

EPILEPSY ACTION

Summary of a meeting of the **Board of Trustees** of the British Epilepsy Association held as a hybrid meeting at New Anstey House and via remote video (Teams) at **10am on Tuesday 16 June 2026**.

Minutes and Matters Arising

The minutes of the meeting held on 24 March 2026 were approved, subject to amendments correcting speaker attribution and the timing of two Trustees leaving the previous meeting.

Financial Report and 2025 Statutory Accounts

Income to 31 May was 1.94% below budget, mainly because of the timing and level of legacy income, while expenditure was approximately 3% below budget because of staff vacancies. The charity reported a surplus of approximately £43,000 and cash at bank of around £2 million.

Trustees discussed the issues with staff sickness levels and delays in recruitment and ways to improve the presentation of financial reports. Suggestions included a clearer legacy pipeline and a simple dashboard in line with the changes to the Income Generation Report for Finance and Strategic Policy Committee. The Board also agreed that revised charity SORP requirements should inform future reporting on performance and impact.

The auditors reported that the 2025 audit had progressed positively, with no material misstatements identified. The Board unanimously approved the Trustees' Report and financial statements for the year ended 31 December 2025, authorised their signature and submission, and noted the need to strengthen succession planning around senior financial expertise.

Chief Executive's Report

The Board welcomed Epilepsy Action receiving the Prolific North award for Best Not for Profit Campaign and noted the strong performance of the National Epilepsy Week "Missing Memories" campaign. An organisational review following positive staff survey results was also discussed, with training and development identified as an area for further attention.

The funded Wales counselling service has ended, although two counsellors have been retained using core funding to provide a service linked to the peer to peer

support. Trustees encouraged wider sharing of the evaluation report with clinical and professional networks.

A detailed discussion was held on sodium valproate and the potential impact of a forthcoming BBC documentary. Trustees agreed that Epilepsy Action should remain focused on advice, information, support and appropriate signposting, while avoiding positions on clinical or legal matters beyond its expertise. A clear organisational position, scenario planning and briefing for staff, volunteers and peer supporters would be prepared.

Strategic Plan Roadmap 2026

Trustees reviewed key performance indicators, including the measurement of volunteer hours, and noted that the current methodology provides a consistent but potentially conservative measure of volunteer contribution.

The Board received an update on the redesign of services around a triage-based Information and Advice Hub, developments in peer support and webinars, and the impact of vacancies and staff absence on implementation. Welfare benefits support was identified as a significant and growing area of demand. Trustees discussed webinars, toolkits, social prescribing and the possible future need for specialist advisory capacity, recognising the balance between need, organisational risk, cost and sustainability.

Risk Register

The revised risk register, structured around seven strategic sections, was approved. Trustees welcomed the clearer alignment with strategic priorities and asked that movement in risk scores be tracked clearly. The staff risk score would be reviewed in light of current staffing pressures.

National Advisory Panels

The Board received updates from the Wales and Northern Ireland National Advisory Panels. Trustees emphasised the importance of two-way communication, Welsh-language materials and succession planning in Northern Ireland. The resignation of the Northern Ireland Panel Chair was formally recorded.

Honorary Roles

The Board broadly supported proposals to refine the honorary roles so that appointments are purposeful, active and aligned with strategic priorities. The framework would focus on the role descriptions and potential candidates for the President and Vice President roles. It was acknowledged that a royal patronage for the role of Patron was not possible at the present time. Trustees also stressed the importance of clear expectations, diversity, due diligence and continuing reputational monitoring.

September Board Meeting and Trustee Changes

Trustees agreed the two-day format for the September meeting, including strategic discussion, a risk appetite session, review of governance progress against the NCVO recommendations and team-building with the potential new Trustees.

The Chair thanked the Trustees who were stepping down and recognised their contribution to the Board and the charity. The next Board meeting would take place on 15 September 2026 as a hybrid meeting.

Decisions Made

- The minutes of the meeting held on 24 March 2026 were approved, subject to amendments.
- The Trustees' Report and financial statements for the year ended 31 December 2025 were approved, and authority was given for signature and submission.
- The revised risk register was approved.
- The recommendations relating to the Wales and Northern Ireland National Advisory Panels were approved, and the resignation of the Chair was acknowledged.
- The Board gave broad support to the proposed direction for honorary roles, with further updates at the next meeting.
- The proposed format for the September two-day Board meeting was agreed.