

As part of our research on Changing Agendas on Sleep, Treatment and Learning in Childhood Epilepsy (CASTLE) studies we are consulting and working with children and young people with rolandic epilepsy and parents/carers through our advisory panels. We have two panels, one based in the North of England and one based in the South of England. Rachael and Sam are the Family Engagement Officers for the CASTLE study and their job is to facilitate the groups. Rachael Martin who leads this work for the North of England and is based near Liverpool explains:

“I am really excited to be part of this project and I am looking forward to working with families to help children and young people with rolandic epilepsy fulfil their potential and have the best quality of life.”

Rachael has been busy meeting with epilepsy support groups and epilepsy nurses and she is extremely keen to hear from anyone who lives in the north and would like to get involved in a panel – please contact Rachael here rachael.martin@edgehill.ac.uk

Sam Lyle is based at King’s College London and leads the family consultation work in the South of England and says:

“Getting involved in research may seem daunting at first, but you are the experts of your experience. My job is to make sure that you get the best opportunity to put those experiences to good use in our research. I really look forward to working with you on the CASTLE study and having some fun along the way!”

Debbie has been sharing her experiences as a mother of a daughter who has rolandic epilepsy with the CASTLE study team and reflects that:

“Working with the researchers can be a bit frightening at first as they sometimes talked in ways that I didn’t understand. However, being on the panel is not only helpful but rewarding. You may mention something that helps another family – that’s a great feeling. Then someone else says something and you think, I never knew that! So while you are helping others you are always learning at the same time”

So far in the South we have had two meetings. Reflecting on these meetings, Sam said:

“We had a really interesting Introduction and Orientation to the work of the Advisory Panel which included giving new members the time to express their reasons for getting involved in research. The best part of my job is to meet and listen to these amazing parents who are not only managing their own busy lives but have found time to work with the CASTLE study to improve our research for children with benign rolandic epilepsy. These parents are an inspiration and I love working with them.”

After our productive meeting Sophie said *“It was lovely to meet Sam and some other mums and to hear all about the different parts of the CASTLE study. I feel very pleased and honoured to be involved in helping in some small way. Knowing that my opinions matter and being able to help CASTLE researchers to implement their studies in ways that are meaningful is really very rewarding”*.



Sam, Allie, Janet and Sophie

Part of our work has been the creating the panel considering which outcomes are most important to measure for children in the CASTLE clinical trial. Sam welcomed Keith and Debbie to lunch at Kings College London, where they met Holly, one of our researchers, who explained the different outcome measures and we talked through which of these seemed to best reflect what was important for parents of children with rolandic epilepsy. The panel had an interesting discussion around how parents’ wellbeing and the health outcomes of their children should not and could not be separated and any research should be interested in both parent and child health outcomes.



Debbie and Keith

Panel members are rewarded for their time and are paid travel expenses.

If you or your child would like to find out more about being part of our Advisory Panel you can find out more on our Patient Public Involvement page. There are also ways in which you can take part in the research by following the link to the CASTLE webpage. We look forward to hearing from you soon!