

HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND

(Private Limited Company by guarantee without share capital use of 'Limited' exemption)

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2024

Trustees' Annual Report (Incorporating the Director's Report) Continued...

The Trustees present their annual report together with the financial statements of the company for the year ended 31 March 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the company's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practices applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2019)

Structure, Governance and Trustees'

Huntington's Disease Association Northern Ireland, which is registered as a charity with the Charity Commission for Northern Ireland, registration number NI104676 is also referred to as HDANI and has the objective of undertaking charitable activities for the benefit of the inhabitants of Northern Ireland.

Achievements and Performance

This past year has been one marked by great ambition and hope. For the first time in the charities' history, we have had five full-time staff allowing us to reach more people than ever before. We didn't arrive at this point by accident or without significant help. Over the past ten years, we have tentatively and persistently gathered evidence, compiled information, studied best practice models and learned from the people we have sought to help. We have devised a service model befitting of the amazing HD community in Northern Ireland, one staffed by people with tremendous skills, willingness to learn and the training and support needed to deliver vital services.

This year, we set out our ambitions and objectives in a five-year strategy. We identified what was needed by our community and plotted a course which would make a real difference to people's lives. The trouble as always is how to finance this plan. We were in year three of a three-year project and although our reserves and bank balance was healthy we were spending more than we were bringing in. We had expanded our services to a point which was clearly justified but difficult to sustain without significant support. We were incredibly grateful for the individual giving and community donations we received but to make a long-term impact we needed more. We identified a range of potential funders but found the criteria increasingly limited and the competition for funds at an unprecedented high. We devised two service models- a bells and whistles Plan A with our full complement of staff and services and a Plan B, stripped-down staffing and service delivery. We brought in professional support to assist the CEO with identifying funders and project cost projections and made applications.

Our Chief Executive has also been busy networking, awareness raising and engaging in lobbying events and activities throughout the year. Progress on key policy areas such as increased statutory nursing provision, the creation of a HD strategy and care pathways continued to progress albeit slower than we would have hoped. That said, our Chief Executive will persevere and continue to keep HD on the agenda of policymakers in the hope of service improvements in the years ahead to ensure that regardless of where a patient lives, they have access to expertise and timely support.

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Achievements and Performance Continued

HDANI was happy to partner with Glenstall IT, who host our database, to enable them to receive funding from the Q Foundation to work on their Patient Experience Mapping project which will help to raise awareness and empower patients living with rare and chronic conditions.

From a family support perspective, our work has continued and expanded, with four full-time family support staff allowing for greatly increased engagement with service users. A significant amount of staff time has been concentrated on advocating on behalf of families to access the services, clinics and statutory support with a steadily increased demand for our services. We have enjoyed a busy year with support groups, social gatherings, youth events and an overnight social and wellbeing event aimed at recharging and reconnecting. At the time of writing, we have been preparing for an annual social and wellbeing event while staff continue to visit service users in their homes to produce and update family support plans.

As a registered charity with the NI Charity Commission we continue to develop and revise policies to ensure best practice. In the year ahead we will continue to professionalise our practices and ensure that our work is above reproach and in doing so consider succession planning to augment the skill set of our committed board. We will continue to work in partnership with other HD organisations across the UK, Ireland and globally as well as on a local level on the broader issues of rare disease and access to drugs. We also look forward to participating in local lobbying opportunities via membership of NICVA, Co3, NIRDP, Patient Client Council, Disability Action, NI Neurological Conditions Alliance, NI Long Term Conditions Alliance, NI Carers Coalition and relevant All Party Groups.

We would like to thank our staff and trustees for their commitment throughout the year and as always, the Huntington's disease community for entrusting us with their care. A special thanks to everyone who showed confidence in our organisation by donating, fundraising, or awarding grants to allow us to continue and to expand our work.

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Going Concern

After making appropriate enquiries, the trustees have a reasonable expectation that the company has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements. Further details regarding the adoption of the going concern basis can be found in the Accounting Policies.

Financial Review

The results for the year ended 31 March 2024 are set out on pages 8 and 9 of the financial statements.

The total income for the year ended 31 March 2024 amounted to £150,352 (2023: £107,266).

The total expenditure was £185,661 (2023: £185,983).

The Trustees consider that the unrestricted funds of the charity is sufficient and adequate to fulfil their obligations. The charity held £117,699 in unrestricted reserves at the year end (2023: £153,007).

Reserves Policy

The trustees have reviewed and considered the unrestricted reserves of the charity and decided to allocate of the unrestricted reserves to the following areas:

Youth Fund	2,008	
Reserves Held	115,691	6 months running costs and wind up costs
Family Support Project	-	
General Fund	-	
	<u>117,699</u>	

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Responsibilities of Management Trustees

The committee are responsible for preparing the financial statements in accordance with applicable law and regulations.

Company law requires the directors to prepare financial statements for each financial year. Under that law, the directors have elected to prepare the financial statements in accordance with the United Kingdom Generally Accepted Accounting Practice. Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the trust and of the surplus or deficit of the trust for that period. In preparing these financial statements, the directors are required to:

- Select suitable accounting policies and then apply them consistently
- make judgements and estimates that are responsible and prudent
- prepare the financial statements on the going concern basis unless it is inappropriate to

The directors are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. The directors are also responsible for safeguarding the assets of the charity and hence to take reasonable steps to prevent and detect fraud and other irregularities.

Disclosures of Information to Independent Examiners

To the knowledge and belief of the board there is no relevant information of which the company's independent examiners are not aware. The board have taken all the necessary steps of which they are aware, provided relevant information and established that the company's independent examiners are aware of the information.

Tax Status

Under Section 505 (i)(a) and (c) of the Income and Corporation Taxes Act 1988, HDANI is entitled to the charity tax exemption.

This report has been prepared in accordance with the provisions applicable to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

Signed on behalf of the Board



Raymond Crilly
Treasurer

16/10/2024

Date: