

EDiTS Study



Christmas 2020 Newsletter



Hello everyone!

The EDiTS Study has now been running for 4 years, so we would like to update you on how everything is going with the EDiTS team, as well as introduce some new and exciting studies that commence in 2021. The EDiTS Study aims to chart development in infants with tuberous sclerosis complex (TSC) in comparison to infants without TSC, in order to identify features of development that predict behavioural outcomes later on in life. We use a range of tests to measure development, from playing with toys, to interacting with one of our researchers and sitting in our special eye-tracking tent to measure attention to different cartoons. Taken together, this work aims to help to design early interventions to improve longer-term quality of life for individuals living with TSC. The EDiTS Study has been funded by the Tuberous Sclerosis Association (TSA).

What have we been doing?

Since the study started 4 years ago, we have now visited 67 families, with a total of 303 home visits! In addition to visits done in the home, we have had a total of 17 families visit us in the Birkbeck Babylab in London to complete more in-depth tests of brain activity and cognitive ability. During the last few months with travel being restricted, we have conducted 11 virtual visits via Zoom. We really appreciate your continued support during these uncertain times.

Upcoming + ongoing studies:

EDiTS-P (Early Development in Tuberous Sclerosis- Preschool) is a follow-up from the EDiTS study which will chart the development of children aged 3 to 5 years old (preschool years). We will invite parents in the EDiTS Study cohort to take part, and we will also be recruiting additional preschoolers to the study. We will be using fun and engaging tablet- and play-based activities to measure behaviour and development in the family home. The EDiTS-P study is funded by a UK charity called the Baily Thomas Charitable Fund.

BEE (Brain development in Early Epilepsy) is a new study aiming to identifying brain-based markers of emerging autism in infants with epilepsy. Up to 40% of autistic people have epilepsy, and this combination can have a considerable impact on quality of life. The BEE study aims to measure brain and cognitive development in infants with and without epilepsy, prior to the emergence of autistic traits, in order to identify features that predict later behavioural outcome. We will use many of the same measures we have used in the EDiTS Study and collect information in the family home. The BEE Study is funded by a joint award from two UK charities called Epilepsy Research UK and Autistica.

CoIN Study

The CoIN study involves completing a series of questionnaires which aim to capture the experiences of families of children with rare neurogenetic disorders during the pandemic. For more information and to take part please visit: www.coinstudy.co.uk

News from the EDiTS Study Team

The EDiTS team is slightly different now in 2020 compared to over the past few years, so here is an update on who you can expect to see working on EDiTS over the next year or so!

Charlotte returned from maternity leave in spring 2020 after welcoming her own baby scientist into the world! Earlier this year, Charlotte was awarded an Epilepsy Research UK & Autistica Fellowship for a new study of infants with epilepsy (called the BEE Study), which will begin in spring 2021. She is also preparing to launch the preschool phase of the EDiTS Study in the new year.



Charlotte + William

Abby is now in her final year as a medical student at St. Georges University of London and hopes to graduate and begin her career as a doctor in August 2021. Abby is still involved in the EDiTS study and is continuing to conduct virtual visits. She is looking forward to hopefully seeing the EDiTS families for in-person visits soon.

Katie is our newest placement student who started in September 2020. She is an undergraduate student studying BSc Psychology at the University of Plymouth who has been working as a research assistant on the EDiTS study and another study investigating the impact of Covid-19 on families of children with rare neurogenetic disorders (CoIN).



EDiTS Study team: Charlotte, Abby, Katie (left to right).

Thank you & Merry Christmas!

Thank you once again for participating in the study, it would not have been possible without your time and effort! If you have any questions about how to get involved in the new upcoming studies, please do not hesitate to contact us. Finally, we would like to wish your family a very Merry Christmas and a Happy New Year and all the best for 2021!

With best wishes,

A handwritten signature in black ink, appearing to read 'Charlotte Tye', written over a thin vertical line.

Dr Charlotte Tye & the EDiTS Study Team

Contact us: EDiTS Study (Charlotte Tye), Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, London SE5 8AF | **Office:** 0207 848 5272 | **Mob:** 07880 394296 | **Email:** edits-study@kcl.ac.uk