

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!

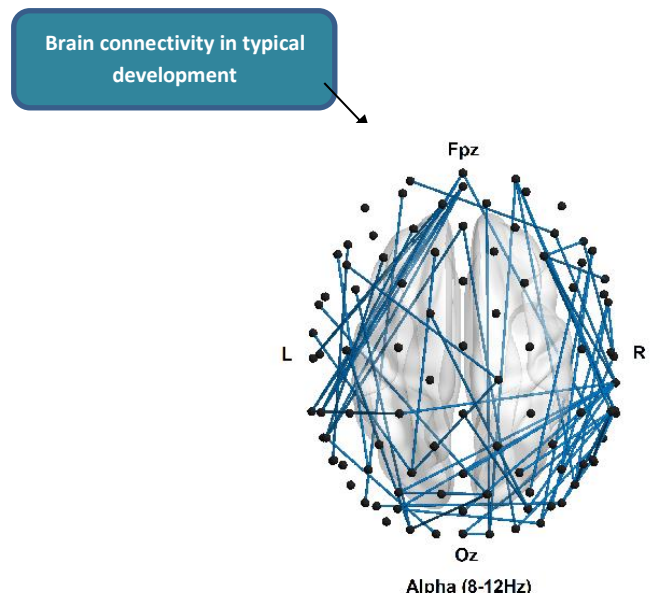
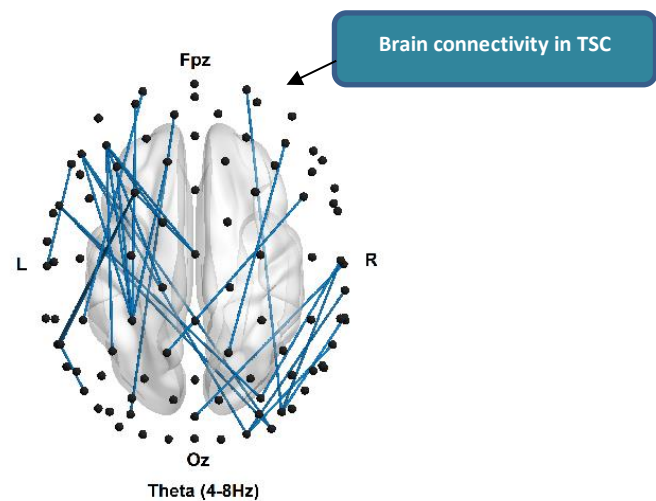
Updates

Prof. Patrick Bolton, the principal investigator since the start of the TS 2000 Study, has recently retired. Although he will continue to be actively involved in the study, Dr Charlotte Tye will be taking over study coordination. Charlotte has been a long running member of the TS 2000 team, joining in 2012, and many of you will have met her as part of the Phase 2 home visits between 2012 and 2015. We wish Prof. Bolton a very happy retirement and thank him for his pioneering work improving our understanding of neurodevelopmental conditions in TSC. We are looking forward to continuing to work together.

Recent publications

Dr Lizzie Shephard worked on Phase 3 of the TS 2000 Study. She has been conducting sophisticated analysis of EEG data to investigate the 'wiring' of the brain in TSC. Dr Shephard compared the connectivity of the brain in the TS 2000 cohort compared to typically developing children and adolescents. The findings confirm previous reports showing reduced brain connectivity in TSC. They also provide initial support showing that altered

neural networks (the way the brain is connected) may be involved in the co-occurrence of autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) in TSC.

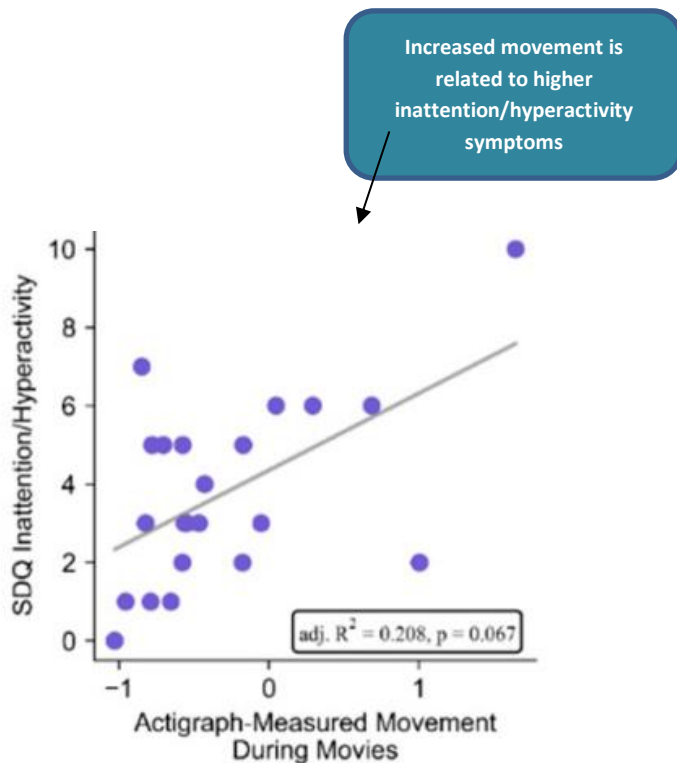


In addition to this, the team has just submitted a scientific paper investigating predictors of ASD in TSC

across development. The team found that the number of tubers in the brain and the severity of infantile spasms predicted ASD symptoms. This will inform early intervention delivery to improve longer-term quality of life.

Finally, the TS 2000 team have published a paper investigating increased movement levels associated with ADHD in TSC. The researchers used actigraphy (a device like a Fitbit) to detect movements while participants watched movie clips. They found that higher movement levels when watching movies were associated with higher parent-rated ADHD symptoms. They also found that increased movement was related to ASD symptoms and reduced intellectual ability. Over time researchers hope that by better understanding motor activity it may be able to be used for diagnosis and treatment monitoring in ADHD.

Get in touch if you would like to know more about these findings.



We are recruiting for a new study!

We are asking members of the TS 2000 Study who have a genetic mutation on the TSC2 gene to visit us in London to provide a blood sample along with some other brain and behavioural measures. This is so that we can learn more about the genetics underlying TSC and the association with different behaviours. All expenses will be paid and you will be reimbursed for your time.

Thank you, to all of those who have filled out the TAND checklist and sent it back to us!

Our research team

Abigail Runicles has just finished her medical degree - congratulations Dr Runicles! Abigail joined the team to distribute and analyse the TSC-Associated Neuropsychiatric Disorders (TAND) checklist. She is now helping Charlotte to recruit for a new study with a subset of the TS 2000 sample looking at genetics.

Charlotte has returned from maternity leave and is taking over coordination of the TS 2000 study, alongside her other projects investigating early development in TSC and epilepsy in young children. She is looking forward to leading the study that first introduced her to TSC research.

Contact details

We are extremely grateful for all your help and support for the TS 2000 Study so far. It is immensely valuable for us to keep in contact and get any updates that you may have you're your details have changed, you have any updates, or no longer want to hear from us,

please do send an email to
ts2000@kcl.ac.uk.

Thank you!

Once again, we would like to thank you
for all your hard work taking part in the
TS 2000 study.

With best wishes,

A handwritten signature in black ink, appearing to read 'C Tye', with a horizontal line underneath.

**Dr Charlotte Tye & the TS2000 Study
Team**