

EPILEPSY ACTION

Summary of a meeting of the **Board of Trustees** of the British Epilepsy Association held by remote video (Teams) at **9.30am on Tuesday 24 March 2026**.

Minutes and Matters Arising

The minutes of the previous meeting (9 December 2025) were approved with amendments, including clarifications on reserve management and AI-generated minutes.

Further updates included office lease reviews, governance review (NCVO to return in September), and a report on the unsuccessful Charity of the Year bid.

Financial Report

The charity reported a surplus of £1.1 million for 2025, with income at £5.3m (ahead of budget) and expenditure at £4.3m. This was the highest income level ever recorded for the charity subject to the auditors signing off the 2025 accounts.

The management accounts for January and February are in line with forecasts and cash reserves are strong, with £1.67m in cash and £3.3m in unrestricted reserves.

Chief Executive's Report

Partnership updates included developing relationships with StepChange, the Angelini Pharma grant submission and an HSBC photo-sensitivity research project.

The sodium valproate roundtable in Parliament faced challenges due to the MP withdrawing but was a successful event.

The "Community of Support" implementation is progressing, following the changes to our membership, with onboarding of new supporters.

Strategic Plan and Programmes

CRM data accuracy reached 90%; chatbot usage on the website continues to grow and website traffic is slightly below target due to the growing impact of AI.

The Self-Advocacy Toolkit was launched and is now available on the website. It was informed by focus groups and webinars are planned to support its use.

Community champion volunteer roles are being piloted in Northern Ireland and Wales, with plans for expansion and online engagement.

The Access to Employment initiative is launching in May, with webinars and mentoring for people with epilepsy.

Diversity, Equity and Inclusion (DEI)

The DEI Action Plan was presented and the Trustees agreed to add a DEI reflection at the end of each meeting and annual reporting via the Impact Report and website.

Trustee Recruitment and Governance

The recruitment and appointment processes were approved, with an emphasis on the skills mix and lived experience, and agreement that a volunteer from the Ethnic Communities' Group should join the panel.

Risk Register and Policies

An updated version of the Risk Register has grouped risks under broader themes, and it was agreed that there should be a Risk Appetite workshop in September.

The Scheme of Delegation and Ethics Policy were discussed; amendments were made to clarify roles and due diligence, especially for pharmaceutical partnerships.

Committee Terms of Reference

Revisions were agreed to some of the roles and responsibilities for Finance and Strategic Policy and Corporate Governance Committees.

Advisory Groups

Administrative support for the Northern Ireland and Wales Advisory Groups was agreed and a joint meeting will be held for future planning.

Honorary Roles

A working group was established to review the President, Patron, and Vice President roles.

Safeguarding and Fundraising

The annual Safeguarding Compliance Report was reviewed and no significant risks were identified. The Fundraising and Delivery Monitoring Plan 2026 was approved.

Decisions Made

- The recruitment and appointment process for new Trustees was approved.
- The updates to the risk register were approved.
- Subject to the amendments agreed in the meeting, the Ethics Policy was approved.
- The updated Terms of Reference for the Finance and Strategic Policy Committee and the Corporate Governance Committee were approved.
- It was decided that the responsibility for staff appeals be added to the Standing Committee Terms of Reference.
- The new appointments in the Wales Advisory Group were approved.
- The Fundraising and Delivery Monitoring Plan 2026 was approved.
