



Annual General Meeting 2022

Minutes of the Annual General Meeting (AGM) of the Huntington's Disease Association held via Zoom on Saturday 15 October 2022. 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 COVID-19 uncertainty earlier in the year at the time when a venue needed to be confirmed. Hugh informed those in attendance that online polls would take place throughout the meeting to find out what members and the Huntington's community want from future conferences. 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 67 people in attendance on the day.

2. An overview of the charity in 2021/22

Cath Stanley provided members with an update of the work and impact of the charity over the last year.

3. Future plans

Hugh Rickards provided members with an overview of the charity's future plans. Hugh informed that the charity is now planning its next five-year strategy and, through consultation with the Huntington's community, has identified key areas of focus to best support people affected by Huntington's disease. It was confirmed that the next steps will be to model these into specific goals that will underpin the strategy and work of the charity for the next five years.

4. Formal opening of the business meeting

Hugh formally open the business meeting.

5. Minutes

Voting members were advised that a copy of the minutes of the 2021 Annual General Meeting had been made available on the charity's website.

A proposal that the minutes of the 2021 Annual General Meeting are accepted as an accurate record of proceedings was presented.

Proposed by Hugh Rickards

Seconded by Nick Heath

Due to the virtual nature of the AGM, voting 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.

6. Treasurer's report

The charity's Treasurer, Nick Heath presented the Accounts for year ending March 2022. 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 informed that the charity's income was at £2.1 million in financial year 2021/22, compared to £1.8 million the year before. Nick informed that income from donations stayed at a similar level to 2020/21, but that there had been a significant increase in money received in legacies. With regards to expenditure, Nick confirmed that spending had increased but only slightly compared to the previous year, largely due to a delay in activities resuming due to the pandemic and also due to a number of staff leaving through retirement in the year which reduced staff costs.

It was confirmed by Nick that the accounts showed, as at 31 March 2021, total assets of £2.48 million compared to £1.74 million in 2020/21 which was a significant increase. Nick informed that it was decided by trustees to invest £500,000 of these funds during the financial year for longer-term benefit. NH informed that the charity had current assets of over £600,000, principally from legacies promised to the charity and over £900,000 in cash, putting the Huntington's Disease Association in a strong position to withhold any downturn in income or any financial impact owing to the wider economic crisis currently facing the UK.

NH highlighted that £184,000 was held for special projects, £65,000 was held in branch accounts and £207,000 was designated in the accounts for the development of the charity's Youth Engagement service, with plans to also submit a bid to the National Lottery to further support children and young people in the Huntington's community.

NH informed that at year-end the charity had £1.9 million of undesignated reserves with a target of retaining £1 million to protect charity activities and operations in the event of a financial downturn. It was confirmed that the charity has now begun to spend down the surplus, projecting a £300,000 deficit for the next three years, using this money for the benefit of the charity's objects. In May 2021, salary costs were £75,000, increasing to £95,000 by May 2022, in September 2022 costs rose to £107,000 and salary costs are projected to reach £120,000 by the end of 2022 as more staff join to better support the Huntington's community and increase the reach and influence of the charity.

It was confirmed by Nick that the charity remains in a strong financial position and that that the board of trustees and relevant sub committees, including the Finance and Audit Committee, will continue to monitor and discuss the charity's finances at meetings throughout the year ahead.

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

It was asked by a member in attendance if money raised for the charity could be used to financially help Huntington's families, or perhaps to purchase a holiday home that families affected by the condition could use for free or at a reduced cost. Chief Executive,

Cath Stanley, informed that the charity has a welfare grant scheme to financially support families affected by Huntington's. With the support of the local Huntington's adviser, or another relevant health or social care professional, families can apply for a grant to improve their quality of life. This could be to fund a product or an experience, such as a holiday. Nick also highlighted that the Victoria Convalescent Trust has contacts with holiday homes and further information can be provided on this via local Specialist Huntington's Disease Advisers. As a result of the current cost of living crisis facing the UK, Cath informed that the charity has developed a cost of living hub, housed on the charity's website, which is regularly updated with information about other organisations that can offer financial support through grants.

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

Proposed by Nick Heath

Seconded by Hugh Rickards

Voting 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. 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 one existing trustee George El-Nimr was standing for re-election and three new people, David Thomas, Hayley Hubberstey and Chloe Holmes, were also standing for election.

Hugh highlighted that trustees Liz Howard and Alan Fryer had decided not to stand for re-election at the end of their three-year term and thanks were expressed to them for their contribution to the board and their many years of service to the Huntington's Disease Association.

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

Proposed by Hugh Rickards

Seconded by Nicholas Heath

Due to COVID-19 social distancing restrictions, voting 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. Appointment of auditors

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

Proposed by Hugh Rickards

Seconded by Nicholas Heath

Due to COVID-19 social distancing restrictions, voting 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.

9. Conclusion

Hugh formally closed the meeting.

This concluded the business meeting.