sclerosis complex: A reflection of improved identification and treatment of epileptic spasms?. *Epilepsia open*, 3(2), 276-280.