
EDiTS Study

Winter 2022 Newsletter

Hello everyone!

Welcome to the EDiTS Study Winter 2022 Newsletter! We have a lot of exciting updates about the team, what we've been up to this past year, and our plans for the future.

The EDiTS Study has been running for six years now and we are achieving great progress in investigating how early development differs in babies and young children with Tuberous Sclerosis Complex (TSC) compared to those without TSC. We have done this over the infant phase of the study, which is now complete, and the pre-school phase of the study, which was successfully launched last year.

What have we been up to?

We officially closed the infant phase of the EDiTS Study in early 2022 after seeing a total of 72 families over 314 home visits.



Since then, we have launched the pre-school phase of the EDiTS Study, following up on children aged 3-5 years from the infant phase and visiting a cohort of new recruits of the same age. We have made great progress with this phase of the study, and have now conducted 41 home visits - 35 with infant phase families and 6 with new recruits.

In these home visits, we have collected invaluable data about participants' development through fun and interactive home-based assessments and questionnaires including games on a touchscreen tablet for children to play on over ten days. We have also been measuring children's sleep activity and movement using an activity watch thanks to our collaborators at the University of Birmingham.

Recent findings!

Another exciting event for the study happened back in June 2022: PhD student Natasha presented some of the EDITS infant phase data (up to 24 months old) at the Neurodevelopmental Disorders Annual Seminar (NDAS), hosted in Edinburgh. Read a summary of the findings below!

The data from the infant phase showed that:

- Adaptive behaviour (i.e. use of daily living, social, and communication skills) and developmental ability in babies with TSC reflects a typical trajectory up to 10 months old. Skills are gained more slowly between 10 and 24 months old.
- Babies with TSC produce language similarly to babies without TSC up until 24 months of age, after which skills are gained more slowly.
- Increased seizure severity in the first year of life was associated with reduced adaptive behaviour and developmental ability (communication, motor and perception skills) in the second year of life.

These results support the development of early interventions which reduce seizure severity in babies with TSC in order to improve developmental outcomes. It also confirms that infancy is a critical period when seizures can alter brain development and future outcomes in babies with TSC.



Catching up with the team...

Here's an update from some familiar faces from the team, and an introduction to some new additions!

Charlotte is the Principal Investigator the EDiTS Study and also the Brain Development in Early Epilepsy (BEE) Study. This year, she also started as a Senior Lecturer in the Department of Psychology at King's College London. She is currently on maternity leave as in May 2022 she welcomed a second baby scientist to the world!

Rowan is a Research Assistant on the EDiTS study and has been part of both the infant and the pre-school phases. She conducts home visits so you can look forward to seeing her next year whilst we continue with visits!

Tasha is a second-year PhD student researching developmental trajectories in infants with early-onset epilepsy within the BEE Study. She also works with our collaborators at the University of Birmingham to organise the activity watch component of the EDiTS Study.

Dolapo is a Postdoctoral Research Associate who works on the EDiTS and BEE studies, both of which she coordinates recruitment for.

Zayna is a BSc Psychology student at King's College London who joined the team as a placement student in August. She coordinates home visits and conducts them alongside Rowan.

The team

*From left to right:
Tasha, Rowan,
Charlotte & Theo,
Kate, Tash,
Zayna, Dolapo*



What's next for the Study?

Once we return from our holidays in the New Year, we will be ready to continue with the pre-school home-visits. We will also be focusing on recruiting new families with children aged 3-5 years who are interested in contributing to our research. Follow us @EDiTS_Study on Twitter, Facebook or keep up with our website at www.edits-study.org to get more information and updates on this!

Thank you & Happy Holidays!

We would like to extend a huge thank you to all the participants and collaborators of the EDiTS Study. We really appreciate all your continued support over the years - we could not have made it this far without it! Please get in contact with us if you have any questions or would like to get involved in one of our studies.

Finally, we wish you and your family Happy Holidays and a wonderful 2023!

With best wishes,



Dr Charlotte Tye & the EDiTS Study Team

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