

TS 2000 WINTER NEWSLETTER 2024

MERRY CHRISTMAS

FROM THE TS 2000 TEAM



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Year in review

December
2024

Advancements in Phase 4

This year marked significant progress in Phase 4 of the TS 2000 Study. Our focus on young adults with TSC and the use of a smartphone app for remote data collection has been a major milestone. The feedback from participants has been invaluable in shaping our understanding of daily challenges and emotional well-being.

Key Highlights

Successfully recruited 15+ participants for the study

Gathered valuable data through a smartphone app, offering insights into the connection between mood, lifestyle and seizures

Expanding Collaboration

We have been engaging with patient organisations, including the **Tuberous Sclerosis Association (TSA)**, to support recruitment efforts for our study.

We also launched our **Instagram page**, where we share study updates, educational content and drive recruitment!

Follow us at [@ts2000study](https://www.instagram.com/ts2000study)

A heartfelt thank you!

We would like to say a huge thank you to everyone who has contributed to making our 2024 a success!

- To our returning participant: Thank you for being a part of the TS 2000 in the past and for rejoining us again for this new phase. Your continued support and involvement is invaluable!
- To new participants: A warm welcome and thank you for joining us in advancing this important research.

What else have we been up to?

TS 2000 Study Advisory Group

To help plan and design the current smartphone study, the team ran an advisory group with two young adults with TSC. The advisors attended 7 online meetings over 4 months. They helped design the advert and the smartphone protocol, piloted the app, and advised on participants' feedback and how we can share the results with the community. We then met for an in-person workshop in London, where we reflected on the advisory group and co-created two guideline documents. These will be shared very soon!



TSA Big Day

In May this year, Kate and Cheyenne (first-year PhD student) travelled to the TSA Big Day event in Reading. Kate presented some of the work from the focus groups and interviews around using smartphones to monitor everyday experiences in young adults with TSC. It was lovely to see some of you there!

MTOR Node Workshop

In December, our very own Dr. Charlotte Tye hosted the mTOR Node Workshop. The day brought together researchers, patients, and organisations to discuss progress on mTOR pathway-related research. The event aimed to improve collaboration, co-create a handbook for making scientific information accessible, and establish regular check-ins between researchers and the community. The next steps will focus on refining this handbook and strengthening connections between researchers and the TSC community.

We Still Need You!

To all our incredible TS 2000 Participants who were involved in earlier phases of the study, we'd love to have you back involved! Your contributions have been invaluable in shaping what we know about TSC, and Phase 4 wouldn't be the same without you.

Why Your Participation Matters

In this phase of TS 2000, we are exploring the daily experiences of young adults with TSC using a smartphone app. By rejoining, you'll help us:

- Understand emotional and physical well-being in young adults with TSC
- Develop tools and resources to better those living with the condition

What's Involved?

- ✓ Complete short daily check-ins through a two-week period on a smartphone app.
- ✓ Share your feedback on using the app and the study.



Your participation is fully remote and flexible! As a thank you for your time, you'll receive a **£75** shopping voucher.

It's not too late to get involved in Phase 4! Visit our website at www.ts2000study.co.uk or email us at ts2000@kcl.ac.uk to sign up or learn more.

2025: What's Next?

TS 2000 Participants, we need your help!

We are introducing Siblings to our study!



Do you have siblings aged above 16?

Why?

In previous phases of the TS 2000 study, we recruited siblings of participants with TSC to understand differences within individuals growing up in the same family.

In this next phase in 2024, we are once again including siblings to explore differences in daily experiences. By comparing young adults with TSC to their siblings, we aim to better understand the unique challenges faced by those with TSC and the broader impact on their families.

If you have any siblings who meet this criteria and are interested in participating in our study, please encourage them to visit our website at ts2000study.co.uk or email us at ts2000@kcl.ac.uk.

Also in 2025! We are organising a more general follow up study for all previous TS 2000 participants. More information about this will follow soon!

Catching up with the Team



Dr Charlotte Tye leads the TS 2000 Study, taking over from Professor Patrick Bolton in 2020 following his retirement. This year she has been overseeing this work, as well as other studies of TSC and early-onset epilepsy, called the Early Development in Tuberous Sclerosis (EDITS) Study and

the Brain development in Early Epilepsy study. She also leads the patient and public involvement initiatives for the mTOR pathway diseases node, working with an advisory panel and a network of patient organisations. She says: "It continues to be a privilege to work with the community so closely in many aspects of our research. The insight we are gaining is making significant advances to our understanding of the experiences and priorities of young people with TSC and related conditions. Thank you so much to all who have participated in our newer work, including interviews and focus groups, and now the smartphone app. This would not be possible without your time and commitment!"

Kate Fifield has been leading this phase of the TS 2000 study and is now in the final year of year of her PhD. She has submitted two papers for review describing the results from the focus groups and interviews from the beginning of the year. She will keep you updated on their progress!



She has also been running an advisory group with two young adults with TSC to help design and evaluate the current smartphone study. She says "I have had an incredible time working with the TS 2000 participants and families over the last two years. Your commitment to research and our study has been amazing and I am very grateful for all your participation. I am really looking forward to 2025 and sharing the results of our work with you all and what we can do next!".

Since joining the TS 2000 Team in late August, **Tamia**, our placement



student has been busy supporting participant recruitment, reaching out to families to get participants involved in our smartphone app study. You may have received a phone call from her inviting you!

She has also been developing social media posts and materials to raise awareness about TSC and epilepsy.

Merry Christmas From the TS 2000 Team!