

Epilepsy12 Youth Advocates



Richard Driscoll
Memorial Award 2018



Clinical Audit Heroes
Volunteer of the Year 2020



RCPCH&Us Volunteer
Awards 2021



Richard Driscoll
Memorial Award 2022



Clinical Audit Heroes
PPI Award 2023

The Epilepsy12 Youth Advocates are a group of young of epilepsy experienced children and young people (CYP) and families. "As a youth advocate I have shared the best and hardest parts of my epilepsy journey to help make it better for others"



Engagement

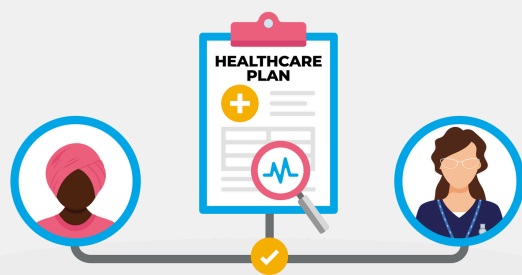
The efforts of the Youth Advocates work collaboratively with CYP, their families and clinicians.

The Youth Advocates kick-start the annual Epilepsy12/OPEN UK conferences, sharing their insights and gathering views from epilepsy specialists to help shape their priority areas.

They also presented at the RCPCH conference and, in 2024, additionally hosted a Purple Day stand.

The Youth Advocates visited local clinics in 2018, finding out what matters to children, young people, and families. These 'clinic chats' pinpointed support gaps and areas for local service improvement.

In 2023, they participated in an engagement project on the experiences of young people with epilepsy from marginalised groups. They also supported the co-delivery of the innovation labs for the RCPCH&Us Impact and Influence project.



Resources

The Youth Advocates have collaboratively developed materials for children and young people with epilepsy.

They developed a leaflet for young people and parents with information about the audit, links to resources, and an epilepsy care checklist.

On Purple Day 2023, the Medicines for Children podcast featured a Youth Advocate, sharing their first-hand experience living with epilepsy.

In 2021, the group developed a School Individual Health Care Plan template, as well as 'top tips' for educators and signposting tools to improve care within education.

In 2020, they introduced a Clinic Chat Checklist, a self-assessment tool which helps epilepsy services evaluate their offer and identify areas for improvement.



Youth Voice

The Youth Advocates act as representatives for CYP with epilepsy across various projects, ensuring their voices are heard.

The influence of Youth Advocate's goes beyond the RCPCH. They have represented CYP on the Project Board of the Epilepsy Information Standard, led by the Professional Records Standards Body (PRSB, and the Royal College of Physicians Young Adult and Adolescent Steering Group.

They also contributed to the evaluation of the Paediatric Epilepsy Training conducted by the British Paediatric Neurology Association.

Within the college, the Youth Advocates have contributed to interviewing the college CEO and contribute to the Epilepsy Programme Board as 'experts by experience'.

Furthermore, they offer assistance and engagement tools to clinical teams involved in the RCPCH Epilepsy Quality Improvement Programme (EQIP).



Audit

The Epilepsy12 Audit considers the perspectives of the Youth Advocates to shape audit methodology and outputs.

The Youth Advocates are integral to reviewing audit data and pulling out key findings and recommendations. They also design a page within the report to describe their priorities and activities.

In 2021, they co-designed a young person and parent guide to the audit to help families with a new diagnosis of epilepsy. This includes an accessible care checklist to support patients and families to advocate for themselves.

With input from the Youth Advocates, Epilepsy12 refined its KPIs down to 10 measures, with a new focus on mental health support. They also contributed to the Epilepsy12 Healthcare Improvement strategy, selecting 5 Improvement Goals for the audit.

Additionally, the group provided insight on how applying the National Data Opt-Out may risk patient safety, supporting the application for an exemption.

For more information visit our website:

www.rcpch.ac.uk/resources/epilepsy12-youth-advocates

