Huntington's Disease Association

Annual General Meeting 2025

Minutes of the Annual General Meeting (AGM) of the Huntington's Disease Association held on Saturday 1 November 2025 at Crewe Hall Hotel and Conference Centre.

1. Welcome from the Chair of the Board of Trustees, Professor Hugh Rickards

Hugh Rickards thanked all for attending the 2025 AGM and Huntington's community conference. Hugh outlined the running order for the conference and the format of the business meeting, highlighting that the AGM presents members with an opportunity to hear about the charity's activities and financial position in 2024-25 and to vote on important decisions for the charity, including the adoption of financial accounts, the election of trustees and appointment of auditors.

2. An overview of the charity in 2024/25

Cath Stanley thanked the event's headline sponsors Wave Life Sciences and Alnylam, and Roche who provided a grant, for their support. Cath directed members to their conference packs to learn more about sponsors, exhibitors and the conference programme and timings.

Cath provided members with an update of the work and impact of the charity over the last year, progress made against the charity's five-year strategy and a summary of future plans for the year ahead. Key highlights in 2024/25 included supporting over 5000 people living with or caring for someone with Huntington's; providing training to over 1000 professionals; providing psychological support courses for the Huntington's community; launching our mental health report 'unseen and unheard'; developing our volunteer ambassador scheme further with over 40 opportunities to raise awareness in the press; holding our BBC Lifeline appeal which helped raise vital funds for the charity; and improving the accessibility of the charity with resources available in translated format, the website now fully disability compliant and the charity now recognised as a disability confident employer.

Cath highlighted that in 2025/26 the charity has plans to continue our pursuit for recognised guidelines for Huntington's disease, continue providing advice and support to the Huntington's community, continue to educate and increase awareness of Huntington's disease, hold a parliamentary reception to engage MPs and policy makers and continue to work with research partners to accelerate progress towards and accessibility of effective treatments.

3. Formal opening of the business meeting

Hugh formally opened the business meeting.

4. Minutes

Members were advised that a copy of the minutes of the 2024 Annual General Meeting had been made available on the charity's website and within the event pack.

A proposal that the minutes of the 2024 Annual General Meeting are accepted as an accurate record of proceedings was presented.

Proposed by Hugh Rickards **Seconded by** Nick Heath

Members present at the AGM were asked to provide a show of hands using coloured voting cards to cast their vote. Members who were unable to vote in person were given the opportunity to vote online prior to the meeting, appointing the chair as their proxy. A collation of votes concluded that the resolution was carried.

5. Treasurer's report

The charity's Treasurer, Nick Heath, presented the Accounts for year ending March 2025. It was confirmed that copies of the Summary Accounts were available on the charity website and in hard copy on request to the Huntington's Disease Association. Nick highlighted that the accounts are also uploaded to the Companies House and Charity Commission websites.

Nick explained that trustees hold responsibility for making sure the charity has the money it needs to support business activity which involves the careful management of cash and investments to ensure the charity can continue to operate smoothly and in accordance with plans.

Nick explained the terms 'general funds' as relating to general activities, 'restricted funds' as monies that have been given for specific purposes, and 'designated funds' as general funds that have been committed by the charity for specific purposes, for example to complete particular projects, or keep them running until alternative funding can be sourced.

Nick provided members with an overview of the charity's income and expenditure in the financial year ending 31 March 2025.

Nick confirmed that the charity had a target year end deficit of £300,000 which had aimed to reduce additional reserves held, and whilst expenditure was largely as planned through the year, income came in a little higher than anticipated and the achieved deficit was £191,000.

Nick confirmed that the charity had reviewed and rewritten the reserves policy with the reserves aim set to include six months of running costs and funds to cover the variable arrival of funds, particularly from legacies bequeathed to the charity.

With regard to reserves at year-end, Nick confirmed that the charity had 2.1 million which was made up of a combination of cash, investments and money owed to the charity.

Nick provided members with a summary of the charity's current financial position, explaining that cash flow is currently holding up well and that a decision had been made recently to raise some cash from investments to strengthen the charity's cash position against the volatility of the stock market.

Member, Maureen Graham from Hampshire and Isle of Wight asked if there are any plans for the charity to employ more advisers in other areas as they are such an important facet of the organisation and could the funds to cover this be added to restricted funds. Nick explained that trustees have to balance where the charity's funds are spent and where they are to be recorded in the accounts, with most of the charity's funds held as unrestricted and only those funds that have to be used for a particular purpose held as restricted, such as when a grant specifies it must be spent on a role or project in particular. Nick confirmed that a lot of the charity's unrestricted funds are spent on the running of the advisory service. Nick confirmed that it is a balance trustees have to achieve to both meet the current needs of the community and prepare for the future. Nick gave the example of the charity's recent investment in policy and public affairs which has seen significant progress in raising awareness of Huntington's disease amongst policy and decision makers and is helping to improve care and support. Cath Stanley confirmed that the services management team are currently carrying out a piece of work where they are looking at areas across the country against available advisers and identifying where there is pressure which will help to inform the need for any future roles.

A resolution for the audited accounts for the financial year to be adopted was presented.

Proposed by Nick Heath **Seconded by** Hugh Rickards

Members present at the AGM were asked to provide a show of hands using coloured voting cards to cast their vote. Members who were unable to vote in person were given the opportunity to vote online prior to the meeting, appointing the chair as their proxy. A collation of votes concluded that the resolution was carried.

6. Election of the Executive Council

Hugh provided an explanation of the role of a trustee of the charity's Executive Council and the trustee election process. He explained that the trustees are all volunteers, serve a term of three years and are accountable to various independent boards including the Fundraising Regulator and the Charity Commission.

Hugh informed that David Thomas was standing for re-election and that Dalvir Padda and Akshay Nair were standing for election for the first time.

A resolution for all proposed trustees to be accepted onto the board of trustees was presented.

Proposed by Hugh Rickards **Seconded by** Nicholas Heath

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7. Appointment of auditors

A resolution for DSG Audit Services Ltd, trading as DSG Audit, to be appointed as Auditors was presented.

Proposed by Hugh Rickards **Seconded by** Nicholas Heath

Members present at the AGM were asked to provide a show of hands using coloured voting cards to cast their vote. Members who were unable to vote in person were given the opportunity to vote online prior to the meeting, appointing the chair as their proxy. A collation of votes concluded that the resolution was carried.

8. Conclusion

Hugh formally closed the meeting.

This concluded the business meeting.