



Trustee (Lived Experience)

Encephalitis International

Voluntary role | Remote with occasional meetings

Encephalitis International is the world's leading charity dedicated to improving the lives of people affected by encephalitis through awareness, support and research. Each year encephalitis affects hundreds of thousands of people worldwide, often leaving survivors and families facing significant long-term challenges.

We are seeking to recruit a **Trustee with lived experience of encephalitis** to join our Board.

This is a particularly important role within our governance. We want to ensure that the voices and experiences of those directly affected by encephalitis help guide our strategy, priorities and work.

We welcome applications from individuals who are:

- **A survivor of encephalitis**, or
- **A parent, family member or caregiver** of someone affected by encephalitis.

We are especially keen to hear from candidates from **under-represented and diverse backgrounds and communities**, including those currently under-represented in charity leadership. Encephalitis affects people everywhere, and we want our Board to better reflect the communities we serve.

The Role

As a Trustee, you will help shape the strategic direction and governance of Encephalitis International. Trustees share collective responsibility for the organisation's performance, sustainability and impact.

You will:

- Contribute lived experience insights to Board discussions and decision-making
- Help ensure our work reflects the needs of patients, survivors and families
- Support the charity's strategic development and oversight
- Act as an ambassador for the organisation and its mission

You do **not** need previous trustee experience. We are committed to supporting and developing new trustees.

What We Are Looking For

We are particularly interested in people who bring:

- Personal experience of encephalitis as a survivor or caregiver
- A passion for improving outcomes for those affected by the condition
- The ability to contribute to thoughtful discussion and decision-making
- A willingness to work collaboratively as part of a committed Board

Time Commitment

- Approximately **4–6 Board meetings per year** (usually virtual) with one in-person away-weekend.
- Occasional participation in sub-committee meetings or attendance at our events
- Preparation time for meetings

This is a **voluntary role**, though reasonable expenses will be reimbursed.

Why Join Us?

By joining the Board of Encephalitis International you will help shape the future of a growing global organisation that is leading efforts to improve **diagnosis, treatment, support and research into encephalitis worldwide**.

Most importantly, you will help ensure that the **lived experiences of patients and families remain at the heart of everything we do**.

How to Apply

To express interest, please send a short statement outlining your interest in the role and your connection to encephalitis along with your CV to ava@encephalitis.info