



Annual General Meeting 2023

Minutes of the Annual General Meeting (AGM) of the Huntington's Disease Association held via Zoom on Saturday 4 November 2023. The meeting was conducted virtually.

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

Hugh Rickards thanked all for attending the virtual AGM and explained the decision to hold it virtually due to a last moment booking cancellation from the planned venue. Hugh informed those in attendance that online polls would take place at the end of the event to find out attendee opinions on the conference. Hugh informed that he hopes that the next conference will be in person again giving the community opportunity to connect with each other. Hugh outlined the running order for the conference and the format of the business meeting. There were 104 people in attendance for the Annual General Meeting.

2. An overview of the charity in 2022/23

Cath Stanley thanked uniQure, Sage Therapeutics and Elysium Healthcare who had sponsored the event and informed members that there was further information about sponsors on the charity's website.

Cath provided members with an update of the work and impact of the charity over the last year and a summary of the charity's future plans. Cath informed that April 2023 saw the charity begin its new strategy, structured around five goals, that will underpin the work and focus of the charity over the next five years.

Cath Stanley introduced Cathy Lyon, a trustee for the Huntington's Disease Association who has recently been given the opportunity to do a PHD in end of life care and Huntington's disease at Leicester University. Cathy gave attendees a summary of her background, which included managing Stanley House Care Home and working as an end of life doula. Cathy informed that she has supported many people affected by Huntington's over the years which has led her to wanting to craft better service and improvements in end of life care. Through her experience and research, Cathy informed that she has found articles and research about end of life and advance decisions to be confusing and often conflicting and she wants to use her experience, and those of the community to create a guidance strategy to help people as they navigate the future. Cathy asked those attending to review the charity's website or contact her for further information on how they can get involved.

3. Formal opening of the business meeting

Hugh formally open the business meeting.

4. Minutes

Voting members were advised that a copy of the minutes of the 2022 Annual General Meeting had been made available on the charity's website.

A proposal that the minutes of the 2022 Annual General Meeting are accepted as an accurate record of proceedings was presented.

Proposed by Hayley Hubberstey

Seconded by Sian Barker

Due to the virtual nature of the AGM, members were given the opportunity to vote to accept the minutes prior to the meeting, appointing the Chair as their proxy. A collation of the votes revealed that all who voted were in favour and the minutes were accepted.

5. Treasurer's report

The charity's Treasurer, Nick Heath, presented the Accounts for year ending March 2023. 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 would also shortly be uploaded to the Company's house and Charity Commission's respective websites.

Nick provided members with an overview of the charity's income and expenditure in the financial year ending 31 March 2023.

Nick informed that income fell slightly from £2.1 million in 2021/22 down to just over £2 million during 2022/23. It was highlighted that being in this income bracket makes the Huntington's Disease Association a medium sized charity compared to the smaller charity it has been in the past.

Nick informed the performance of different income streams altered a little during the year but overall income was maintained. It was highlighted by Nick that income from legacies had reduced but other sources of income such as Jingle Jam funding of £240,000 for the youth engagement service and individual donations had boosted income during the year.

Nick informed that unrestricted funds were reduced during the year and restricted funds were increased. 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 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.

It was confirmed by Nick that the value of the charity's investments had reduced in the year due to a downturn in investment markets, however Nick explained that the charity has a number of long-term investments and therefore it is not a concern if the value drops in the interim as they are a means of the charity building funds to use in the future. Nick confirmed it is the responsibility of the Executive Council and delegated responsibility of the Finance Committee to ensure that the charity's assets are appropriately managed.

It was confirmed by Nick that it is the charity's aim to hold £1 million in reserves and that trustees had budgeted for a loss of between £200,000 to £300,000 in order to use reserves that had been boosted substantially during the pandemic following an increase in income and a reduced capacity to spend due to constraints at the time. However, total expenditure during the financial year was £2.034 million which meant the year ended with a much smaller deficit than planned due to incredible fundraising initiatives and generous donations from the Huntington's community during the year.

It was confirmed by Nick that salary expenditure increased to £1 million which evidences the charity's development with 41 staff in 2022/23 compared to 33 staff in 2021/22. Nick confirmed that salary costs made up over half of the charity's total expenditure, with remaining expenditure relating to the cost to deliver the charity's services ranging from advice and support, to communications and policy and public affairs engagement. It was confirmed by Nick that the charity's overall expenditure increased from last year.

Nick provided members with an overview of the charity's current financial position, informing that the charity is budgeting for a deficit in financial year 2023/24 to reduce reserve levels to the target amount and use additional funds to develop the charity in line with its charitable objects going forward. It was confirmed by Nick that as at the end of September 2023, there was a deficit of just under £100,000, which was under the budgeted deficit. However, in October the charity received notification of legacies in excess of £350,000 which means it is unlikely the charity will achieve its deficit target. Nick reaffirmed that this is positive as it provides the charity with more funds to continue to grow and expand and support the Huntington's community further in accordance with the ambitious plans within the charity's five-year strategy.

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

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

Proposed by Nick Heath

Seconded by Hugh Rickards

Members were given the opportunity to vote on the resolution prior to the meeting, appointing the Chair as their proxy. A collation of the votes revealed a majority in favour and 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 three existing trustees, Nayana Lahiri, Sian Barker and Cathy Lyon were standing for re-election.

Hugh explained that trustee, Bridget Waters, had decided to stand down after election paperwork had been circulated to members and confirmed that she wouldn't be standing for a new term of office. Hugh thanked Bridget for her three years of service on the board and her invaluable insights and guidance.

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

Proposed by Hugh Rickards

Seconded by Nicholas Heath

Members were given the opportunity to vote on the resolution prior to the meeting, appointing the Chair as their proxy. A collation of the votes revealed a majority in favour and the resolution was carried.

7. Appointment of auditors

A resolution for DSG Chartered Accountants to be appointed as Auditors was presented.

Proposed by Hugh Rickards

Seconded by Nicholas Heath

Members were given the opportunity to vote on the resolution prior to the meeting, appointing the Chair as their proxy. A collation of the votes revealed a majority in favour and the resolution was carried.

8. Conclusion

Hugh formally closed the meeting.

This concluded the business meeting.