

SHAPE NETWORK Application Clinic Volunteer

About EPILEPSY RESEARCH UK

Epilepsy Research UK is the only UK charity exclusively driving and enabling life changing, life saving research into epilepsy. Our vision is 'a life free from epilepsy'.

Our funded research programmes are being carried out in hospitals and universities throughout the UK and range from clinical projects that provide help for people living with the condition today, to pioneering lab-based research that will advance the science of the understanding of epilepsy and provide hope for tomorrow. Our funded research is already having significant impact on understanding the causes, diagnosis and treatments of epilepsy and associated conditions.

About the SHAPE EPILEPSY RESEARCH NETWORK

In October 2020, Epilepsy Research UK launched the SHAPE EPILEPSY RESEARCH NETWORK to provide an opportunity for people affected by epilepsy to be involved in helping to shape the future of research into epilepsy. The SHAPE NETWORK will support Epilepsy Research UK's strategy to support capacity building activities for researchers and integrate the voices of people affected by epilepsy in the core mission of the charity.

Epilepsy Research UK's SHAPE NETWORK will be the UK's largest ever population of research-interested people affected by epilepsy. The network provides an opportunity for people affected by epilepsy to get involved in all aspects of research, from identifying and evidencing priorities to making decisions on the projects we fund. The guidance from experts by experience when designing, implementing and evaluating research has the potential to make studies more effective, more relevant and more cost-effective. SHAPE NETWORK members will also support Epilepsy Research UK to advocate for increased research funding through speaking about their lived experiences to raise awareness of epilepsy and the life-changing, life-saving potential of research.

Through the SHAPE NETWORK, Epilepsy Research UK will ensure research is focused on the most important outcomes identified by people living with epilepsy and will provide the evidence needed to secure greater research funding. Together, we will create a powerful community of people affected by epilepsy, who will shape the future of research.

We are currently inviting applications SHAPE NETWORK members for the role of Application Clinic Volunteers. The role is detailed below:

APPLICATION CLINIC VOLUNTEER

We want to ensure that the research Epilepsy Research UK funds:

- Is important to people affected by epilepsy
- Involves people affected by epilepsy in a meaningful way
- Will be able to recruit people to take part and not put any unnecessary barriers in the way of people who might be eligible
- Has an accessible summary of the proposed research written in plain English
- Will share results with people affected by epilepsy

We want to help researchers who apply to us for funding to meet these criteria.

Research has shown that early involvement of patients and public in research leads to better quality of research and improved outcomes for patients. This year, all researchers who are shortlisted at the initial application stage of the grant round will be invited to a virtual meeting with two members of the SHAPE NETWORK, in advance of submitting their full application. Researchers are encouraged to use this opportunity to consider how people affected by epilepsy would best be involved in the proposed research, how to make the language explaining the complex underlying science accessible, or how best to communicate the potential impact of this research.

As an application clinic volunteer you will:

- Read an extract from the research application of around 3 pages
- Attend a virtual call (on Zoom) of around 40 minutes with the researcher and one other SHAPE NETWORK member to discuss their research application. Any topics that the researcher would like your specific insight on will be sent to you in advance. The call will be facilitated by the Epilepsy Research UK Research Team who will be in attendance at all times.

Time commitment: Approximately 30 minutes to read the application and 40 minutes on the application clinic Zoom call.

When: Application clinics will take place in November and December 2021 and will be arranged around your availability.

Location: Home-based. All of the meetings and related activities will be via Zoom, email or phone.

Deadline to apply: 4pm on 15th November 2021

To volunteer in the Application Clinics, we will request that you treat all applications as confidential.

ABOUT YOU

The experience and skills you will need:

- Experience of living with epilepsy – either because you have epilepsy yourself, or because someone you know has epilepsy. We would like to involve people with a range of different experiences of epilepsy
- Enthusiasm about research into epilepsy
- Listening skills and a respect for different opinions
- Ability to give comments and constructive criticism succinctly
- Some computer skills or a willingness to acquire these quickly (you'll need to be able to join meetings on Zoom, and to download, read and comment on short documents)

Why should I get involved?

By joining getting involved in our application clinics, you will help influence the research that is funded by Epilepsy Research UK. You will also learn more about the work of Epilepsy Research UK and about how your experiences can add value to the research we fund and support.

Volunteer expenses

We believe that no Epilepsy Research UK volunteer should be out of pocket because of expenses incurred when carrying out volunteering activities on our behalf. As a volunteer you can claim £5 for every clinic you take part in, to help to cover the cost of WiFi or data used.

If you have any questions or would like to discuss becoming an Application Clinic Volunteer, please contact our Head of Research, Caoimhe Twohig-Bennett (caoimhe.bennett@eruk.org.uk).