

CASTLE

Changing Agendas on Sleep, Treatment and Learning in Epilepsy

Would you like to contribute to research about rolandic epilepsy?

Do you have rolandic epilepsy and are aged between 5 and 18?

Are you a parent or carer of a child with rolandic epilepsy?

Do you want to make a difference to the rolandic epilepsy community?

If so, we need your help. We are looking for people to join our advisory groups to provide our research with independent advice and guidance. In return, you will be financially compensated for your time.

What our research is about

Rolandic epilepsy is the most common type of epilepsy - affecting about one-sixth of all children with epilepsy in the UK - that means over 10,000 people! We use the simple term “rolandic epilepsy” although you may also hear it referred to as “benign rolandic epilepsy” or “benign childhood epilepsy with centrotemporal spikes.”

The aim of our research is to improve medicines, sleep and quality of life for children with rolandic epilepsy. We call it the CASTLE study which stands for Changing Agendas on Sleep, Treatment and Learning in Childhood Epilepsy. The advisory groups will ensure that the work we do is useful and relevant and meets the needs of children, young people and their families.

Why we need someone like you to help with our research

Research into rolandic epilepsy is most effective when those with experience of this condition have direct involvement in the research process. Having people like you as a partner in our advisory groups to provide us with independent guidance on our research is a way you can be meaningfully involved.

Could you be who we are looking for?

As an advisory group partner, you will be:

- ✓ Someone with rolandic epilepsy aged between 5 and 18 **OR**
- ✓ A parent/carer of a child (aged 5 – 18) with rolandic epilepsy
- ✓ Able to attend two meetings per year (in London OR Liverpool)
- ✓ Happy to share your views on the research in small and larger group meetings
- ✓ Confident to contribute your thoughts and ideas on different aspects of the research either by email or phone/skype or post
- ✓ Willing to speak up about things which matter to you in relation to rolandic epilepsy

We will provide all our advisory group partners with:

- ✓ An introduction to the work of the advisory groups and the research programme
- ✓ Ongoing support and training
- ✓ Payment for your time (in a format that suits your circumstances) and reimbursement for travel to meetings
- ✓ Some childcare costs
- ✓ Refreshments

Want to find out more?

You can email Rachael or Sam at castle-study@kcl.ac.uk to learn more about this opportunity.