



**Huntington's
Disease
Association**

Annual General Meeting 2024

Minutes of the Annual General Meeting (AGM) of the Huntington's Disease Association held on Saturday 26 October 2024 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 first in person AGM and Huntington's community conference since the pandemic had paused in person activities. Hugh highlighted that it was fantastic that the community were able to spend time together connecting with each other and learning more about Huntington's disease and the work and future plans of the charity. Hugh outlined the running order for the conference and the format of the business meeting.

2. An overview of the charity in 2023/24

Cath Stanley thanked the event's headline sponsors Sage Therapeutics and Wave Life Sciences and sponsors uniQure, Roche and Prilenia and informed members that there was further information about sponsors within the event booklet, and on the charity's website.

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 2023/24 included the development of the charity's volunteer ambassador scheme which helped to raise awareness of Huntington's; further development of the youth team which provided more opportunities for children and young people to get support; and the fantastic fundraising endeavours of the community, including a Club Triumph classic car procession, which helped to raise vital funds and awareness of the charity and the condition. Cath highlighted that in the year ahead the charity has plans to strengthen its infrastructure, continue to educate and increase awareness of Huntington's disease and improve support, including the development of a care pathway to help standardise and streamline support.

In relation to the care pathway update, a member present asked if it would be useful for people to share their experiences and stories with the charity to help strengthen evidence and showcase the need for NICE to recognise the charity's care pathway and signpost professionals to it. Cath informed this would be incredibly useful and asked anyone interested in doing so to let their local adviser know.

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 2023 Annual General Meeting had been made available on the charity's website and within the event pack.

A proposal that the minutes of the 2023 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 2024. 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 provided an overview of the financial structure of the organisation, explaining that the charity had employed a Finance Manager, Heidi Hughes during the year, who took over from contracted accountant Sharon Bakewell, and it is part of Heidi's role to oversee book keeping and accounting practices and provide monthly updates on the accounts to the charity's Finance and Audit Committee. Nick explained that the sub committee includes himself as the Committee Chair, four trustee representatives, Finance Manager Heidi Hughes, Chief Executive Cath Stanley and two independent external advisers and they meet on a quarterly basis to review the charity's finances and year end accounts following the annual audit. Updates and recommendations are then communicated to the board of trustees and discussed, alongside current management accounts, during their meetings through the year to ensure the sound governance of the charity.

Nick provided members with an overview of the charity's income and expenditure in the financial year ending 31 March 2024.

NH confirmed that the charity ended the year with strong reserves levels, total income of £2,266,817 and a year-end deficit of -£41,492. NH confirmed that the charity had intended to reach a deficit target of -£300,000 by the end of the year through increased expenditure on key projects and roles in order spend down excess reserve levels, however,

due to some large legacy donations received and the incredible fundraising efforts of the community, the deficit was less than planned at £41,492.

Nick confirmed that the charity is currently holding a sufficient level of cash in the bank and funds in investments that can be easily accessed to ensure there are funds to cover monthly staff wage bill which currently stands at £160,000 per month.

With regard to expenditure, Nick confirmed that the charity had spent £2,078,792 to run charitable activities during the year with the main cost being those associated with employing the staff team. Nick highlighted that the charity's expenditure in relation to fundraising, both on activities and staff, is low in comparison to other charities of a similar size and therefore presents an excellent return on investment.

Nick explained to members that unrestricted funds are funds that the charity can use for any purpose relating to charity activity, whereas restricted funds are those that have been given to the charity for a specific purpose, such as research. Nick confirmed that at year-end there was £61,979 restricted to research and that it would be a target for the year ahead for the Board of trustees to discuss how best to utilise these funds. Nick went on to explain that designated funds within the accounts are those that have been ringfenced by the charity for branch activity, or for a particular project or activity. Nick highlighted that the youth development project is included within designated funds and is funded alongside National Lottery funding.

With regard to the current financial year, NH provided an update of the charity's finances to date. Nick confirmed that after the first six months of activity, accounts are showing a deficit of -£200,000 which means that the charity is on track to achieve the target deficit of -£300,000.

Nick provided members with the opportunity to ask any questions they had about the accounts.

Heather Thomas asked if some of the funding could be used to increase the number of local advisers. Nick explained that staff numbers and requirements are under constant review and recruitment is prioritised in accordance with current needs and having sufficient funds available to sustain the ongoing expenditure of a new role.

Barry Mitchell asked what the charity's reserve target is. Nick responded that the charity aims to have 1.4 million in reserves, which provides six months of running costs, and reserves are split between cash and investments. Barry went on to ask what the charity had spent excess reserve levels on, and Nick confirmed that projects and events had been invested in and both adviser and youth worker numbers had increased, along with some essential roles to support the infrastructure as the charity grows and develops.

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 he and two other existing trustees, Nick Heath and Steve Duckett were standing for re-election and that Sharon Bakewell was 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.