

The UK Paediatric Epilepsy Programme Board is looking for new Experts by Experience

We believe that children, young people, families and carers are key to informing and influencing the services of the future, bringing with them expertise from their experience.

The UK Paediatric Epilepsy Programme Board brings together patient and family representatives (Experts by Experience - EBE) with charities, paediatricians, epilepsy specialists and other interested organisations to discuss challenges, issues and ideas relating to epilepsy care and service provision.

Having seen the /incredible benefit that Experts by Experience bring, the Board has agreed to expand and we are excited to announce we now have seven opportunities for new Experts by Experience to join the board.

To help share the voice and views of children, young people, families and carers across the UK we are looking for:

- Three young people/young adults aged 16 - 23 who have their own epilepsy experience to join an existing EbE who will be moving in to their 2nd term
- Four parent/carers aged 18+ who support a child or young person with epilepsy or supported someone who is not with us today

The UK Paediatric Epilepsy Programme Board currently meets three times a year using MS Teams (online) or in the London office. Dates of the 2023 meetings are still being confirmed but likely to be :

May

September

November

We asked the members of the board; how would they explain being part of the UK Paediatric Epilepsy Programme Board?



We also asked them to think about the difference having Experts by Experience makes to the work of the UK Paediatric Epilepsy Programme Board. They said:

“

- They bring insight and real world experience we don't have
- They make it real
- They remind us why we are here
- They have practical ideas and sense check our thinking
- They are key members of the panel, giving true meaning to the group

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Which epilepsy experiences are we looking for from young people or parent/ carers?

Epilepsy comes in many different forms and impacts everyone's life in a different way. Diversity of experience is important to us, so we want to hear from everyone. Maybe you or your children:

- Have been diagnosed for years or have been newly diagnosed
- Have absence, myoclonic, tonic clonic, atypical, atonic or another type of seizure
- Have experience of having epilepsy with other conditions or disabilities
- Are seizure free or still experiencing seizures
- Have wider experience such as side effects of medication, living with epilepsy, worries or anxieties, education and transitions

How will we support you?

- Meet to look at the agenda and identify topics to raise from the Experts by Experience
- Help link with networks of patients and families with epilepsy experience
- Catch up after the meeting to confirm actions or next steps
- Cover your travel expenses for in-person meetings

Ready to apply?

Your next steps are:

Part one:

Get in touch by emailing and_us@rcpch.ac.uk to share your answers to these questions (two or three paragraphs in total). Please also include your name and if you are a young person with epilepsy or a parent/carer who has supported childhood epilepsy:

1. Please tell us why you would like to join the UK Paediatric Epilepsy Programme Board
2. Please tell us about your epilepsy experience and your epilepsy networks that would support the work of the UK Paediatric Epilepsy Programme Board
3. Please let us know about your experience of sharing views, ideas or perspectives in meetings or forums
4. Please share with us what you would like to learn or take home from your role on the UK Paediatric Epilepsy Programme Board
5. Finally, let us know how you found out about this opportunity to join the UK Paediatric Epilepsy Programme Board.

You can also make a short video if easier to answer the questions (2 mins max) or send a voice note to **07715 659795**. The deadline for part one is **15th August 2023**.

Part two:

If you are selected to move onto the next stage, we will arrange a phone/video conversation in **end of August/early September** where we will ask you some more questions about your experience, skills and hopes linked to the UK Paediatric Epilepsy Programme Board role.

We love that you are interested in making a difference in Epilepsy, if this opportunity turns out not to be for you, we have lots of other projects with RCPCH or other charities you can get involved with. Please let us know if you'd like to join our network or sign up at: <https://www.rcpch.ac.uk/work-we-do/rcpch-and-us/sign-up>

If you have any questions, please get in touch with Emma Sparrow via and_us@rcpch.ac.uk or by **texting 07715 659795**. Thank you for your interest!