



## Christmas Newsletter 2021

Welcome to the BEE Study!

Merry Christmas from the BEE Study team!



We are looking forward to launching the BEE study and thought this would be the perfect time to introduce ourselves and the work we are doing. We would like to share with you details of the study, including how to get involved, as well as information about our parent priorities project, BEE-PP. While the BEE Study is yet to open recruitment, the BEE-PP is currently looking for participants to respond to the survey, so please read further to find out how to get involved!

### The BEE Study

The BEE study is investigating behavioural and brain development in babies with epilepsy, with an aim to understand its impact on later development, such as the emergence of autism. Epilepsy and autism commonly co-occur (around 40% of epilepsy cases in children co-occur with a diagnosis of autism) but the reasons for this co-occurrence are mostly unknown. The BEE study wishes to better understand how both of these conditions affect early development and behaviour, in order to improve later outcomes for those living with them.



During the study itself, we will be using a combination of parent report questionnaires, interviews, play-based assessments with babies, as well as an EEG and eye tracking task to measure babies' brain activity. All of this will give us lots of information about areas such as behaviour, communication and sleep, allowing us to draw important links between our observations of epilepsy and autism. Critically, we will be visiting families in their homes over the first two years of life, in order to examine behaviour in the child's home environment.





## BEE-PP

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The BEE-PP Project is set within the BEE study and aims to document the experiences of families of children with early-onset epilepsy. This includes the attitudes and behaviours of siblings of children with epilepsy, as well as the opinions and experiences of parents. We also aim to identify a set of shared priorities for research into early development and behaviour in epilepsy.

The first stage of BEE-PP involves collecting responses on our survey, where parents are given the opportunity to anonymously contribute their own opinions surrounding research in epilepsy. There are extra activities offered after completion of this survey, one of which is an optional focus group in which parents can discuss priorities with other parents in more depth and

see other priorities from different perspectives. There will also be an opportunity to review the outputs generated by the project and an invitation to write a short blog post summarising your experience within the BEE-PP project. These extra activities are optional and do not affect parents responses to the main BEE-PP survey.

The BEE-PP project is a Patient and Public Involvement (PPI) study which assumes that those directly affected by what's being studied (in this case epilepsy) are best able to provide additional, valuable insights into what related research needs to focus on. This type of research is important because it allows the collaboration of ideas between researchers and the public to positively influence research, leading to more relevant research and eventually wider support for the patient groups.

The BEE-PP project is funded by the Wellcome Trust's Institutional Strategic Support Fund and King's College London.

**Survey  
open  
now!**

If your child is aged 1-month to 15-years 11-months and was diagnosed with epilepsy between 1-month to 24-months old, then we would love to hear from you!

Click [here](#) to take the BEE-PP survey!





## Meet the Team!

Meet the core study team and find out more about our roles in the BEE study!

Charlotte Tye



Hello! I am Senior Lecturer in the Department of Psychology at King's College London. I graduated in Experimental Psychology from the University of Bristol and completed doctoral and postdoctoral training at King's College London. My research focuses on characterising development in young children with rare neurogenetic conditions and epilepsy, and identifying infant precursors of later emerging neurodevelopmental conditions, such as autism and ADHD. I have received prestigious fellowships from the Tuberous Sclerosis Association, Epilepsy Research UK and Autistica, and was awarded the Vicky H Whittemore prize in 2015 and the British Academy of Childhood Disability/Castang Foundation Fellowship in 2019

Natasha Lindsay



Hi, I am a first year PhD student researching developmental trajectories in infants with early-onset epilepsy within the BEE Study at King's College London. My research project is motivated by an interest in neurodevelopmental conditions and what psychosocial factors may predict their emergence. My role on BEE over the next year will involve visiting families to complete assessments with parents and babies as part of our data collection. I have worked on longitudinal projects researching atypical development in children since my undergraduate degree, so I'm really looking forward to working with families on the BEE Study once recruitment opens!

Chlöe Sanders



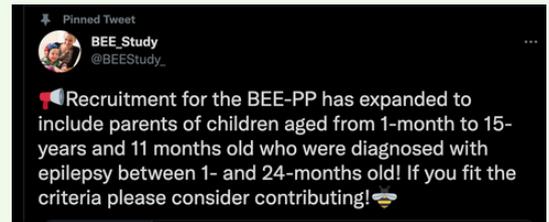
Hi my name is Chlöe! I am an undergraduate psychology student on a placement year within the BEE study. My main interests lie in epilepsy as well as other neurodevelopmental conditions, so I am very excited for the BEE study to get underway! My main responsibilities currently involve managing the BEE social media accounts and managing incoming responses from the BEE-PP, supervised by both Charlotte and Tasha.



# News from the Core BEE Study Team

## Social media activity

As we continue to advertise the BEE study on our Twitter and Facebook, we hope to see more potential participants engaging with the website and the survey so we can collect even more information for the BEE-PP! Take a look at some of our recent recruitment tweets (left) for more information, and visit us on Twitter @BEEStudy\_ We also post updates regularly on Facebook @TheBEEStudy!



As Epilepsy Awareness Month spanned the month of November, we wanted to show our support for those with epilepsy through our social media platforms, in order to keep the conversation on epilepsy active.

## Research Roundtable - Epilepsy and Autism

Charlotte has been busy initiating conversation about the BEE Study in academic interviews and blog posts, and recently took part in a seminar series focussing on new research on epilepsy and/or autism! Charlotte's blog post and research talk can be found below!

Click below  
to watch Charlotte talk about the BEE Study

**RESEARCH ROUNDTABLE**  
Epilepsy & Autism

With guest speakers...

Susanna      Dr Colin Reilly      Dr Charlotte Tye

DISCUSSING NEW RESEARCH  
COMMISSIONED BY:

EPILEPSY RESEARCH UK      autistica      Young Epilepsy

↓ Click here to read Charlotte's blog post ↓

**What can early development tell us about the link between epilepsy and autism?**

HOME / RESEARCH BLOG / WHAT CAN EARLY DEVELOPMENT TELL US ABOUT THE LINK BETWEEN EPILEPSY AND AUTISM?



## BEE Study PhD Student Blog!



Hello!

My name is Natasha and I am a PhD student and a member of the BEE Study research team. I joined the team in Jan 2021 as a Research Assistant but have recently moved onto a PhD Studentship which has been an incredibly exciting transition! During my PhD, I will be one of the researchers attending home visits on the BEE Study to collect information on the course of development of infants with early-onset epilepsy over their first two years of life. The aim of my research project is to gain a better understanding of the social, behavioural and cognitive profile and trajectory of development of infants with focal seizures and/or infantile spasms. It is important for us to understand this pathway so that we can identify what might predict the emergence of later developmental conditions, such as autism. There is not much of a consensus in research in regards to whether 'regression', i.e. the loss of skills over time also occurs in young babies/children with early-onset epilepsy, which is another topic I am interested in exploring. I'm really excited to start testing and meeting families on the BEE Study, and I hope that my project will be able to contribute to knowledge of early-onset epilepsy during such a crucial period of early development.



## Coming Up!

Recruitment is NOW OPEN for the BEE-PP project! To get involved please visit our website for a link to the survey and more information about additional activities within the BEE-PP!

We are also NOW recruiting participants to take part in our pilot study for BEE! If you have a baby aged between 9-months and 24-months old, then you are perfect to participate! The study will involve a series of fun, interactive tasks including toy-based games with our researchers. We will also be measuring babies' brain activity by wearing a special cap, and tracking eye movements to learn more about how they respond to their environment. All of these assessments are baby-friendly and we hope this will help us in the future to test babies with early-onset epilepsy, including in the BEE study! If you're interested, please join us in our accessible and friendly lab in Denmark Hill! Sessions can be arranged at a day and time that suit you, or we can visit you at home for a brief session. Expenses up to £10 will be reimbursed, or a Love2Shop voucher of equivalent price.

To find out more details or let us know you'd like to take part, email Natasha Lindsay or Chlöe Sanders at [beestudy@kcl.ac.uk](mailto:beestudy@kcl.ac.uk).

We are looking forward to seeing all of the measures in practice as our piloting plan progresses and as we move closer to recruiting participants for BEE, hopefully in the new year!



## Thank you for reading!

### **Contact us!**

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Festive wishes from the BEE study team!

