

# HUNTINGTONS DISEASE ASSOCIATION

England & Wales · Charity number 296453

## Details

---

**Other names** THE ASSOCIATION TO COMBAT HUNTINGTON'S CHOREA

**Status** Registered

**Legal form** Charitable company

**Company number** [02021975](#)

**Registered** 1987-03-20

**Register** [View on the Charity Commission register](#)

## Contact

---

**Address** Suite 24  
The Liverpool Science Park  
Innovation Centre 1  
131 Mount Pleasant  
Liverpool  
L3 5TF

**Phone** 01513315444

**Email** [info@hda.org.uk](mailto:info@hda.org.uk)

**Website** [www.hda.org.uk](http://www.hda.org.uk)

## Activities

---

**Objects:** THE RELIEF AND TREATMENT OF THOSE SUFFERING FROM OR BELIEVED TO BE SUFFERING FROM HUNTINGTON'S DISEASE AND TO PROVIDE FINANCIAL SUPPORT FOR BOTH SUCH PERSONS AND THEIR FAMILIES IN NEED AND FOR RESEARCH AND THE DISSEMINATION OF THE RESULTS OF SUCH RESEARCH FOR THE PUBLIC BENEFIT INTO THE CAUSE AND POSSIBLE CURES WHETHER PARTIAL OR COMPLETE AND POSSIBLE PREVENTION OF THE SAID DISEASE.

**Activities:** Relief and treatment of those suffering from or believed to be suffering from Huntington's Disease and to provide support to them and their families. The Association also sponsors research and is involved in disseminating the results of research.

## Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability, The Prevention Or Relief Of Poverty
- **Who:** Children/young People, Elderly/old People, People With Disabilities, People Of A Particular Ethnic Or Racial Origin, Other Charities Or Voluntary Bodies, Other Defined Groups

## Geography

- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£2,531,843	£2,716,817	£2,150,787	51
2024-03-31	£2,266,817	£2,372,725	£2,342,631	45
2023-03-31	£2,003,578	£2,034,566	£2,384,123	41
2022-03-31	£2,166,325	£1,419,521	£2,488,774	33
2021-03-31	£1,880,169	£1,301,314	£1,745,907	33

## Trustees

Name	Role	Appointed
<b>Prof Hugh Rickards</b>	Chair	2015-07-09
Catherine Lyon		2017-10-14
Dalvir Padda		2025-11-01
David Rhys Thomas		2022-10-15
Dr Akshay Nair		2025-11-01
Dr Nayana Swales		2020-11-18
NICHOLAS HEATH		
Sharon Bakewell		2024-10-26
Sian Baker		2017-10-14
Stephen Duckett		2018-10-13

**HUNTINGTONS DISEASE ASSOCIATION**

England & Wales - Charity number 296453

---

# Accounts

---



**Huntington's  
Disease  
Association**

# **Annual report and financial statements**

For the year ended  
31 March 2025

---

*Inspired by our community*

# Contents

---

**Patrons**  
Tony Hadley  
George Rainsford

**Trustees**  
Professor H Rickards (Chair)  
Ms S Barker (Vice Chair)  
Mr N M Heath (Hon Treasurer)  
Ms C K Holmes  
Mr D R Thomas  
Ms H Hubberstey  
Dr N Swales  
Mr S Duckett  
Ms C Lyon  
Dr G El-Nimr  
Ms S Bakewell (apptd. 26 Oct 2024)

**Chief Executive**  
Mrs C Stanley BEM

**Charity number**  
296453

**Company number**  
02021975

**Registered office**  
Liverpool Science Park  
Innovation Centre 1  
131 Mount Pleasant  
Liverpool  
L3 5TF

**Auditor**  
DSG Audit Services Limited  
Castle Chambers  
43 Castle Street  
Liverpool  
L2 9TL

**Bankers**  
National Westminster Bank plc  
66/68 St John's Road  
Battersea  
London  
SW11 1PB

4	Welcome from our Chair and Chief Executive	74	Reserves policy
6	Trustees' report	76	Future plans
8	Our vision, our mission, our values	80	Structure, governance and management
10	Our strategy	83	Statement of trustees' responsibilities
12	Our impact	84	Independent auditor's report
14	Our year in numbers	89	Statement of financial activities
16	Goal 1	90	Balance sheet
28	Goal 2	91	Statement of cash flows
38	Goal 3	92	Notes to the financial statements
50	Goal 4	110	Acknowledgements
60	Goal 5		
73	Financial review		

# Welcome from our Chair and Chief Executive

First of all, a huge thank you to all the people in our incredible Huntington's community who have supported us this year. We are so grateful for everything you do to help us achieve our mission.

Thanks to your support, we are able to work every day to help people affected by Huntington's disease live life to their full potential.

Our Specialist Huntington's Disease Advisers continue to provide invaluable support and advice to families affected by Huntington's disease at every stage of their journey.

HDYES, our Youth Engagement Service, has gone from strength to strength, helping to build resilience in the children and young people who grow up in families with Huntington's disease.

We've continued to develop our varied education and training offer, and developed our Ambassador scheme.

This year, we were delighted to see friends old and new at our first in person Huntington's Community Conference and AGM since 2019. It was a memorable weekend at a spectacular new venue.

We have an amazing number of volunteers, and we can't thank them enough for all they have contributed this year. They are our biggest advocates and have helped us reach more people and share the voices of people with Huntington's disease.

Against the backdrop of sharp cuts in health and social care, we continue to work with our partner organisations to ensure the voices of people with Huntington's disease are heard. Through our broadening policy and public affairs work, we're fighting against disability reforms to highlight the difficulties the families in our community are facing. We're also working with umbrella bodies, such as the Neurological Alliance, to raise awareness of the needs of people with a diagnosis of Huntington's disease.

Although there is not yet a cure for Huntington's disease, it's an exciting time for research into the condition. We now have a realistic hope of seeing some form of effective treatment that might delay the onset of symptoms. Even five years ago, that wouldn't have seemed possible.

Every day, we draw inspiration from our brilliant community of families, supporters, volunteers, campaigners, partners and professionals. Together, we have the power to build a better life for people affected by Huntington's disease.



**Prof. Hugh Rickards**  
Chair



**Cath Stanley**  
Chief Executive

# Trustees' report

*(including Directors' report) for the year ended 31 March 2025*

The trustees present their annual report and financial statements for the year ended 31 March 2025.

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 charity's Memorandum and Articles of Association, the Companies Act 2006 and *Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)* (effective 1 January 2019).

## Charity objects

The Huntington's Disease Association's objects are the relief and treatment of those suffering from or believed to be suffering from Huntington's disease and to provide financial support for such persons and their families in need and for research and the dissemination of the results of such research for the public benefit into the cause and possible cures, whether partial or complete, and possible prevention of the said disease.

## About the Huntington's Disease Association

We are the only national charity that supports people affected by this rare disease across England and Wales.

Huntington's is a profoundly disabling neurological disease caused by a faulty gene. If one of your parents has the disease, you have a 50% chance of inheriting it. There is no cure and the disease is terminal. People usually start showing symptoms between the ages of 30 and 50. Over time, the person with Huntington's loses their ability to walk, talk, think clearly, swallow and control their movements. Eventually, the person will need complete care.

Established in 1971 as a peer support group and registered in 1987, we have worked with and for the Huntington's community for over 50 years and remain community-led. We have a membership of over 5,000 people, including people living with Huntington's disease, family members, and health and social care professionals. We have 14 local branches and 20 support groups led by volunteers.



# Our vision, mission and values

## Our vision

Together we will build a better life for anyone affected by Huntington's disease.

## Our mission

To enable everyone affected by Huntington's disease to live life to their full potential by:

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community by working together
- Influencing decision makers to tackle discrimination and secure equity of access to services

## Our values

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive
- Inspirational

## Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.



# Our strategy

This is the second year of delivering our Strategy 2023-27. The strategy was developed with and for our community. It sets out what we want to achieve over five years and has five goals:

*Over the following pages, we report on what we've achieved under each goal this year.*

1.

We will ensure that everyone affected by Huntington's disease gets the care and support they need.

2.

We will help make each day with Huntington's disease the best possible day.

3.

We will make sure the voices of people affected by Huntington's disease are heard and at the heart of everything we do.

4.

We will not rest until everyone with Huntington's disease has access to treatments.

5.

We will be a resilient charity.

# Our impact

In the face of a profoundly disabling and incurable disease, we help people to make progress against four key outcomes. This year, our evaluation data showed that, because of our support:

96%

of 924 respondents have a better knowledge and understanding of the disease

86%

of 223 respondents feel less isolated

90%

of 643 respondents feel more resilient and better able to cope with challenges

90%

of 740 respondents feel more prepared for the future

We evaluate our impact through polls, surveys, feedback and case studies.

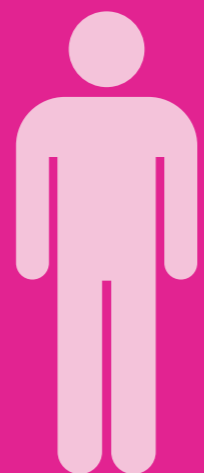
This year, we received one formal complaint and recorded two accidents. The complaint was investigated, and appropriate action was taken in response. The two accidents were both fully investigated and no serious injuries were reported.



# Our year in numbers

# 5,081

people supported through our Advisory service and Youth service.



Including:

**2,385**  
people with the disease

**734**  
people at risk of having the disease

**1,065**  
carers

We welcomed **1,178** new people to our support this year

**6** online courses for our community with...

**42** attendances

**19** webinars with...

**470** attendances

Webinar recordings viewed **3,179** times on YouTube



**53**  
HD Voice members

**17**  
HD Youth Voice members

**44**  
Ambassadors



**45**  
welfare grant applications

**42**  
welfare grants awarded with a total value of **£14,296**



**14**  
branches

**20**  
support groups



**2** Certificated courses attended by **116** professionals

**1** Mental Health study day attended by **72** professionals

**7** HD Champions courses attended by **43** professionals

**105** training and information sessions attended by **1,086** professionals

**12** drop-in sessions attended by **691** professionals



**10** care homes now accredited through our Quality Assured scheme

**3** care homes retained their accreditation



**96%** of **924** respondents have a better knowledge and understanding of the disease

**86%** of **223** respondents feel less isolated

**90%** of **643** respondents feel more resilient and better able to cope with challenges

**90%** of **740** respondents feel more prepared for the future



# Goal 1

---

## Our ambitions under this goal are:

- Anyone affected by Huntington's disease has the best support and is aware of the Huntington's Disease Association
- Everyone can access high quality care, including a multi-disciplinary team
- People are able to make an informed choice about genetic testing
- People know what advice and support are available

## This year, we:

- Ensured the best support through our Specialist Huntington's Disease Advisory service
- Helped children and young people to thrive
- Championed the importance of high quality care and support
- Shared real-life stories and professional insights into genetic testing
- Raised awareness of the advice and support we offer

*This year, we supported 5,081 people through our Advisory service and Youth Engagement service. This included...*

- 2,385 people with the disease
- 734 people at risk of having the disease
- 1,065 carers
- We welcomed 1,178 new people to our support this year

### **We ensured the best support through our Specialist Huntington's Disease Advisory service**

Our Specialist Huntington's Disease Advisers work with anyone affected by Huntington's disease. This is our core service and it is in high demand. Our team of Specialist Advisers support people across all regions of England and Wales by:

- Providing practical advice and emotional support
- Delivering our telephone helpline service
- Communicating with medical, health and social care professionals
- Working with specialist Huntington's disease clinics
- Advocating for the person with Huntington's disease to get the best support
- Educating medical, health and social care professionals to support better diagnosis and ongoing care
- Organising and attending local support networks and carers' group meetings
- Providing a listening ear
- Providing information resources on symptoms and how to manage them
- Connecting younger family members with HDYES - our Youth Engagement Service
- Giving support for sensitive end-of-life care

*"The Adviser has a caring, practical approach and this always leaves me feeling encouraged that I am not alone in this journey. She has helped me so much and has been instrumental in helping me to get medical support. I really don't know where I would be now without her."*

Family member supported by one of our Specialist Advisers

## Camilla's Story...

### **Finding support from our Specialist Advisers**

*"For me, the best thing about the Huntington's Disease Association Advisers is knowing you're not on your own," says Camilla, who has used our Specialist Huntington's Disease Advisory service. She added: "Huntington's is a rare genetic disease and no one's really heard of it, unless they've got it in their family. You can really feel alone. So, it's been amazing to bounce ideas off the Specialist Advisers and to know I'm supported."*

Camilla received a diagnosis of Huntington's in 2022, but only discovered the disease ran in her family in 2017. Her great auntie Lonnie had become reclusive and was no longer caring for herself properly. Camilla battled with doctors and social services to get Lonnie the right support and finally an Approved Mental Health Professional gave a diagnosis of four possible conditions. One was Huntington's disease.

*"At first, I thought Lonnie couldn't have Huntington's because there was no family history of the disease," says Camilla. "But when I looked it up, I discovered symptoms that matched her behaviour. And eventually, Lonnie did receive a diagnosis of Huntington's disease."*

Camilla was devastated by the news. *"I freaked myself out," she says. "My kids were only four and six at the time. If I'd known there was Huntington's in my family, I'd never have had children without being tested."*

Camilla contacted the Huntington's Disease Association and was put in touch with Charles, one of our Specialist Advisers. *"He was my saviour," says Camilla. Charles helped her find an appropriate care home for Lonnie and even delivered training on Huntington's to the care home staff.*

Supported by Charles, Camilla decided to talk openly to her children about the disease. *"Since they were young, they've heard about Huntington's, so it's not a scary word for them. And now they're teenagers, both my kids engage with Jack, the local Huntington's Disease Association Youth Worker. It helps them to know there are other young people in the same position."*

Following Charles' retirement, Justine took over as our Specialist Adviser for the South West. *"Justine is lovely," says Camilla. "She's spoken to me over the phone and helped me set up an event for families with Huntington's. I've also attended coffee meetings locally and on Zoom."*

Camilla is passionate about raising awareness of Huntington's and has taken part in the #HDHike, walking 100 miles in a month to fundraise for us. She told us: *"I want everyone who has Huntington's in their family to have the same support that I've had. It's a hard and lonely fight when you're trying to deal with it on your own. Having the Huntington's Disease Association team on your side makes such a difference."*



*"It's a hard and lonely fight when you're trying to deal with it on your own. Having the Huntington's Disease Association team on your side makes such a difference."*



### We helped children and young people to thrive

The data below relating to HDYES covers Year two of the project, with data captured from 1 June 2024 to 30 April 2025. This reflects the project’s reporting cycle to The National Lottery Community Fund and includes activity and support delivered during this specific period, rather than a full financial year.

With funding from The National Lottery Community Fund, HDYES, our Youth Engagement Service, continued to flourish. Through HDYES, we support children and young people aged 8-25 who are impacted by Huntington’s disease. We also support parents and guardians, as well as helping professionals to understand Huntington’s disease so that they can provide better support to children and young people who are affected.

Our aim is to provide intensive, direct support to 300 children and young people over three years. This is our second year of delivery and so far, 292 children and young people have received direct support from a Youth Worker and 109 have attended an event. 40 children and young people aged 8–25 were new to the service this year.

We aim to support 150 parents and guardians and 200 professionals over three years. So far, we have directly supported 78 parents and guardians and reached 162 overall. We have supported 177 professionals since the start of the project.

In Year two of the project, our team of Youth Workers delivered 663 support sessions for 240 children and young people. Since the start of the project, we have delivered 1,219 support sessions for 292 children and young people.

In Year Two of the project, we delivered 17 in person events based on what children and young people told us they wanted, including Go Ape, escape rooms, Monopoly Lifesized and a Bake Off day. We also delivered six virtual events. In total, we had 220 attendances by 84 unique children and young people at events this year. Since the start of the project, we have delivered 25 in person and seven virtual events with a total 341 attendances by 109 unique children and young people. For some children and young people, attendance at an event is their first point of contact with the service.

Our ambitious and inspiring HD Youth Voice group recruited eight new members this year and retained nine. We now have 17 inspiring young leaders aged 16 – 27 who are helping to shape HDYES. In Year two of the project, HD Youth Voice co-produced our refreshed guides for children and teenagers and the new HD Passport document. We’ve also co-produced social media content, including our first Instagram Live, blogs and new website content for children and young people.

Our *You are not alone* film, which HD Youth Voice co-produced last year, was a Finalist in the Smiley Charity Film Awards. The film has now been viewed more than 2,400 times on YouTube.

We continued to work with consultants, Trust Impact, to capture longitudinal change for children and young people who have experienced ongoing support from a Youth Worker. In year one of the project, we identified positive signs of early change. In year two of the project, this trend continued with patterns of positive change seen across all key outcomes in line with the support received from a Youth Worker. Knowledge appeared to be the area of quickest and greatest change, while resilience appears a more complex area to affect - although users still experienced improvements. Connection to others and future preparedness both showed greatest, or more consistent, change in the medium-long term (20+ sessions with a Youth Worker).

***“Chatting to people my own age reassured me and made me feel less alone.”***

Child who attended our HDYES camp

# Survey responses

Of 119 children and young people who responded to a survey this year:

**85%** Respondents agreed / strongly agreed that they have a better understanding of Huntington's disease.

**73%** Respondents agreed / strongly agreed that they are less isolated.

**72%** Respondents agreed / strongly agreed that they are more resilient.

We only start to deliver content around preparing for the future from the age of 13 onwards. Of 74 children and young people aged 13 or above:

**73%** Agreed / strongly agreed that they are more prepared for the future.

Of 38 parents / guardians who responded to a survey this year:

**61%** Agreed / strongly agreed that they have a better understanding of Huntington's disease. This is below our target of 70%. However, some respondents already had significant knowledge and lived experience of the disease before engaging with HDYES.

**87%** Agreed / strongly agreed that they can better support a child / young person who is affected by Huntington's disease.

**62%** Agreed / strongly agreed that they are less isolated.

**58%** Agreed / strongly agreed that they are more resilient.

**79%** Agreed / strongly agreed that they are more prepared for the future.

Of 22 professionals who responded to a survey this year:

**100%** Agreed / strongly agreed that they have a better understanding of Huntington's disease.

**95%** Agreed / strongly agreed that they can better support a child or young person who is affected by Huntington's disease.

### We championed the importance of high quality care and support

This year, we have continued to advocate for the importance of care homes being accredited for the specialist support of people with Huntington's disease.

Our Quality Assured programme sets the standard for excellence in the care of people with Huntington's disease. It recognises care homes that demonstrate the right behaviours, culture and specialist knowledge to support people living with Huntington's disease. Being Quality Assured not only highlights a home's commitment to high quality, person-centred care, it also builds trust with families and professionals looking for specialist support.

We currently have ten care homes across England and Wales that are accredited through our Quality Assured programme. The most recent to be accredited is Maypole Grove in Birmingham.

We have carried on fighting for all people with Huntington's disease to access the care and support they need from mental health services.

In early 2025, we coordinated a letter from 16 consultant neuropsychiatrists, which was submitted as written evidence to the Health and Social Care Committee's inquiry into community mental health services. We're delighted that so many leading mental health professionals joined our call to help improve care for people with Huntington's disease.

Their letter highlighted the barriers faced by people with Huntington's disease when attempting to get support from local Community Mental Health Teams and made recommendations for change. We also submitted our own response to the inquiry.



### We shared real-life stories and professional insights into genetic testing

Research suggests that, in the UK, less than 20% of people who are at risk of Huntington's disease chose to have the predictive test to see if they have inherited the gene<sup>1</sup>. Genetic testing is a personal decision, and no two journeys are the same. This year, we listened closely to our community to better understand their experiences. We shared stories like Niall's, who spoke about the invaluable role of counselling in helping him navigate the process. Niall told us: "To be honest, I don't think there is ever a right time to get tested, but I knew that finding out at this time would help us as a family better prepare and plan for the future."

We also heard from Gemma, who waited ten years before choosing predictive testing. Her story highlighted the importance of getting the timing right and feeling ready to take the test. Gemma said: "For me personally, I don't think there was ever going to be such thing as the perfect time to go through the testing process. I'm sure that most people in the Huntington's disease community can relate when I say that my life is more than a little turbulent even on the best day imaginable! So, when we're faced with this decision, we can only make the best judgement call that we can based on what feels right for us at the time."

By sharing the real-life experiences of people in the Huntington's community, we're helping others feel more informed, supported and empowered to make the decision that's right for them.

Our Specialist Adviser Chris, shared his experience as a former Genetic Counsellor in a Q&A blog. His perspective helped break down the process and offered reassurance to those considering testing. Consultant Clinical Geneticist, Dr Nayana Lahiri discussed the genetics of Huntington's disease in an webinar. The webinar looked at topics such as risk, CAG repeats, family planning options and the development of potential therapies.

### We raised awareness of the advice and support we offer

In a world where quick, accessible information is more vital than ever, our website continues to be a powerful platform for communication, support and advocacy.

We've continued to review and improve our content so that our site is not only informative, but compassionate and easy to navigate. Our HD Youth Voice group looked at how to make the website more accessible for young people, leading to a redesign of the Youth Engagement services pages.

**1. Baig SS et al.; UK Huntington's Disease Prediction Consortium.**  
22 years of predictive testing for Huntington's disease: UK experience. Eur J Hum Genet. 2016;24(10):1396-1402. doi:10.1038/ejhg.2016.36. PMID: 27165004; PMCID: PMC5027682.



We also installed Recite Me, a language and accessibility toolbar that helps make our content more user-friendly for people with disabilities or who have English as a second language. People used Recite Me to access 702 pages, with top languages including Italian, Polish and Welsh.

This year, our website welcomed 496,940 visits. Whether people are newly diagnosed, supporting a loved one, fundraising or seeking professional advice, they often choose our site as a safe first step.

In the last 12 months, the most visited pages after the home page were:

- What is Huntington's disease?
- Information and support
- Symptoms of Huntington's disease
- The 'Learn in 5' Awareness Month campaign

This shows that people are actively seeking to understand the condition and support their families. Meanwhile, new visitors to our 'Learn in 5' campaign page proved that people want to learn more about the disease.

Over 11,000 people visited the 'Learn in 5' webpage during Huntington's Disease Awareness Month in May 2024. This campaign built on the momentum created by the BBC Lifeline appeal that aired at the end of April, and aimed to explain Huntington's in a simple way.

We asked people to give just five minutes of their time to get to know Huntington's disease, and we shared a factsheet about the condition as well as details of the support we offer.

Through social media adverts, the campaign directly targeted professionals who may not have heard about Huntington's before.

Social media is an increasingly important way to reach our community. We currently have nine channels, including a new channel developed for young people on Instagram.

We now have 29,674 followers across all our social media channels, an increase of 61.8% from 18,345 on the previous year. We have adapted our content to be more video-driven, as this has proved more engaging. In total, our videos were watched 336,352 times this year. One of our community member's stories alone was seen over 15,000 times on TikTok.

- Facebook: We had 43,574 video views this year a 706% increase compared to the previous year
- X: Although we are spending less time on X, we have been posting consistently and have had 2,353 likes this year
- TikTok: We had 232,066 views, 589% increase from 33,689
- LinkedIn: We had 141,934 impressions and 485 post shares, showing our content resonates with a professional audience
- YouTube Shorts: We now have over 30 short videos, which gained 14,450 views

This year, we were delighted to host our first Instagram Live, which was about HD Youth Voice, a volunteer programme that gives young members of our community the opportunity to shape our future. Young people discussed how they'd found out about HD Youth Voice, fundraising and their favourite moments. There was a short Q&A, a lively chat and lots of laughter. Altogether, we reached 114 people through the event, which helped to extend our engagement with young people.

During the event, Charlotte, a member of HD Youth Voice, described how she found out about Huntington's disease. She said: "I actually learnt about it in GCSE Science, and I remember it being mentioned in a class. I'm so glad that my mum and dad told me about it at that point because I think, you know, children always find out in weird and wonderful ways, especially with the Internet now."

We continued to engage with people through our mailing list, which this year has grown to over 6,500 people. We have now given people the option to choose if they would like to hear more about particular subjects, such as fundraising and campaigning.



## Goal 2

---

We will help make each day with Huntington's disease the best possible day.

### Our ambitions under this goal are:

- People understand the choices they can make to live with Huntington's disease
- People have the best quality of life available
- People have access to tools that can make life easier

### This year, we:

- Brought people together at our Community Conference and AGM
- Supported people through online and in-person events
- Helped people with the cost of living
- Provided psychological support through online courses
- Shared advice on keeping active

### We brought people together at our Community Conference and AGM

This year we were delighted to return to our first in person Community Conference and AGM since 2019. 139 people joined us at the spectacular Crewe Hall, a beautiful and accessible venue for the Huntington's disease community to come together.

Huntington's Disease Association Chair, Professor Hugh Rickards, said: "It was incredible to be back together in person. The energy, the speakers, and the sense of community made it a truly uplifting and memorable event for anyone affected by Huntington's disease."

The event opened with our Annual General Meeting. Our Chief Executive, Cath Stanley, provided updates on our achievements. Our conference programme then covered a range of subjects delivered by exceptional speakers.

Professor Ed Wild, Consultant Neurologist at the National Hospital for Neurology and Neurosurgery shared an engaging update on the latest research news.

Dr Sarah Gunn, Lecturer in Clinical Psychology, discussed psychological therapies for people affected by Huntington's disease. Her outstanding degree students gave a series of lightning talks.

Our community Ambassador, Chris Leak, talked about his personal journey with Huntington's disease. He called for the charity to "arm the ambassadors" so they can raise awareness of Huntington's disease and received a standing ovation from delegates.

Rachel Taylor, a Clinical Nurse Consultant at the National Hospital for Neurology and Neurosurgery shared practical tips for managing symptoms of Huntington's disease.

People had the chance to network and enjoy catching up over lunch – and the opportunity to enjoy the beautiful surroundings of this converted Jacobean mansion. Giving families the opportunity to relax and have fun, the event included dinner, a disco, and the chance to use the pool and spa. Workshops included reflexology and scrap-booking. Our Youth Engagement team provided fun activities for younger delegates.

Thank you to our main event sponsors Sage Therapeutics and Wave Life Sciences. We are grateful for their dedication to Huntington's disease research and for helping make this event possible. Thanks also to our other sponsors, UniQure, and Prilenia. Thank you to Roche for their educational grant.



### We supported people through online and in-person events

This year, we worked with people of all ages, offering both virtual and in-person events, supporting them so they can live their life to the fullest.

We developed our work with young adults (aged 18-40) by running a residential event and a day event. These events covered a range of topics, with speakers contributing their thoughts.

*"At the event, I shared my experience and talked about being part of the HD Youth Voice group. Just talking about Huntington's really helps. It can be quite lonely if you don't know anyone who's going through something similar. But as soon as you talk to other people who understand, it helps combat the loneliness."*

Young person who attended an in-person event



Alongside our in-person events, we offered online events with education and peer support sessions. Peer support enables people to talk openly with each other. Some of these online events are now run by HD Youth Voice, giving young people a chance to connect.

Due to feedback from the community, we also extended our offer to people aged 40 plus, by running online educational and peer support events for this age group.

Our family events continued to be popular this year, giving family members the opportunity to meet other people affected by Huntington's disease. We held a Family Education Event in Lancashire, a Family Conference in North Wales and a Family Event in Hertfordshire.

These events provided a safe space where families affected by Huntington's disease could hear from experts, share information and support each other. In North Wales, children enjoyed taking part in an art session, and participants also made Christmas wreaths in Hertfordshire.

Family members appreciated hearing about the latest research and meeting people with similar experiences.

33 people from our community took part in our Juvenile Huntington's Disease weekend at Calvert Lakes, near Keswick. This much loved annual event brings children, young people and families together to enjoy inclusive adventure activities, get respite and peer support, and learn new coping strategies.

This year, activities included canoeing, rock climbing, swimming, horse riding and a trip to a wildlife park. The majority of children and young people attending the weekend use a wheelchair and families enjoyed a trail walk that was suitable for wheelchair users. Families enjoyed a movie night and beach-themed party with crafts including jewellery making and graffiti art. Everyone could get involved, including those in the more advanced and most disabling stages of the disease. Children and young people went home with a sense of achievement and families made lasting memories.

*"The best thing about the weekend is being able to be truly me and allow my emotions to flow, which have been blocked all year. It's as though this weekend, because of being with other families, allows me to be ME! Thank you so much."*

*"Everyone is there for each other, whether it is just a friendly chat or discussing day to day struggles. No judging, no criticism. Just pure compassion."*

JHD Weekend participants

We regularly share information through webinars, which enable us to reach more members of our community and cover subjects of interest. This year, webinar topics included looking after oral hygiene, updates on current research, how to get involved with research through Enroll-HD, understanding genetics, supporting family communication and advice on caring for someone with Huntington's disease. Each session welcomed guest speakers who are experts in their field.

In total, we held 12 webinars this year which attracted 405 participants in total. We record and upload these webinars to YouTube. This year, 3,179 people watched our webinars on YouTube, which demonstrates the benefit of making this content available to watch on demand. We ran seven 'Finding Your Way' sessions, these are sessions for families and professionals who would like to know more about what the charity can offer.

### Our Creative Journey

We worked with our community to co-produce *Our Creative Journey*, an art exhibition held over five days in St John Baptist Church, Cirencester. The exhibition highlighted how eight talented artists continue to express their creativity whilst living with Huntington's disease. The exhibition was covered by BBC News and BBC Gloucestershire.

Thank you to all the artists, volunteers and to Cirencester Art Society for making this exhibition possible.



### We helped people with the cost of living

People with a diagnosis of Huntington's disease can be financially vulnerable for a variety of reasons. We have continued to provide extra support by offering welfare grants to people with Huntington's disease. This year, we awarded 42 grants with a total value of £14,296

One of our grants funded a personalised synthetic voice for a person who uses an augmentative and alternative communication device (AAC). This helped her to feel more of a sense of ownership towards her AAC, and encouraged her to use it more often to communicate with people around her.

The Victoria Convalescent Trust made a grant of £10,000 towards our welfare grants programme for 2025 and 2026. These grants can help improve quality of life, reduce risk or help support the purchase of useful items by people affected by Huntington's disease.

### We provided psychological support through online courses

Huntington's disease can have a severe impact on mental health. It can also have a significant impact for people who are at risk of having the disease or caring for a loved one with the disease.

This year, we offered psychological support through our Keeping Yourself in Mind course, which is led by Clinical Psychologist, Dr Sarah Gunn, with support from our Specialist Advisers. The course programme is based on Acceptance and Commitment Therapy and designed to help people accept and live with challenges while respecting their values and goals.

This course has been made available for parents of a child or young person with Juvenile Huntington's disease, those who are gene positive, people at risk of developing the disease, people with early symptoms and carers.

In feedback, 100% of attendees on the Keeping Yourself in Mind course agreed they felt better equipped to deal with the challenges of life with Huntington's disease.

*"It reminded me that you need to take care of yourself, in order to take care of others."*

Keeping Yourself in Mind participant

This year, we also ran Narrative Therapy sessions, led by Clinical Psychologist Mariangels Ferrer, with support from our Specialist Advisers. Narrative Therapy uses creative activities as a powerful tool to help participants explore and strengthen their sense of identity. Through guided reflection on personal values, core beliefs and support networks, individuals are encouraged to build resilience, self-understanding and emotional wellbeing.

We held a Narrative Therapy session at our Young Adults weekend and ran a Narrative Therapy session for family carers.

*"A really delightful concept presented with passion. Really nice to interact and talk with other carers too."*

Narrative Therapy participant





### We shared advice on keeping active

Research shows that for people with Huntington's disease, exercise can improve balance, confidence, mobility, independence, posture and breathing. Physical activity also has general health benefits, such as improved sleep and improved quality of life, and helps in managing anxiety and depression.

This year, we continued our collaboration with Dr Una Jones at Cardiff University to promote physical activity. We continued to promote the Keeping Active resources that we co-produced with Dr Jones and HD Voice. Dr Jones gave talks at Family Days and wrote a blog for us called Positive impact of physical activity in Huntington's – professional perspective.

Our community member Charly and her mum Sarahjane also wrote a blog for us, talking about how keeping mentally and physically active helps them.

## Chloe's Story...

### Using her voice to help other young people



*“Now I encourage everyone affected by the disease to reach out for support to the Huntington's Disease Association. You're not alone and there's such a lovely, genuine, friendly community of people here.”*

*“Huntington's disease is such a rare condition that it can feel as though you're the only person in the world who's dealing with it,”* says Chloe, who's in her 20s and works in the NHS.

As a child, Chloe's understanding of Huntington's disease was extremely limited. *“I knew that my grandad had died of the condition when he was only 44,”* she says. *“But I didn't know that the disease was genetic or that you could be tested for it.”*

During her teens, Chloe learned that Huntington's disease was genetic, but was reassured by her family that the gene hadn't been passed on. At this point, no tests had been done.

While she was at university, Chloe discovered that without a genetic test, you couldn't be certain that you didn't carry the gene. This led her to realise that she was at risk of developing the disease herself. *“It was a big shock. My mind went into a spiral, not just worrying about my own health and future, but also what it might mean for my closest relatives.”*

Chloe found details of the Huntington's Disease Association online, but it took her three years before she was ready to contact us. Eventually, encouraged by a colleague, she sent us an email. Someone got back to her the next day and, within a week, she had her first call with James, a Youth Worker.

*“I was really nervous before I talked to James, but he was so friendly,”* says Chloe. *“It was the biggest relief just talking to someone who understood my situation, gave me factual information and reassurance, and validated my feelings.”*

James gave Chloe emotional support as they discussed the possibility of her taking a test to discover whether she had the faulty gene that causes the condition. *“I was at risk of having Huntington's, but it took me over a year to decide to take the test,”* she says. *“I tested negative, so I won't go on to develop the disease, but I know that members of my family are still at risk.”*

Inspired by the support she'd received, Chloe was keen to use her experience to benefit other young people. She helped set up the HD Youth Voice group and became a Trustee on the Huntington's Disease Association board.

Chloe has also talked at a parliamentary event to raise awareness about Huntington's disease. *“It was a big step to speak on behalf of the charity,”* says Chloe. *“I'm quite a quiet person, so I feel really honoured to have been asked to talk to MPs.”*

*“Now I encourage everyone affected by the disease to reach out for support to the Huntington's Disease Association. You're not alone and there's such a lovely, genuine, friendly community of people here.”*

*“As young people, we can have a huge impact on how the next generation deals with this condition. By speaking up, we have the potential to change lives.”*



## Goal 3

---

We will make sure the voices of people affected by Huntington's disease are heard and at the heart of everything we do.

### Our ambitions under this goal are:

- Our work is driven by people affected by Huntington's disease
- We will understand and advocate the needs of everyone affected by Huntington's disease
- We will increase our reach and work with all communities affected by Huntington's disease
- We will increase people's skills to enable them to support people living with Huntington's disease

### This year, we:

- Raised awareness and funds through our BBC Lifeline appeal
- Put community voice at the heart of research through HD Voice
- Continued to put youth voice at the heart of our charity with HD Youth Voice
- Shared our Ambassadors' stories to inspire others
- Listened to our community's priorities
- Launched our report into Huntington's and mental health
- Trained and educated professionals

### We raised awareness and funds through our BBC Lifeline appeal

Our BBC Lifeline appeal was an amazing opportunity to raise awareness of Huntington's disease, show the impact it has on people's lives, and raise funds.

Fronted by Liverpool-born actor Alison Steadman, the appeal aired on BBC One and BBC Two in April.

Our community members Chris, Charlotte, Elaine, Natalie and Heather generously shared their stories, talking candidly about what life is like with Huntington's disease.

Charlotte, who started caring for her Nan when she was just ten years old, told viewers, "There were definitely breaking points for me as a young person. I've seen my nan right to the end of her life and I'm now watching my mum going through those stages. Knowing that's going to be me one day is quite terrifying to be honest."

The appeal also showcased the broad range of support we offer, including HDYES, our Specialist Huntington's Disease Advisory service, our Support Groups and the training we provide for care home staff.

Talking about how HDYES has helped her daughter, Charlotte's mum, Elaine, told viewers, "I feel less anxious because I know that she can reach out to people her age. It has changed her life. She has a sparkle there."

Chris talked about the impact of our one-to-one support and Support Groups. Having previously been left feeling "useless" and struggling with mental health because of his symptoms, Chris described how "it started to give me a sense of purpose having that guidance and support, not just for me but for my daughters as well. It was a huge comfort."

Following a significant deterioration in her symptoms, Natalie's mum, Heather, moved to a care home. Natalie told viewers: "When Mum went into the care home, they didn't really know how to handle her anxiety outbursts. She was quite hard to handle at the time, the symptoms of the illness were making her that way."

Natalie decided to move Heather to a care home where staff had been trained by our charity. She described the difference this made, "They just seemed to know what to do, which was so assuring for us. Mum started to become happier, she was having less anxiety outbursts. It's nice to know we can still enjoy the rest of the time that Mum has got left. We'll be forever grateful for the support the charity gives."

Thanks to generous donations, our BBC Lifeline appeal raised £39,504.

### We put community voice at the heart of research through HD Voice

HD Voice is our patient and public involvement group, which gives people affected by Huntington's disease a voice in research and the work we do. There are currently 53 people in the group and many have been involved in activities, ranging from guidance on our surveys and input into new leaflets to advice on research surveys.

HD Voice has been working with the NIHR Policy Research Unit in Dementia and Neurodegeneration (DeNPRU Exeter) at the University of Exeter. DeNPRU Exeter had already recruited experts for its research thanks to HD Voice.

"This year, we built on that during our consultations around living alone with Huntington's disease, where we reached more people to better understand this living situation," says Dr Catherine Charlwood of DeNPRU Exeter.

Dr Charlwood continued, "A member of HD Voice reached out to the community herself and gathered anonymised responses from six further carers and two people living alone with Huntington's disease. It's invaluable to hear these voices and incredible to have a route through trusted individuals."

HD Voice members have educated people in the DeNPRU Exeter team by making 'Train the researchers' videos about their experiences. They have also co-created a guide on the best way to involve people with neurodegenerative conditions in policy research.





### We continued to put youth voice at the heart of our charity with HD Youth Voice

HD Youth Voice, our youth leadership and co-production group, continued to go from strength to strength. Recruiting eight new members this year and retaining nine, we now have 17 inspiring young leaders aged 16 – 27. A member of HD Youth Voice is also a Trustee for the charity. Another member is also a Young Adult Executive Committee Member for the European HD Network.

HD Youth Voice meets online monthly and came together for a three- night residential this year. This event was an opportunity for peer support, co-production of projects, community activities and building social connections. The group also took part in social media and content production training. Members continued to support our social media content and blogs, including our first Instagram Live.

This year, HD Youth Voice co-produced our refreshed guides for children and teenagers, new website content, and the HD Passport. Children and young people can personalise this document and share it with the professionals who support them, such as teachers and employers. The HD Passport can include information such as caring responsibilities and the support they need.

Following specialist training in peer support and safeguarding, HD Youth Voice members launched their HD Connect virtual peer support sessions this year. The bi-monthly sessions include fun activities and discussion topics.

### We shared our Ambassadors' stories to inspire others

We now have a group of 44 Ambassadors who are willing to share their experience of Huntington's disease with the press and on our platforms. By sharing their stories, they raise awareness of the condition and are able to help others.

This year, our Ambassadors participated in 41 opportunities to talk about their experiences. This included creating content for blogs, social media stories, and press stories, and being guest speakers at our Community Conference and AGM.

In March, we held a special celebration to thank our Ambassadors for everything they'd achieved and to ask for their ideas on how they wanted to be involved in future. In feedback after the event, all attendees said they found it positive and agreed that being an Ambassador made them feel that their voice is heard at the Huntington's Disease Association.

*"Thank you for organising - it was really lovely to hear about other people's stories and how they are doing all things Huntington's Disease Association in their local area."*

Ambassador who attended the celebration in March

*"Being an Ambassador means I'm a part of an incredible team of people just as passionate about raising awareness and getting our voices heard in the wider community. I have been seen, heard and valued by all. I feel incredibly lucky to have been given the opportunity to meet others and have the support network that I now do. The Huntington's Disease Association have always helped me, so I believe this is me doing my part to thank them and return the favour. I will always strive to do my best, so that the world understands what Huntington's is, and how we must continue to believe - with fundraising for the Huntington's Disease Association - that we can fund vital support for those affected and fund research, leading to one day finding a cure."*

Hannah, Huntington's Disease Association Ambassador





### We listened to our community's priorities

We carried out a survey to discover the main priorities of people in the Huntington's disease community. We had a fantastic response, with 171 people taking part.

People said that they want us to focus on:

- Coordinated care - ensuring everyone living with Huntington's disease has a care coordinator who understands their needs and can help them access services and support. Almost nine in ten people (89%) said this should be a top three priority for us.
- Guidance for health professionals - providing guidance for health professionals on what good care and support looks like for people living with Huntington's disease. Over eight in ten people (82%) said this should be a top three priority.
- Improving the benefits system - ensuring that the benefits system meets the needs of people living with Huntington's disease. Three in four people (75%) said this should be a top three priority.

Almost half of people (44%) told us that improving access to mental health services should be a priority.

By taking part in our campaign survey, our community helped guide our work to influence decision makers, including the Government, to improve care and support for people affected by Huntington's disease. Thanks to the feedback from our community, we're now responding to the Government's consultation on disability benefits and developing guidelines for health professionals on Huntington's disease.

### We launched our report into Huntington's and mental health

Following our recent survey, we know that mental health is a priority for almost half the people in our community.

As a result, in November 2024, we launched our mental health report, *Unseen and Unheard: The Need to Improve Mental Healthcare for People Living with Huntington's Disease*. To ensure we reached more members of our community, we published this report in both English and Welsh.

The report highlights the mental health challenges faced by people living with Huntington's disease and sets out recommendations for change.

If you are living with Huntington's disease and struggling with your mental health, you want help from professionals who understand your needs and offer support. We found that time and again this isn't happening.

Around a third (32%) of 109 people said they or their relative was denied access to mental health services because of having Huntington's disease.

Almost all of the 83 health professionals we surveyed (99%) said the people with Huntington's disease they supported had experienced mental health issues.

We've since met with mental health providers and commissioners in 11 areas of England and Wales to discuss the findings of our mental health report. This has led to:

- Ongoing work with providers to improve pathways and care
- A better understanding of local mental health service provision and how to access support
- Raising awareness of the mental health needs of people with Huntington's disease, including through presentations to local mental health leaders and frontline professionals
- Better links between specialist Huntington's disease teams and mental health services

In March 2025, we followed this up with a Study Day for professionals focusing on mental health and Huntington's disease. This helped spread awareness of how best to support the mental wellbeing of people with Huntington's disease.

## We trained and educated professionals

We offer training and education opportunities for professionals who work with people with Huntington's disease, from three-day certificated courses to webinars. These are for any professional who wants to know more about the condition, including GPs, nurses, care home staff and social care professionals.

This year, 116 professionals took our three-day Understanding Huntington's Disease certificated course, which we ran twice.

*"We came away feeling as though we had a widened knowledge of all aspects that affect individuals with Huntington's disease and how to amend the care that we provide to them. The information and training provided was fantastic and improved our knowledge greatly."*

Delegate on our three-day course for professionals

72 professionals attended our Mental Health Study Day, which built on the findings of our mental health report, Unseen and Unheard: The Need to Improve Mental Healthcare for People Living with Huntington's Disease.

To encourage better understanding of Huntington's disease among professionals, we ran 105 training sessions for individual organisations. Delivered both in person and online, these sessions supported 1,086 professionals.

We continued to provide monthly drop-ins for professionals who wanted an overview of Huntington's disease. We attracted 691 attendees to these monthly online sessions. These sessions are aimed at staff in care homes that are caring for patients with Huntington's disease. 43 staff from care homes attended our HD Champions courses and 48 attended our in-person education event for North West care homes. We updated our core presentations for our Welsh community to a bi-lingual format.

*"This has been a great training session - thank you so much! Really summarised the main symptoms and what can be done practically to help, but also things to keep in mind when supporting patients and their families."*

Participant in online session for care homes

*"Loved the event, especially having the different speakers and covering so many areas. I was given a greater insight how to formulate care plans and support the nursing team."*

Delegate at our North West care home event



We delivered 19 webinars this year, covering topics such as research, medication, and oral hygiene. We held our first webinar specifically for GPs to help them gain more knowledge about Huntington's disease. The goal was to equip them with the skills and confidence to offer better care to their patients. In total, 470 people attended our webinars and the recordings were viewed 3,179 times on our YouTube channel.

We launched our professional networking sessions. These online lunchtime sessions are for professionals working with people with Huntington's disease and have become a valuable platform for peer support.

In partnership with the British Association of Social Workers, we published a new guide for social workers who support adults with Huntington's disease. The guide provides essential information for social workers on how to effectively support families affected by Huntington's disease, ensuring they're aware of common challenges. The guide has been shared with 22,000 social workers. We hosted an exhibition stand in Cardiff at the British Association of Social Workers' Cymru annual conference to talk through the new guide and share information about Huntington's disease.

Creating an additional resource, we wrote an article on Huntington's disease for Skills for Care, a newsletter for professionals in the social care sector. This covered how to identify the disease, and shared tips on caring for people displaying common symptoms experienced by people with Huntington's disease.

*"We're delighted to have worked in partnership with the Huntington's Disease Association to develop this practice guide. As Huntington's disease is so rare, many social workers will not have experience of supporting someone with the condition. That's why this guide is so important."*

Dr Luke Geoghegan, Head of Policy and Research, the British Association of Social Workers

## Dawn's Story...

### Getting support for her whole family

*"From the moment I first spoke to Poppy, my local Huntington's Disease Association Adviser, I felt like I was having arms wrapped around me. She was really non-judgemental, a shoulder to cry on. She's been an absolute rock," says Dawn, a charity worker and mother of two. "Without Poppy's help, I think we would have been completely adrift. She armed me with the knowledge to get the right care for my husband, Rob."*

Dawn contacted us for advice and support when Rob received a diagnosis of Huntington's. He had discovered by accident that his family was affected by the condition. *"He'd had some mental health problems and had taken long-term sick leave from his job. To pass the time, he started researching his family history. He hadn't seen his father or anyone from that side of the family for over 20 years, so he began with internet searches,"* Dawn explains.

It was a huge shock when Rob saw his grandad's death certificate, which said he'd died of Huntington's disease. *"It was absolutely horrendous,"* says Dawn. *"Rob had no idea that his family was affected."*

Rob decided to have the test for the faulty gene that causes the condition, and was devastated when it came back positive. *"He was already in a fragile mental state. Now, he went into psychosis and was having suicidal thoughts. Meanwhile, I was trying to keep going with work and family life. Bethanie was ten and Freya was just 11 months old,"* Dawn says. *"I went into survival mode. I couldn't bear the thought that my girls could possibly have this awful disease. If you spend too much time thinking about it, you'll go under."*

The situation got worse when doctors insisted that Rob was suffering from a mental health problem, rather than Huntington's disease. They didn't realise the condition can affect mental health, as well as causing cognitive impairments and involuntary movements. *"At that point, Poppy's support was vital,"* says Dawn. *"She helped me to make sure Rob got the right treatment."*

Dawn and her daughters are now also supported by HDYES, our Youth Engagement service. *"We told Bethanie about the diagnosis when she was 12,"* says Dawn. *"She got wonderful support from her Youth Worker at the Huntington's Disease Association."*

Freya was just 11 months old when her father received his diagnosis, so she grew up knowing about Huntington's disease. *"When she was 13, her dad died, and that's when she needed more support,"* says Dawn. *"Her Youth Worker, Jack, has been amazing. He encouraged Freya to become part of the HD Youth Voice group, which has really helped her come out of her shell."*

For Dawn and her daughters, the charity's support has been essential. *"Huntington's is often hidden in families and it can feel very isolating,"* says Dawn. *"When nobody else has understood us, the Huntington's Disease Association has always been there for us."*



*"When nobody else has understood us, the Huntington's Disease Association has always been there for us."*



## Goal 4

---

We will not rest until everyone with Huntington's disease has access to treatments.

### Our ambitions under this goal are:

- We will continue to support the community in accessing any new treatments
- We will advocate for equity of access to research opportunities
- We will support our partners in the global Huntington's disease community to find treatments for the disease

### This year, we:

- Supported the development and accessibility of new treatments
- Amplified our community's voice in research
- Engaged with the latest research at the EHDN conference
- Continued our involvement in EHDN working groups
- Continued to strengthen our relationship with NICE
- Partnered with universities to promote research



### We supported the development and accessibility of new treatments

We continued to collaborate with pharmaceutical companies, researchers and healthcare providers to accelerate the development and accessibility of treatments for Huntington’s disease. By providing information and resources to both trials, design support and clinical trial participants, we have enabled clinical trials to be more inclusive.

Much of the current focus in pharmaceutical research is on developing treatments that intervene early in the Huntington’s disease journey, sometimes even before symptoms emerge. While this represents exciting progress, it also presents new challenges. Potential trial participants at this stage may not yet be attending specialist clinics and this makes recruitment more challenging. In addition, those who are still working and living without clear symptoms may be understandably cautious about participating in trials that carry potential risks.

Recognising this, we have worked closely with individuals who may be eligible for early-stage trials to better understand the barriers they face. Their insights have been shared with pharmaceutical partners to help ensure that future trials are designed with participants’ real-world concerns in mind, ultimately improving accessibility and supporting more inclusive research.



By working with pharmaceutical companies, we can share updates on new and potential drug developments with our community. This year, we shared important research updates and opportunities with our community, including:

- Prilenia, a biotechnology company, sought approval to market pridopidine in EU member countries. Pridopidine has the potential to treat cognition so could help people’s function and quality of life.
- The launch of two Medical Research Council Centres of Research Excellence dedicated to cutting-edge gene therapy that could pave the way for breakthroughs to improve the quality of life for people affected by Huntington’s disease.
- UniQure’s AMT-130 gene therapy showed promising results in trials, offering hope for a disease-modifying treatment for Huntington’s disease. The therapy aims to reduce the production of the mutant huntingtin protein, which is responsible for the progression of Huntington’s disease.
- Wave Life Sciences announced positive results from its SELECT-HD trial. Over the course of the 28-week trial, the mutant huntingtin gene was lowered by 44% while the healthy gene was preserved.

While we celebrate progress, we also acknowledge the challenges inherent in drug development. Sage Therapeutics announced the discontinuation of their Huntington’s disease treatment programme after the therapy failed to meet efficacy endpoints in clinical trials. Although this is disappointing, it underscores the complexity of developing effective treatments for neurodegenerative diseases and reinforces our resolve to support all companies looking to develop potential treatments for Huntington’s disease.

### We amplified our community’s voice in research

Throughout the year, our HD Voice and HD Youth Voice groups have continued to shape research by providing meaningful, first-hand feedback to studies across the Huntington’s disease community.

As part of our commitment to breaking down barriers to research participation, we met with representatives from the Enroll-HD clinical research programme to share feedback from our community. This included insights from our Young Adults research consultation and from HD Voice. Feedback highlighted the practical and emotional challenges that people face when engaging with research.

### We engaged with the latest research at the EHDN conference

In September, representatives from the Huntington’s Disease Association, including our Chief Executive Cath Stanley, attended a joint conference in Strasbourg held by the European Huntington’s Disease Network (EHDN) and the Enroll-HD clinical research programme.

This collaborative event offered a unique opportunity for delegates to hear about the latest advances in Huntington’s disease research. Our team engaged directly with researchers who are leading the way in drug development and clinical innovation.

We are proud to be part of this movement, not just as observers, but as active contributors, advocates and champions for people living with Huntington’s disease in England and Wales.

*“The amount of research is truly promising, with trials exploring various methods, which offer hope in tackling Huntington’s disease from different perspectives.”*

Cath Stanley, Chief Executive, Huntington’s Disease Association

### We continued our involvement in EHDN working groups

We continued our involvement with many of the European Huntington’s Disease Network (EHDN) working groups that actively contribute to the Huntington’s disease community.

We are part of the following groups:

- Psychological Interventions and Approaches - looking at assessing psychological interventions to improve psychological wellbeing.
- Genetic Counselling and Testing – reviewing and updating guidelines related to genetic counselling and testing, addressing challenging ethical and legal cases and providing support and training for EHDN members on genetic counselling issues.
- Paediatric HD - ensuring that children and young people with Huntington’s disease have the option of being included in research programmes.
- Multidisciplinary Treatment and Care - aiming to make expert treatment and care accessible for patients worldwide by offering evidence-based guidelines and coordination processes.
- Occupational Therapy - striving to provide quality occupational therapy by developing consensus on best practices through guidelines and clinical tips.
- Physiotherapy - this group has developed clinical guidelines for physiotherapists working with people with Huntington’s disease, focusing on caregiver training, passive range of motion exercises, respiratory management, seating adaptations, and optimal positioning for comfort.

We also contributed to the EHDN’s review of Juvenile Huntington’s Disease.



Photo credit: © Gabriele Stautner / artifox.com for EHDN & Enroll-HD

## We continued to strengthen our relationship with NICE

As part of our commitment to ensuring everyone with Huntington's disease has access to effective treatments, we've continued to strengthen our relationship with the National Institute for Health and Care Excellence (NICE).

NICE decisions shape whether and how new treatments are made available on the NHS. That's why we've made it a priority to ensure that NICE understands the needs of people with Huntington's disease.

In March, we attended the NICE annual conference in Manchester. This gave us an important opportunity to listen, learn and connect with key decision-makers, helping to ensure that the unique needs of people with Huntington's disease are part of the national conversation.

Following this, in April we met with Professor Jonathan Benger CBE, NICE's Chief Medical Officer and Deputy Chief Executive. During this meeting, we shared real-life examples of the delays, misdiagnoses and barriers that our community encounter across the care pathway.

Our message was that people affected by Huntington's disease need earlier intervention, more consistent care and fairer access to emerging treatments. By engaging at this level, we're working to influence national frameworks that determine what 'good care' looks like, not just in theory, but in practice.

This relationship with NICE is ongoing. We will continue to work with stakeholders across the health system to push for greater recognition of Huntington's disease within national policy.

## We partnered with universities to promote research

We partner with academic institutions across the UK to promote their research. We highlight university-led Huntington's disease studies and help universities to enrol people from our community onto their research studies. These studies look at areas such as improving care pathways and supporting the development of future treatments, and rely on real-world insights from those with lived experience.

This year, we promoted a range of new and ongoing studies from leading universities, including:

- **The University of Reading** - exploring how everyday thinking and cognitive processes are affected by Huntington's disease, to help develop more tailored support and interventions.
- **The University of Birmingham** - understanding individual experiences of receiving a diagnosis of Huntington's disease in people with no known family history.
- **University College London** - discovering Intergenerational Genes in Huntington's disease (DIGG-HD).
- **Cardiff University** - promoting and supporting participation and social connectedness for people with progressive neurological conditions to reduce loneliness and isolation.
- **University of Hull** - developing a new self-report tool to better understand eating behaviours and weight loss in Huntington's disease. The HD-EAT Pilot Study is testing a digital questionnaire, co-produced with professionals and people with Huntington's disease to explore eating challenges and compare results with other quality of life and nutrition measures.
- **University of Leicester** - understanding gaps in mental health support for people affected by Huntington's disease with the study seeking people with the gene expansion, family members, and healthcare professionals.
- **Plymouth University** - a study looking at how much children and young people with chronic conditions feel included at school, focusing on children with Juvenile Huntington's disease.

*"The experience of working with the Huntington's Disease Association has been overwhelmingly positive, it was very straightforward, everyone I spoke to was professional, and understanding, and took an active interest in supporting the research. I am planning an educational webinar for the Huntington's Disease Association later in the year covering the evidence base for weight management, eating behaviours, and unexplained weight loss in Huntington's disease."*

Callum Schofield, PhD student, University of Hull

*"Thanks to your help, we exceeded our target for family members and even had more interest than we could accommodate. We have found working with the Huntington's Disease Association really positive as always. Each social media post you shared generated a high volume of interest the following week. Working with the charity enables us to reach out to so many wonderful people who generously give their time and support, and we couldn't be more appreciative of the Huntington's Disease Association and the Huntington's disease community."*

Suzanne Buswell, PHD student University of Leicester

# Research inspired by our community

*“Our early data suggests that people’s mental health seems to improve substantially immediately after the course.”*

Dr Sarah Gunn, Lecturer in Clinical Psychology at the University of Leicester, talks about her team’s work with our charity this year.



**What inspires your research?**

People with Huntington’s, and their families, experience a lot of difficulties with mental wellbeing, but there’s very little psychological support available. I hope the new therapies we’re developing will help people feel more able to manage these difficulties and improve their wellbeing.

**How would you describe your collaboration with the Huntington’s Disease Association?**

It’s one of the great joys of my professional life! Everyone is so lovely, skilled, committed and empathic. I’m delighted that our collaboration has opened up opportunities to support people with courses, blogs, webinars and talks.

**What are the highlights of your work with the Huntington’s Disease Association over the last year?**

This year, we’ve concentrated on delivering the Keeping Yourself in Mind programme. This eight-week online course helps people to find the best way to live alongside the challenges that come with Huntington’s. It’s for anyone affected by Huntington’s, including people with the gene expansion, people at risk, family members and caregivers.

We’re currently writing up papers on the outcomes of these programmes, and have shared findings through the European Huntington’s Disease Network 2024 conference, the Huntington’s Disease Association Community Conference, and a range of presentations in the UK and internationally. It’s lovely to see the positive response from the international Huntington’s community.

**How important is it for the Huntington’s community to be closely involved with your research?**

It’s absolutely crucial. Researchers need to understand the community’s needs and wishes. If our work isn’t important to the community, then it’s not important.

**What do you hope to achieve with your research in the future?**

Our team aims to improve how we understand, assess and support people with Huntington’s who experience psychological difficulties. We also hope to train other healthcare professionals to deliver our therapies so we can reach even more people.



## Goal 5

We will be a resilient charity.

### Our ambitions under this goal are:

- Everyone feels valued and welcome
- The charity is financially stable, well governed and with a clear plan for managed growth
- Our staff and volunteers are invested in and supported
- The charity is well connected through partnerships
- The Huntington's disease community has active champions

### This year, we:

- Formed our colleague-led EDI group
- Carried out a governance review
- Developed and invested in our volunteers
- Worked with our community and partners to fundraise
- Influenced change through partnerships

### We formed our colleague-led EDI group

We want to reach as many people as possible who are affected by Huntington's disease, and ensure that our services are accessible. In support of this, colleagues from across the charity came together this year to form our Equity, Diversity and Inclusion (EDI) group. The EDI group co-produced a mission statement, which says:

*We want to ensure that the Huntington's Disease Association is an open and welcoming community for everyone, whatever their journey. Led by our charity values, we want to create an environment that is inclusive, supportive and representative. We want everyone to feel valued and treated with fairness and respect. By recognising and celebrating differences within our team and community, we can learn and benefit from a variety of perspectives to create a diverse and inclusive charity.*



We have developed our approach to EDI this year by:

1. Exploring our data to better understand who uses our services - understanding who uses our services can help use see who isn't accessing support. This is essential to addressing inequalities and ensuring fair access across all communities, especially those who may face additional barriers (e.g. minorities, ethnic groups, people with disabilities, rural communities, LGBTQ+ individuals).
2. Reviewing our fundraising activities to ensure there is more choice –we understand not everyone can fundraise in the same way. By offering a wider range of fundraising options that take into account, levels of physical involvement or time commitments, we are ensuring more people can participate regardless of ability, or lifestyle.
3. Making more resources available in different languages - language should never be a barrier to understanding or receiving support. Providing resources in different languages helps ensure that everyone, regardless of their first language, has equal access to vital information about Huntington's disease.
4. Making sure that our website is disability compliant by using WCAG 2.2 success criteria ensuring that people with disabilities can access the same information, support, and opportunities as everyone else whether they use screen readers, keyboard navigation, or other assistive technologies.
5. Colleagues received EDI training at our Full Team Away Day and we are now a Disability Confident Employer. This accreditation demonstrates that we have the knowledge, skills and confidence we need to attract, recruit, retain and develop disabled people in the workplace.

### We carried out a governance review

Our Executive Council is a board of 11 trustees. The Executive Council met five times during the year supported by a number of committees, including the Finance and Audit Committee.

This year, we carried out a governance review to evaluate and improve the charity's governance practices, ensuring they remain effective, align with our mission, and meet legal and regulatory requirements.

We also conducted a skills audit to identify any knowledge gaps within our board and make sure that we have appropriate resources to govern the charity. This will help to inform our board's training and recruitment needs for the future.

### We developed and invested in our volunteers

We recruited a new Volunteering Manager this year and expanded our volunteer network. The Volunteering Manager has strengthened connections with volunteers across the charity, including those leading our branches and support groups. In collaboration with our branch treasurers, we reviewed and improved the annual return process, making it more user-friendly and efficient.

We introduced a more structured volunteer recruitment process, including clear documentation and a comprehensive matrix of required checks. We mapped volunteering opportunities across the charity and identified areas for growth.

New volunteers joined us in HD Youth Voice and as part of our motivational cheer team for fundraising events. Keen to inspire and develop the volunteers of the future, we presented opportunities to young adults at their residential event.

### We worked with our community and partners to fundraise

Once again, our incredible community played a vital role in raising funds to sustain our lifeline services. From individual challenges and team events to community campaigns and appeals, our supporters continued to demonstrate unwavering dedication and creativity. We are so grateful for every effort made on our behalf, from marathons and abseils to bake sales and quiz nights. We receive less than 1% of our income from statutory sources and rely on the kindness and generosity of our amazing supporters to continue making a difference.

In total, we raised £648,679 from community and activity events over the course of the year, which represented an increase of 25% compared to the previous year.

We invested in fundraising by creating a new Community Fundraising Coordinator role. This created additional capacity for our National Activity Events Coordinator to drive the charity's representation across a wider geographical area and variety of activity than ever before.

During the year, we delivered targeted fundraising campaigns to increase participation and engagement. Our inclusive campaigns reached a wide range of supporters across schools, care homes and online communities.

Our second Odds and Socks Day generated funds of £13,587. We received a total of 78 sign ups which included individuals, schools, businesses, care homes, hospital wards and neurological centres. This is our most inclusive fundraising event and it was great to see our community - and many four-legged friends - having fun at the same time as raising awareness and funds for our cause.

Our HD8000 series of events – HDMove, HDHike and HDBike – contributed £11,474 to our fundraising total for the year, engaging 71 community fundraisers. The name HD8000 is a reminder that around 8,000 people in the UK have Huntington's disease.

Our community showed up in force at flagship fundraising activities. #TeamHDA runners raised funds through iconic events including:

- The TCS London Marathon, where our team of 26 raised £97,637
- The Great North Run, where our team of 21 runners raised £19,321

Looking at our individual giving, our income from regular and single donations from supporters continued to perform well. We raised £100,141 from regular donations and £184,315 in single donations. This was boosted by our BBC Lifeline appeal, which raised £39,504. The appeal, fronted by actor Alison Steadman, was a potent vehicle for raising awareness of Huntington's disease.

In legacy income, we had another exceptionally strong year. We received notifications of £769,921 from gifts in wills this year. Our membership of the National Free Wills Network has helped us grow the number of people pledging a legacy through this service to 37. These gifts help secure the long-term future of our services and provide a lasting legacy for families affected by Huntington's disease.

In July, we gathered to celebrate the outstanding contributions of our community of fundraisers at our Huntington's Disease Association Awards, which were kindly sponsored by FI Real Estate Management. Following community nominations and hundreds of votes, the winners were announced as:

- Young Fundraiser of the Year (under 18 years): Oliver Ritchie who took part in the Junior Great North Run
- Fundraiser of the Year (over 18): Charlotte Conn and her CrossFit challenge
- Fundraising Group of the Year: Otterburn Care Home who took part in a zip wire challenge
- Excellence in Health or Social Care: Abbie Corns, Social Worker in Torbay
- Founders' Award: Nick Heath for his tireless work and commitment to supporting our community and the Huntington's Disease Association.

This year, we secured £355,993 against a target of £330,000 from trusts and foundations, a 19% increase on funds secured last year. This growth in support is particularly welcome during a time of increased uncertainty as many grantmakers pause, close or re-evaluate their strategies. We value the continued support of our trusts and foundations partners, many of whom have supported us over several years. In an increasingly competitive fundraising environment, their continued generosity and kindness are more valuable than ever.

We successfully managed and reported on the first year of our £418,360 three-year grant from The National Lottery Community Fund in support of HDYES, our Youth Engagement Service. This significant funding is making a huge difference to how we support children and young people affected by Huntington's disease.

We were grateful to continue relationships and receive funding from our statutory partners: Dorset Healthcare University NHS Trust, NHS Devon ICB, NHS Lancashire and South Cumbria ICB, NHS North East and North Cumbria ICB, and Birmingham City Council.

In addition, we received generous support from a range of corporate partners including:

- Futureheads, who chose us as their charity of the year for the second year.
- Our Community Conference exhibitors: Exemplar Health Care, Fieldbay, Cornerstone Healthcare, St Andrew's Healthcare and PJ Care.
- Our AGM main sponsors: Sage Therapeutics and Wave Life Sciences. Other sponsors were, Prilenia, Roche (via an educational grant) and UniQure.

We meet or exceed all statutory and regulatory obligations. We are members of the Fundraising Regulator and the Chartered Institute of Fundraising, following their best practice guidance and the Charity Commission guidance for Charity Trustees (CC20). We received zero complaints about our fundraising this year. We comply with the Privacy and Electronic Communications Regulations (PECR). We work with people who are vulnerable and follow the Chartered Institute of Fundraising's guidance on Treating Donors Fairly, which responds to the needs of people in vulnerable circumstances.



### We influenced change through partnerships

We continued to work with our partners to bring about change for our community.

We worked with other disability charities through the Disability Forum to challenge changes to the benefits system, which will affect people with Huntington's disease.

We also worked with service leads at NHS Integrated Care Boards to establish which services are available for people with Huntington's disease and to push for better services.

We provided condition-specific guidance to all benefit assessor agencies to ensure assessors have prior knowledge of Huntington's disease, which should make applying for benefits easier.

In April, we presented at a Royal College of Psychiatrists event to mental health doctors across Wales on the need to improve specialist support for people living with Huntington's disease.

Our Chief Executive, Cath Stanley, is the Chair of the Neurological Alliance. This year we have supported campaigns run by the Neurological Alliance and encouraged our community to complete the My Neuro Survey. This survey is helping to build a picture of treatment, care and support for people who are affected by Huntington's disease and other neurological conditions.

Last year, the Neurological Alliance's #BackThe1in6 campaign highlighted the needs of the 1 in 6 people in the UK who have a neurological condition. The campaign called on the government to create a Neuro Taskforce to improve treatment, care and support. This year, in response, the UK Government launched the UK Neuro Forum, the first ever forum to address gaps in treatment and care for people affected by neurological conditions. The Huntington's Disease Association is part of the forum along with clinical leaders, other charities and organisations, and people with lived experience of neurological conditions.

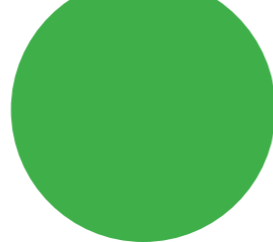
### This year, we supported partner events including:

- The launch of the Huntington's Disease Centre in Cardiff
- The new Leicestershire Huntington's Disease Network events
- A professional study day in Milton Keynes
- The North of England Huntington's Disease Conference
- A research party at The Barberry in Birmingham
- The Northern Ireland Association annual family conference
- The UKHDN meeting
- The Predictive Testing Consortium

On the Isle of Man, we met with 24 professionals and discussed the challenges they faced and how we could support them and the families they work with.

We also contributed to National Institute of Health Research initiatives and the National Advocacy Board with the Providers of Functional Assessments for PIP.





Our Chief Executive, Cath Stanley, raised awareness of the needs of people with Huntington’s disease by writing articles, campaigning for change and playing an active role in partner organisations. This year, her partnership activities included:

- Reviewing the manuscript for a new book about Huntington’s disease for Routledge. As a result, the book will now be published. In this moving story, a daughter who works in medicine describes her father’s journey with Huntington’s disease.
- Raising the issue of discrimination against people with a negative genetic test for Huntington’s disease with the Association of British Insurers and the Department of Health and Social Care.
- Writing a letter of support for a neuro-palliative care grant, which resulted in Severn Hospice being awarded a grant to create an end of life care pathway for Huntington’s disease.
- Working as part of the UK Dementia and Neurodegeneration Funders’ Forum (UKDeNFF) to ensure Huntington’s disease is considered in any available grants.
- Sitting on the Hospice UK neurodegeneration assessment panel, raising the profile of Huntington’s disease in hospice grants for people with progressive neurological conditions.
- Co-authoring a study entitled Data-driven Huntington’s Disease Progression Modelling and Estimation of Societal Cost in the UK, which was published in the Royal Society Open Science journal.
- Writing the foreword for a book on the psychiatric journey of someone with Huntington’s disease, highlighting the impact of psychiatric care on the whole family.
- Working as a member of the Premanifest HD Burden of Illness advisory board, consulting with professionals and people with Huntington’s disease to understand the burden of the disease, even before symptoms have started.
- Publishing an article in Neuro Rehab Times about discussions at the European Huntington’s Disease Network (EHDN) conference.

# Do it for Dom...

## Property industry supports the Huntington’s Disease Association with incredible energy and ingenuity

“We’ve done some crazy things to raise money,” says Graham Wilson, Founder of Do It For Dom – Agents Do Charity. Since 2018, Do it for Dom has raised well over £200,000 for the Huntington’s Disease Association – an incredible achievement!

This year, the team held an Adventure Challenge in Northampton. Graham told us, “People took part in a sack race, a Space Hopper race and a foam tunnel challenge. Adults dressed up in chicken costumes and threw themselves around an obstacle course on the hottest day of the year. All that effort paid off though, as we were able to give £30,000 of the funds we raised to the Huntington’s Disease Association.”

“It all started when my good friend Dominic was diagnosed with Huntington’s disease in 2017,” Graham explains. “Our close friends, Suzanna and Simon, suggested doing something to help him. So, Do It For Dom was born.”

People from across the property industry came together to take on fundraising challenges, and the Do It For Dom community swelled, from a handful of friends to several hundred people.

“We were very sad and concerned when we first heard about Dom’s diagnosis,” says Graham, “not just for him, but for his family too, as Huntington’s is hereditary. Huntington’s is one of the forgotten diseases that you don’t tend to hear about unless you know somebody who’s got it.”

Graham continues, “We wanted to give Dom some moral support to show that, no matter what he was going through, we were there for him.”

“As a charity, we’re almost entirely funded by philanthropy, so it’s vital for us to receive this support from Do It For Dom,” says Louise Merrin, Head of Fundraising at the Huntington’s Disease Association.

Louise continues, “We’re amazed not just by the huge amount of money they’ve raised for us, but by the heart and determination behind their fundraising. When we say that we’re inspired by our community, this is what we’re talking about.”



“Adults dressed up in chicken costumes and threw themselves around an obstacle course on the hottest day of the year. All that effort paid off, though, as we were able to give £30,000 of the funds we raised to the Huntington’s Disease Association.”

# Financial review

---

The results for the year show an overall deficit of £191,844 (2024: deficit £41,492) made up of a deficit on the general fund of £200,349 (2024: surplus £34,951) and a surplus on the restricted funds of £8,505 (2024: deficit £76,443). The overall performance was boosted by income from legacies and fund raising centrally, in branches and by our supporters throughout England and Wales. Details of particular activities and sources of funds are given elsewhere in the Trustees' Report.

At the year end the restricted funds balance amounted to £158,039 (2024: £149,534). Details are given in note 24 of the specific conditions applicable to these funds. The designated funds which have been set aside for specific purposes were £443,974 (2024: £301,835) and are detailed in note 25 and show their application during the year.

The Trustees have considered the need to match general reserves with the target calculated in accordance with the Reserves Policy. The deficits in 2024 and 2025 have contributed to this, and the budget for 2026 has been set to continue this trend. Careful control of expenditure and a positive outlook for income, which has shown consistent increases over recent years, leaves the charity in a strong position.



# Reserves policy

The general and designated reserve requirements of the charity have been re-evaluated for the 2025 accounts in order to update our policy and ensure comprehensive consideration of financial risks and commitments of the charity. We have identified that general reserves need to cover the salaries of staff members and running costs in the event of short-term income fluctuations which arise not only as a result of general economic functions but also from the timing of legacy receipts and major fund-raising events. The commitments at 31st March 2025 to support projects part funded by third parties have been recognised in Designated Funds being established to provide assurance that the charity will have adequate resources to complete those projects and maintain them whilst alternative revenue is sourced.

It was agreed that the target for general reserves should be set at six months recurring costs being approximately £1.2m plus £200,000 to cover legacy receipt variations, giving a total of £1.4m. At the year end, free reserves available excluding designated funds and tangible fixed assets but including fixed asset investments stood at £1,531,707 (2024: £1,869,548) and therefore exceeded target.



# Future plans

We will continue to deliver on the commitments of our Strategy 2023-2027 in the coming year.

We'll continue our pursuit for recognised guidelines for Huntington's disease. Having begun work with professionals to write our own guidelines for Huntington's disease, we are asking NICE to support them to ensure that people with Huntington's disease receive the best possible care.

We will continue to deliver our Youth Engagement service, which is partly funded by The National Lottery Community Fund. In year three of the project, we'll continue supporting children, young people, parents and guardians. We'll continue to engage and educate professionals. We'll deliver more activity events for children and young people, including a residential camp.

HD Youth Voice will continue to deliver its peer support sessions, become more involved in fundraising, and co-produce a Wellbeing Box that can be sent to other children and young people who need support.

We'll deliver support for young adults aged 18-40, including regular online calls. Young adults will come together at an in person event, which will include a wellbeing workshop and sessions on genetics and research. Peer support is a huge part of our in person events, and young adults will have the chance to meet others who understand what they are going through.

2025 marks the 20th anniversary of our JHD Weekend and we are planning to make the event extra special for the children, young people and families who join us.

Our 2025 Awareness Month campaign, Behind the Gene will lead with stories from our community. The campaign will highlight the real lives behind Huntington's disease, sharing the invisible challenges and untold stories of people affected by the condition. The campaign includes a factsheet for healthcare professionals and a pop-up pack that will help people in our community to hold their own awareness event.

People's stories will continue to be at the heart of all our communications. We'll continue to grow our team of courageous Ambassadors, who generously share their experiences to support others in the community.

Our community will come together again at our Huntington's Community Conference and AGM. The agenda is shaped around what people have told us they want and will provide a mix of information, activities and support. We will include news on current research, relaxation workshops, strategies for coping with challenging behaviours and psychological support. The event will again take place at the beautiful Crewe Hall Hotel in Cheshire.

We'll continue to deliver our network for professionals who support people with Huntington's disease. Our drop-in sessions offer a valuable opportunity for professionals who might be working in isolation and dealing with difficult situations to get advice and support from peers.

We'll continue to improve people's knowledge and understanding of Huntington's disease. Enhancing our training and education offer, we will work with an experienced provider to produce a distance learning package for professionals.



We'll continue to work with Enroll-HD to accelerate progress towards effective treatments. We'll continue our work alongside pharmaceutical companies as they develop drugs that could delay symptoms, improve symptoms, and hopefully find a cure. We'll continue to work with our university partners on research. HD Voice will continue to put community voice at the heart of research.

We'll continue to work strategically and collaboratively to ensure effective engagement with policy makers. Working with partners such as the Neurological Alliance and Genetic Alliance UK enables us to align and amplify our advocacy. We will host a parliamentary event where people affected by Huntington's disease will talk directly to MPs about the huge impact that Huntington's disease has on their lives.

We'll continue to support and develop our volunteers. We will bring members of our patient and public involvement group, HD Voice, together in the HD Forum. In this way, members will be able to share their experiences, connect with each other and strengthen HD Voice.

We'll create a supportive network for our branches and support groups. We'll also establish a Volunteer Committee and volunteers from across our charity will play an active role in developing our volunteering programme. We'll survey our volunteers to better understand their experience with us – and findings will support the creation of our Volunteering Strategy.

We look forward to recognising and thanking our volunteers during Volunteers Week.

We will create an Equity, Diversity and Inclusion Strategy to ensure that everyone affected by Huntington's disease regardless of their background, identity, or circumstances feels seen, heard, respected, and supported by the charity and has equitable access to services, support, and information. We'll assess how our translated resources are performing and being received.

Our colleague EDI group will continue to inform our approach to Equity, Diversity and Inclusion. We will launch a staff survey and deliver bespoke training. We will celebrate Global Inclusion Day.

In the coming year, we will investigate the impact that our charity has on the environment. We will look at every aspect of our operations to see where we can make improvements.



# Structure, governance and management

## Governing document

The company is a registered charity founded in 1971 and incorporated on 21 May 1986. The charity is governed by the Memorandum and Articles of Association.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

<b>Professor H Rickards (Chair)</b>	<b>Dr N Swales</b>
<b>Ms S Barker (Vice Chair)</b>	<b>Mr S Duckett</b>
<b>Mr N M Heath (Hon Treasurer)</b>	<b>Mrs C Lyon</b>
<b>Ms C K Holmes</b>	<b>Dr G El-Nimr</b>
<b>Mr D R Thomas</b>	<b>Mrs S Bakewell (apptd. 26 Oct 2024)</b>
<b>Mrs H E Hubberstey</b>	

## Recruitment and appointment of trustees

The Trustees are elected to serve a term of three years at the Annual General Meeting by the voting members of the Association who are the guarantors.

## Qualifying third party indemnity provisions

All trustees are covered by the charity's directors and officers insurance.

## Organisational structure

The charity is managed by an Executive Council made up of the trustees, which met on seven occasions during the year.

The Executive Council members focus on the strategic decisions required for the overall governance of the Huntington's Disease Association and devolve operational running to the management team.

The Chief Executive and senior managers oversee the operational management of the Huntington's Disease

Association within the policies and guidelines approved by the Executive Council. Prior to board meetings, the Chief Executive provides a written update report to the Executive Council on the operational management of the charity, which all senior managers have an input into. These reports provide the Executive Council with a detailed overview of the operational progress of the Association. The Chief Executive attends board meetings to discuss the management reports further and answer any questions the trustees may have.

## Induction and training of trustees

Most trustees are already familiar with the work of the charity and their training involves briefings on their duties and liabilities. Additionally, new trustees receive an induction pack covering:

- The duties of charity trustees;
- An induction pack outlining duties and responsibilities;
- The Association's Memorandum and Articles of Association, strategic plan, latest published annual report and accounts, financial projections and budgets, project and programme plans and publications;
- Trustee details and staff structure;
- The Essential Trustee: what you need to know (Charity Commission);
- Minutes and reports submitted to the previous three meetings of the board of trustees.

### Auditor

DSC resigned as auditor on 11 September 2024. DSC Audit were appointed on 11 September 2024 and in accordance with section 485 of the Companies Act 2006, a resolution proposing that they be re-appointed will be put at a General Meeting.

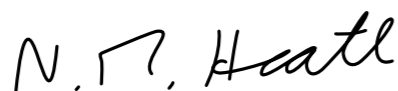
### Disclosure of information to auditor

Each of the trustees has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

### Small company provisions

This report has been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The trustees' report was approved by the Board of Trustees.



**Mr N M Heath (Hon Treasurer)  
Trustee**

**12 August 2025**

## Statement of trustees' responsibilities

The trustees, who are also the directors of Huntington's Disease Association for the purpose of company law, are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures
- disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that 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. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

# Independent auditor's report

---

## Opinion

We have audited the financial statements of Huntington's Disease Association (the 'charity') for the year ended 31 March 2025 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2025 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

## Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

## Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

## Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and

- the directors' report included within the trustees' report has been prepared in accordance with applicable legal requirements.

### **Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

### **Responsibilities of trustees**

As explained more fully in the statement of trustees' responsibilities, the trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

### **Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

### **Capability of the audit in detecting irregularities, including fraud**

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

Based on our discussions with the charity's management and the Trustees, we identified that the following laws and regulations are significant to the entity:

- Those laws and regulations considered to have a direct effect on the financial statements include UK financial reporting standards and Charity Law.
- Those laws and regulations for which non-compliance may be fundamental to the operating aspects of the charity and therefore may have a material effect on the financial statements include compliance with the charitable objectives, public benefit, fundraising regulations, safeguarding and health and safety legislation.

These matters were discussed amongst the engagement team at the planning stage and the team remained alert to non-compliance throughout the audit.

Audit procedures undertaken in response to the potential risks relating to irregularities (which include fraud and non-compliance with laws and regulations) comprised of: inquiries of management and the Trustees as to whether the entity complies with such laws and regulations; enquiries with the same concerning any actual or potential litigation or claims; inspection of relevant legal correspondence; review

of Trustee meeting minutes; testing the appropriateness of journal entries; and the performance of analytical review to identify unexpected movements in account balances which may be indicative of fraud.

No instances of material non-compliance were identified. However, the likelihood of detecting irregularities, including fraud, is limited by the inherent difficulty in detecting irregularities, the effectiveness of the entity's controls, and the nature, timing and extent of the audit procedures performed. Irregularities that result from fraud might be inherently more difficult to detect than irregularities that result from error. As explained above, there is an unavoidable risk that material misstatements may not be detected, even though the audit has been planned and performed in accordance with ISAs (UK).

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



**Andrew Moss BA FCA**  
(Senior Statutory Auditor)

**For and on behalf of DSG**  
**Audit, Statutory Auditor**  
**Chartered Accountants**  
**Castle Chambers**  
**43 Castle Street**  
**Liverpool**  
**L2 9TL**

**12 August 2025**

## Statement of financial activities

Including income and expenditure account.  
For the year ended 31 March 2025.

	Note	Unrestricted Funds 2025 £	Restricted Funds 2025 £	Total 2025 £	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total 2024 £
<b>Income from</b>							
Donations and legacies	3	1,890,663	92,387	<b>1,983,050</b>	1,673,330	95,106	<b>1,768,436</b>
Charitable activities	4	110,142	329,279	<b>439,421</b>	40,404	296,735	<b>337,139</b>
Other trading activities	5	48,219	-	<b>48,219</b>	83,709	-	<b>83,709</b>
Investments	6	61,153	-	<b>61,153</b>	77,533	-	<b>77,533</b>
<b>Total income</b>		2,110,177	421,666	<b>2,531,843</b>	1,874,976	391,841	<b>2,266,817</b>
<b>Expenditure on</b>							
Raising funds	7	318,590	-	<b>318,590</b>	293,933	-	<b>293,933</b>
Charitable activities	8	1,981,613	413,161	<b>2,394,774</b>	1,610,508	468,284	<b>2,078,792</b>
Other expenditure	13	3,453	-	<b>3,453</b>	-	-	<b>-</b>
<b>Total expenditure</b>		2,303,656	413,161	<b>2,716,817</b>	1,904,441	468,284	<b>2,372,725</b>
<b>Net gains/(losses) on investments</b>	14	(6,870)	-	<b>(6,870)</b>	64,416	-	<b>64,416</b>
<b>Net income/(expenditure) and movement in funds</b>		(200,349)	8,505	<b>(191,844)</b>	34,951	(76,443)	<b>(41,492)</b>
<b>Reconciliation of funds</b>							
Fund balances at 1 Apr 2024		2,193,097	149,534	<b>2,342,631</b>	2,158,146	225,977	<b>2,384,123</b>
<b>Fund balances at 31 Mar 2025</b>		1,992,748	158,039	<b>2,150,787</b>	2,193,097	149,534	<b>2,342,631</b>

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

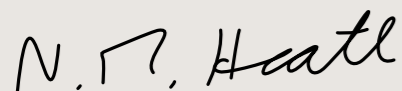
## Balance sheet

As at 31 March 2025.

	Note	2025 £	2025 £	2024 £	2024 £
<b>Fixed assets</b>					
Tangible assets	16		17,067		21,714
Investments	17		1,032,693		1,039,563
			<b>1,049,760</b>		<b>1,061,277</b>
<b>Current assets</b>					
Stocks	19	11,730		8,175	
Debtors	20	728,179		440,245	
Cash at bank and in hand		533,487		987,706	
		<b>1,273,396</b>		<b>1,436,126</b>	
<b>Creditors: amounts falling due within one year</b>					
	21	<b>(172,369)</b>		<b>(154,772)</b>	
<b>Net current assets</b>			<b>1,101,027</b>		<b>1,281,354</b>
<b>Total assets less current liabilities</b>			<b>2,150,787</b>		<b>2,342,631</b>
<b>The funds of the charity</b>					
Restricted income funds	24		158,039		149,534
Unrestricted funds	25		1,992,748		2,193,097
			<b>2,150,787</b>		<b>2,342,631</b>

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 12 August 2025



Mr N M Heath (Hon Treasurer)  
Trustee

Company Registration Number 02021975 (England and Wales)

## Statement of cash flows

For the year ended 31 March 2025.

	Note	2025 £	2025 £	2024 £	2024 £
<b>Cash flows from operating activities</b>					
Cash absorbed by operations	30		(504,272)		(218,868)
<b>Investing activities</b>					
Purchase of tangible fixed assets		(11,100)		(14,631)	
Purchase of investments		-		(100,000)	
Investment income received		61,153		77,533	
<b>Net cash generated from/(used in) investing activities</b>			50,053		(37,098)
<b>Net cash used in financing activities</b>					
			-		-
<b>Net (decrease)/increase in cash and cash equivalents</b>			(454,219)		(255,966)
Cash and cash equivalents at beginning of year			987,706		1,243,672
<b>Cash and cash equivalents at end of year</b>			<b>533,487</b>		<b>987,706</b>

# Notes to the financial statements

## 1 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

## 2 Accounting policies

### Charity information

Huntington's Disease Association is a private company limited by guarantee incorporated in England and Wales. The registered office is Liverpool Science Park, Innovation Centre, 131 Mount Pleasant, Liverpool, L3 5TF.

### 2.1 Accounting convention

The financial statements have been prepared in accordance with the charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)". The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention except for the revaluation of fixed asset investments in accordance with the Charities SORP.

### 2.2 Going concern

The Trustees have considered the potential effects of current inflationary pressures and general economic uncertainty on the charity.

At the time of approving the accounts the Trustees consider that the charity has adequate reserves and diverse revenue streams to continue in operational existence for the foreseeable future taking account of economic uncertainties caused by the pandemic. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the accounts.

### 2.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Designated funds comprise funds which have been set aside at the discretion of the trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the accounts.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the accounts.

### 2.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Investment income consists of interest and dividends received and receivable.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is disclosed as a contingent asset.

No amounts are included in the financial statements for services donated by volunteers.

Grants, including grants for the purchase of fixed assets, are recognised in full in the statement of financial activities in the year in which they are receivable.

Deferred income represents grants received in advance of the expenditure to which it is allocated to support.

No amounts are included in these financial statements for goods donated to charity shops or services donated by volunteers.

Income from merchandise sales and fundraising income is recognised as earned (that is, as the related goods or services are provided).

## 2.5 Expenditure

All expenditure has been accounted for on an accruals basis and includes irrecoverable VAT where applicable. Expenditure is allocated to relevant activity categories on a basis that is consistent with the use of that resource. Support costs have been attributable to charitable activity in accordance with best estimates.

Research grants are made each year after approval and recommendation by the Medical Advisory Panel. The amount charged to the profit and loss account represents the cost of projects approved during the year.

## 2.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings 25% straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

## 2.7 Fixed asset investments

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

## 2.8 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment

loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

## 2.9 Stocks

Stocks are valued at the lower of cost or selling price less selling costs, after making due allowance for obsolete and slow-moving items. Cost is calculated using the first-in first-out basis of valuation.

## 2.10 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts.

## 2.11 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

### Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

### Impairment of financial assets

Financial assets, other than those held at fair value through income and expenditure, are assessed for indicators of impairment at each reporting date. Financial assets are impaired where there is objective evidence that, as a result of one or more events that occurred after the initial recognition of the financial asset, the estimated future cash flows have been affected.

If an asset is impaired, the impairment loss is the difference between the carrying amount and the present value of the estimated cash flows discounted at the asset's original

effective interest rate. The impairment loss is recognised in net income/(expenditure) for the year.

If there is a decrease in the impairment loss arising from an event occurring after the impairment was recognised, the impairment is reversed. The reversal is such that the current carrying amount does not exceed what the carrying amount would have been, had the impairment not previously been recognised. The impairment reversal is recognised in net income/(expenditure) for the year.

#### Derecognition of financial assets

Financial assets are derecognised only when the contractual rights to the cash flows from the asset expire or are settled, or when the charity transfers the financial asset and substantially all the risks and rewards of ownership to another entity, or if some significant risks and rewards of ownership are retained but control of the asset has transferred to another party that is able to sell the asset in its entirety to an unrelated third party.

#### Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

#### Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

### 2.12 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

### 2.13 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

### 2.14 Branch funds

The funds of the Association's branches have been consolidated in the accounts.

## 3 Donations and legacies

	Unrestricted Funds 2025 £	Restricted Funds 2025 £	Total 2025 £	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total 2024 £
Donations and gifts	1,156,250	9,040	1,165,290	996,636	87,273	1,083,909
Legacies receivable	686,858	83,063	769,921	626,258	7,833	634,091
Branch income	47,555	284	47,839	50,436	-	50,436
	<b>1,890,663</b>	<b>92,387</b>	<b>1,983,050</b>	<b>1,673,330</b>	<b>95,106</b>	<b>1,768,436</b>

## 4 Income from charitable activities

	Unrestricted Funds 2025 £	Restricted Funds 2025 £	Total 2025 £	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total 2024 £
Grants received	33,600	324,893	358,493	3,500	296,735	300,235
Merchandise	19,790	-	19,790	14,808	-	14,808
Other income	56,752	4,386	61,138	22,096	-	22,096
	<b>110,142</b>	<b>329,279</b>	<b>439,421</b>	<b>40,404</b>	<b>296,735</b>	<b>337,139</b>

## 5 Income from other trading activities

	Unrestricted Funds 2025 £	Unrestricted Funds 2024 £
Sponsorships	38,336	51,876
Consultancy	9,883	31,833
Other trading activities	48,219	83,709

**6 Income from investments**

	<b>Unrestricted Funds 2025 £</b>	Unrestricted Funds 2024 £
Income from listed investments	31,537	29,469
Interest receivable	29,616	48,064
	<b>61,153</b>	<b>77,533</b>

**7 Expenditure on raising funds**

	<b>Unrestricted Funds 2025 £</b>	Unrestricted Funds 2024 £
<b>Fundraising and publicity</b>		
Staging fundraising events	40,022	26,675
Other fundraising costs	52,039	57,435
Staff costs	226,529	209,823
	<b>318,590</b>	<b>293,933</b>

**8 Expenditure on charitable activities**

	<b>Charitable Expenditure 2025 £</b>	Charitable Expenditure 2024 £
<b>Direct costs</b>		
Staff costs	1,427,687	1,281,977
Welfare grants	30,888	32,052
Travel and training	82,412	69,431
Telephone and internet	40,895	45,688
Other costs	162,712	143,279
Website	8,482	17,727
Marketing	31,652	74,467
Event costs	74,886	37,441
	<b>1,859,614</b>	<b>1,702,062</b>
<b>Share of support and governance costs (see note 9)</b>		
Support	523,518	364,039
Governance	11,642	12,691
	<b>2,394,774</b>	<b>2,078,792</b>
<b>Analysis by fund</b>		
Unrestricted funds	1,981,613	1,610,508
Restricted funds	413,161	468,284
	<b>2,394,774</b>	<b>2,078,792</b>

**9 Support costs allocated to activities**

	<b>2025 £</b>	<b>2024 £</b>
Staff costs	310,681	208,524
Depreciation	12,294	13,276
Head office costs	200,543	142,239
Governance costs	523,518	364,039
	<b>11,642</b>	<b>12,691</b>
	<b>535,160</b>	<b>376,730</b>
<b>Analysed between:</b>		
Charitable Expenditure	<b>535,160</b>	<b>376,730</b>
<b>Governance costs comprise:</b>		
Audit fees	9,318	8,874
EC meeting costs	2,324	3,817
	<b>11,642</b>	<b>12,691</b>

Support costs are allocated on the basis of time spent.

**10 Net movement in funds**

	2025 £	2024 £
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	9,318	8,874
Depreciation of owned tangible fixed assets	12,294	13,276
Loss on disposal of tangible fixed assets	3,453	-

**11 Trustees**

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year (2024: £nil). Seven trustees were reimbursed expenses totalling £1,250 for travel expenses (2024: no trustees were reimbursed expenses).

**12 Employees**

	2025 Number	2024 Number
<b>The average monthly number of employees during the year was:</b>		
Specialist HD Advisors	26	25
Management	1	1
Fundraising	6	5
Youth Worker	5	5
Administration	10	6
Communications	3	3
<b>Total</b>	<b>51</b>	<b>45</b>

	2025 £	2024 £
<b>Employment costs</b>		
Wages and salaries	1,740,910	1,501,293
Social security costs	175,435	156,408
Other pension costs	48,552	42,623
	<b>1,964,897</b>	<b>1,700,324</b>

	2025 Number	2024 Number
<b>The number of employees whose annual remuneration was more than £60,000 is as follows:</b>		
£80,001 - £90,000	1	1
	1	-

2025  
£

2024  
£

**Remuneration of key management personnel**

The remuneration of key management personnel, which consists of the Chief Executive and the heads of departments, is as shown below.

Aggregate compensation	369,537	315,348
------------------------	---------	---------

**13 Other expenditure**

	Unrestricted Funds 2025 £	Unrestricted Funds 2024 £
Net loss on disposal of tangible fixed assets	3,453	-

**14 Gains and losses on investments**

	Unrestricted Funds 2025 £	Unrestricted Funds 2024 £
<b>Gains/(losses) arising on:</b>		
Revaluation of investments	(6,870)	64,416

**15 Taxation**

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

**16 Tangible fixed assets**

	Fixtures and fittings £
<b>Cost</b>	
At 1 April 2024	60,780
Additions	11,100
Disposals	(19,925)
<b>At 31 March 2025</b>	<b>51,955</b>
<b>Depreciation and impairment</b>	
At 1 April 2024	39,066
Depreciation charged in the year	12,294
Eliminated in respect of disposals	(16,472)
<b>At 31 March 2025</b>	<b>34,888</b>
<b>Carrying amount</b>	
<b>At 31 March 2025</b>	<b>17,067</b>
At 31 March 2024	21,714

**17 Fixed asset investments**

	Listed investments £
<b>Valuation</b>	
At 1 April 2023	1,039,563
Valuation changes	(6,870)
<b>At 31 March 2025</b>	<b>1,032,693</b>
<b>Carrying amount</b>	
<b>At 31 March 2025</b>	<b>1,032,693</b>
At 31 March 2023	1,039,563

**18 Financial instruments**

	2025 £	2024 £
<b>Carrying amount of financial assets</b>		
Instruments measured at fair value through profit or loss	1,032,693	1,039,556

**19 Stocks**

	2025 £	2024 £
Merchandise	11,730	8,175

**20 Debtors**

	2025 £	2024 £
<b>Amounts falling due within one year:</b>		
Trade debtors	5,249	15,338
Other debtors	639,947	355,844
Prepayments and accrued income	82,983	69,063
	<b>728,179</b>	<b>440,245</b>

Other debtors include £595,091 (2024: £307,978) of legacies receivable.

**21 Creditors: amounts falling due within one year**

	2025 £	2024 £
Other taxation and social security	40,084	37,190
Trade creditors	42,505	38,709
Other creditors	12,402	20,945
Accruals and deferred income	77,378	57,928
	<b>172,369</b>	<b>154,772</b>

Included in accruals and deferred income is deferred income of £36,165 (2024: £41,250) relating to income received for future periods.

## 22 Retirement benefit schemes

	2025 £	2024 £
<b>Defined contribution schemes</b>		
Charge to profit or loss in respect of defined contribution schemes	48,552	42,623

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

The charge to the statement of financial activities in respect of defined contribution schemes was £48,552 (2024 - £42,623).

## 23 Contingent asset

The charity has been notified of a potential legacy of approximately £300,000 from the estate of a deceased individual. However, the charity has also been informed that the deceased's daughter, who was not provided for in the will and is believed to be a potential beneficiary due to her health condition, may challenge the estate. At the date of approval of these financial statements, no formal legal proceedings have been initiated, and the charity has not received confirmation of entitlement or probate documentation.

Given the uncertainty surrounding the outcome of the potential challenge and the lack of sufficient evidence to confirm entitlement, the legacy has not been recognised as income in these financial statements. The charity will continue to monitor the situation and will recognise the legacy if and when the recognition criteria under the Charities SORP (FRS 102) are met.

## 24 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	Balance at 1 Apr 2023 £	Incoming resources £	Resources expended £	Balance at 1 Apr 2024 £	Incoming resources £	Resources expended £	Balance at 31 Mar 2025 £
Research	14,384	47,595	-	61,979	59,490	-	121,469
The National Lottery Community Fund	-	136,452	(90,168)	46,284	137,178	(158,393)	25,069
Specialist HD Advisory Service (SHDA)	-	171,944	(164,944)	7,000	189,226	(196,226)	-
Lancashire Training Events	4,849	-	-	4,849	-	(4,519)	330
The Big Give - JHD weekend	-	16,926	-	16,926	-	(16,926)	-
The Big Give - Kind2mind	-	13,160	(3,664)	9,496	3,172	(11,520)	1,148
JHD Weekend	-	3,000	-	3,000	13,000	(16,000)	-
Access Foundation	-	-	-	-	5,000	(2,307)	2,693
AGM	-	-	-	-	4,000	(4,000)	-
Victoria Convalescent Fund	-	-	-	-	10,000	(2,670)	7,330
B&Q Foundation	2,699	-	(2,699)	-	-	-	-
Welfare Fund	1,040	2,764	(3,804)	-	600	(600)	-
Jingle Jam	203,005	-	(203,005)	-	-	-	-
	<b>225,977</b>	<b>391,841</b>	<b>(468,284)</b>	<b>149,534</b>	<b>421,666</b>	<b>(413,161)</b>	<b>158,039</b>

### Research

Research funds are raised to promote medical and social/therapeutic research of direct significance to Huntington's Disease sufferers and their families. Our Medical Advisory Board reviews all applications on an annual basis before a decision is taken by our Executive Council. Funds were received from individuals, organisations and Branches requesting their donation be spent on this activity.

### The National Lottery Community Fund

Multiyear funding through The National Lottery Community Fund Reaching Communities programme to support the development of our Huntington's Disease Youth Engagement Service (HDYES).

### Specialist HD Advisory Service (SHDA)

The network of Specialist HD Advisers was maintained during the year. Restricted funding relating purely to this service and for each geographical area was received from numerous sources in the period.

### Lancashire Training Events

Money raised towards an awareness/training event in the Fylde Coast area.

### The Big Give - JHD Weekend

Restricted funding to support our annual JHD Weekend for families impacted by Juvenile Huntington's Disease.

**The Big Give - Kind2Mind**

Restricted funding to support our psychological support programmes.

**JHD Weekend**

These relate to individual donations and grants that have been or are to be spent on the JHD weekend.

**Access Foundation**

Funding to run 13 community education courses.

**AGM**

Grants towards the AGM / Community conference held in October.

**Victoria Convalescent Fund**

Funds for welfare grants.

**B&Q Foundation**

Funding received from B&Q Foundation for enhancing quality of life and helping to reduce risks by providing financial assistance to maintain, repair or improve housing.

**Welfare Fund**

Funding received towards welfare grants.

**Jingle Jam**

Jingle Jam is the World's largest gaming event which took place in December 2022. We were one of 12 charities that benefited from the event and secured funding of £240,925 towards our Youth Engagement Services.

**25 Unrestricted funds**

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2024 £	Incoming resources £	Resources expended £	Transfers £	Gains and losses £	At 31 March 2025 £
<b>Designated funds</b>						
Special projects fund	125,000	-	-	(125,000)	-	-
Branch funds	57,558	-	-	(7,084)	-	50,474
Huntington's Disease Youth Engagement Service	119,277	-	(123,674)	368,397	-	364,000
West Midlands Specialist Huntington's Disease Advisory	-	-	-	29,500	-	29,500
<b>General funds</b>	1,891,262	2,110,177	(2,179,982)	(265,813)	(6,870)	1,548,774
	<b>2,193,097</b>	<b>2,110,177</b>	<b>(2,303,656)</b>	<b>-</b>	<b>(6,870)</b>	<b>1,992,748</b>

A designated special projects fund of £400,000 was established as a result of legacies received during 2013. This was reduced in the years to 31st March 2024 and the balance at that date has been allocated to the Huntington's Disease Youth Project. This covers the Association's costs to completion of £214,000 in addition to the three year funding from the National Lottery and £150,000 to ensure this valuable and successful project can be maintained for a period after externally promised grants have ended.

A similar logic has been applied to the West Midlands Specialist Huntington's Disease Advisory role for which £29,500 has been designated.

The Branch funds are also considered designated since they are held by individual branches for expenditure in their areas.

Previous year	At 1 April 2023 £	Incoming resources £	Resources expended £	Transfers £	Gains and losses £	At 31 March 2024 £
<b>Designated funds</b>						
Special projects fund	142,890	-	-	(17,890)	-	125,000
Branch funds	65,002	37,844	(45,288)	-	-	57,558
Huntington's Disease Youth Engagement Service	183,532	-	-	(64,255)	-	119,277
<b>General funds</b>	1,766,722	1,837,132	(1,859,153)	82,145	64,416	1,891,262
	<b>2,158,146</b>	<b>1,874,976</b>	<b>(1,904,441)</b>	<b>-</b>	<b>64,416</b>	<b>2,193,097</b>

A designated special projects fund of £400,000 was established as a result of legacies received during 2013. This was reduced in the years to 31st March 2024 to cover the establishment of new posts covering National Support, Policy and Public Affairs, Data Management and Volunteer Support.

The Huntington's Disease Youth Engagement Service (Youth Project) designated fund was established to cover the commitment to spend £183,532 of our own resources in addition to 3 years of funding from the National Lottery for the project.

The Branch funds are also considered designated since they are held by individual branches for expenditure in their areas.

**26 Analysis of net assets between funds**

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £
<b>At 31 March 2025:</b>			
Tangible assets	17,067	-	17,067
Investments	1,032,693	-	1,032,693
Current assets/(liabilities)	942,988	158,039	1,101,027
	<b>1,992,748</b>	<b>158,039</b>	<b>2,150,787</b>

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2023 £
<b>At 31 March 2024:</b>			
Tangible assets	21,714	-	21,714
Investments	1,039,563	-	1,039,563
Current assets/(liabilities)	1,131,820	149,534	1,281,354
	<b>2,193,097</b>	<b>149,534</b>	<b>2,342,631</b>

**27 Operating lease commitments**

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2025 £	2024 £
Within one year	34,177	31,104
Between two and five years	24,990	39,058
In over five years	2,098	-
	<b>61,265</b>	<b>70,162</b>

**27 Related party transactions****Transactions with related parties**

Mr Nick Heath, a trustee, is chair of Victoria Convalescent Trust which made grants totalling £10,500 (2024: £2,544) to the charity in the year.

Ms Catherine Lyon, a trustee, received a grant from the charity of £1,000 (2024: £2,000) towards funding for her PhD on end of life care and Huntington's Disease.

A trustee appointed during the period was paid £8,450 for bookkeeping services provided prior to their appointment. No payments were made following their appointment.

There were no other related party transactions in the year.

**29 Branch funds**

Reports received from branches are set out below and incorporated into the accounts.

	2025 £	2024 £
<b>Cash balances</b>		
At 1 April 2024	57,558	65,002
Receipts in year	47,840	50,483
<b>Less:</b>		
Local welfare grants	(16,592)	(16,640)
Sent to head office	(9,385)	(12,639)
Branch activities, local newsletters, equipment, research etc.	(28,947)	(28,648)
At 31 March 2025	<b>50,474</b>	<b>57,558</b>

**30 Cash generated from operations**

	2025 £	2024 £
Deficit for the year	(191,844)	(41,492)
<b>Adjustments for:</b>		
Investment income recognised in statement of financial activities	(61,153)	(77,533)
Loss on disposal of tangible fixed assets	3,453	-
Fair value gains and losses on investments	6,870	(64,416)
Depreciation and impairment of tangible fixed assets	12,294	13,276
<b>Movements in working capital:</b>		
(Increase)/decrease in stocks	(3,555)	832
(Increase)/decrease in debtors	(287,934)	(49,452)
Increase/(decrease) in creditors	17,597	(83)
<b>Cash absorbed by operations</b>	<b>(504,272)</b>	<b>(218,868)</b>

# Acknowledgements

**We value the support of our trusts, foundations and statutory supporters. Thank you for caring about people with Huntington's disease and for making a meaningful difference.**

## Trusts

- The Access Foundation
- Alice Ellen Cooper Dean Foundation
- The Ardwick Trust
- Barbour Foundation
- Boshier-Hinton Foundation
- Bruce Wake Charitable Trust
- Chapman Charitable Trust
- The Christopher Laing Charitable Trust
- Douglas Arter Foundation
- The D'Oyly Carte Charitable Trust
- The Drapers' Company
- The Dyers' Company Charitable Trust
- Ethel & Gwynne Morgan Trust
- The Eveson Trust
- Florence Turner Trust
- The Frederick and Phyllis Cann Charitable Trust
- The Goldcrest Charitable Trust
- The Hadfield Charitable Trust
- Hadrian Trust
- The Hull and East Riding Charitable Trust
- The Ian Askew Charitable Trust
- Inter-Church Caring Trust
- J Reginald Corah Foundation Fund
- JD Foundation
- John James Bristol Foundation
- The Joseph and Lena Randall Charitable Trust
- Lord Cozens-Hardy Trust
- Lord Leverhulme's Charitable Trust
- Maximus Foundation UK

- Meridiem Charitable Foundation
- Milles Charitable Foundation
- Miss Pannett Charitable Trust
- The Mollie Croysdale Charitable Trust
- The National Lottery Community Fund
- Nationwide Colleague Grants
- Nigel Scott Will Trust
- The Norman Family Charitable Trust
- P F Charitable Trust
- PH Holt Foundation
- The Pilkington Charities Fund
- Proven Family Trust
- Roger De Haan Charitable Trust
- Sandra Charitable Trust

- The Sir James Knott Trust
- Sir James Reckitt Charity
- Sir James Roll Charitable Trust
- Squire Patton Boggs Charitable Trust
- The Strangward Trust
- The Sunrise (Sidmouth) Charitable Trust
- The Sylvia and Colin Shepherd Charitable Trust
- Tesco Community Grants
- The Ursula Keyes' Trust
- Veritas Charitable Foundation
- Victoria Convalescent Trust
- The Worshipful Company of Plumbers

## Statutory

- Birmingham City Council
- Dorset HealthCare University NHS Foundation Trust
- NHS Devon ICB
- NHS Lancashire and South Cumbria ICB
- NHS North East and North Cumbria ICB

---

## Get in touch

For advice and support or to speak to a Specialist Huntington's Disease Adviser

email [info@hda.org.uk](mailto:info@hda.org.uk)  
phone **0151 331 5444**

[www.hda.org.uk](http://www.hda.org.uk)

---

## Get involved

For your fundraising pack, please get in touch with the fundraising team

email [fundraising@hda.org.uk](mailto:fundraising@hda.org.uk)  
phone **0151 331 5445**

*Join the conversation*



**Huntington's Disease Association**  
Liverpool Science Park IC1,  
131 Mount Pleasant, Liverpool L3 5TF

Registered Charity No. 296453  
A company limited by guarantee.  
Registered in England No. 2021975

**HUNTINGTONS DISEASE ASSOCIATION**

England & Wales - Charity number 296453

---

# Accounts

---

Charity registration number 296453

Company registration number 02021975 (England and Wales)

**HUNTINGTON'S DISEASE ASSOCIATION**  
**COMPANY LIMITED BY GUARANTEE**  
**ANNUAL REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2024**

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE LEGAL AND ADMINISTRATIVE INFORMATION

---

<b>Patrons</b>	Tony Hadley George Rainsford
<b>Trustees</b>	Ms S Barker Mr S Duckett Dr G El-Nimr Mr N M Heath (Hon Treasurer) Ms C K Holmes Ms H Hubberstey Ms C Lyon Professor H Rickards (Chair) Mr D R Thomas Dr N Swales
<b>Chief executive</b>	Mrs C Stanley BSc (Hons)
<b>Charity number</b>	296453
<b>Company number</b>	02021975
<b>Registered office</b>	Suite 24 Liverpool Science Park Innovation Centre 131 Mount Pleasant Liverpool L3 5TF
<b>Auditor</b>	DSG Castle Chambers 43 Castle Street Liverpool L2 9TL
<b>Bankers</b>	National Westminster Bank Plc 66/68 St John's Road Battersea London SW11 1PB

---

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE CONTENTS

---

	<b>Page</b>
Welcome from our Chair and Chief Executive	1
Trustees' report	2 - 22
Statement of trustees' responsibilities	23
Independent auditor's report	24 - 26
Statement of financial activities	27
Balance sheet	28
Statement of cash flows	29
Notes to the financial statements	30 - 51

---

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
WELCOME FROM OUR CHAIR AND CHIEF EXECUTIVE  
*FOR THE YEAR ENDED 31 MARCH 2024***

---

A heartfelt thank you to all of you who have generously given your time, energy, voices, and donations this year. We are grateful to everyone who is dedicated to helping us achieve our mission to enable everyone affected by Huntington's disease to live life to their full potential.

Thanks to this incredible support, we're in a strong position to achieve our ambitions and new strategic vision. In 2023, we reflected on all we've accomplished over the past 50 years and developed a new five-year strategy that highlights the significant investments being made to treat Huntington's disease. While there is still no cure, more than 55 pharmaceutical and biotech companies are working on developing drugs to delay or improve the symptoms of Huntington's disease.

Thanks to the hard work of our volunteer led branch and support groups, we've been able to reach and connect with more people than ever before, allowing us to provide even greater support.

Our community inspires us every day. Together, we will build a better life for anyone affected by Huntington's disease.

***Professor Hugh Rickards, Chair  
Cath Stanley, Chief Executive***

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024**

---

The trustees present their annual report and financial statements 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 charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)".

## **Objectives and activities**

### **Charity objects**

The Huntington's Disease Association's objects are the relief and treatment of those suffering from or believed to be suffering from Huntington's disease and to provide financial support for such persons and their families in need and for research and the dissemination of the results of such research for the public benefit into the cause and possible cures whether partial or complete and possible prevention of the said disease.

The trustees have considered the Charity Commission's general guidance on public benefit in relation to the objectives of the charity. This report sets out those objectives and describes how they have been met in the current year.

### **About the Huntington's Disease Association**

We are a charity that supports people affected by this rare disease across England and Wales.

Huntington's is a profoundly disabling neurological disease caused by a faulty gene. If one of your parents has the disease, you have a 50% chance of inheriting it. There is no cure and the disease is terminal. People usually start showing symptoms between the ages of 30 and 50. Over time, the person with Huntington's loses their ability to walk, talk, think clearly, swallow and control their movements. Eventually, the person will need complete care.

Established in 1971 as a peer support group and registered in 1986, we have worked with and for the Huntington's community for over 50 years and remain community-led. We have a membership of over 5,000 people, including people living with Huntington's disease, family members, and health and social care professionals. We currently have 17 local branches and 17 support groups led by volunteers.

### **Our vision**

Together we will build a better life for anyone affected by Huntington's disease.

### **Our mission**

To enable everyone affected by Huntington's disease to live life to their full potential by:

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community by working together
- Influencing decision makers to tackle discrimination and secure equity of access to services
- 

### **Our values**

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive
- Inspirational

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

***Our strategy***

This year, we launched our Strategy 2023-27. Developed with and for our community, our strategy sets out what we want to achieve over the next five years. Our strategy has five goals:

1. We will ensure that everyone affected by Huntington's disease gets the care and support they need
2. We will help make each day with Huntington's disease the best possible day
3. We will make sure the voices of people affected by Huntington's disease are heard and at the heart of everything we do
4. We will not rest until everyone with Huntington's disease has access to treatments
5. We will be a resilient charity

Over the following pages, we report on what we've achieved under each goal this year.

***Our impact***

In the face of a profoundly disabling and currently incurable disease, we help people to make progress against four key outcomes. This year, our evaluation data shows that, because of our support:

- 93% of respondents had a better knowledge and understanding of the disease
- 87% of respondents felt less isolated
- 80% of respondents felt more resilient and better able to cope with challenges
- 83% of respondents felt more prepared for the future

We evaluate our impact through surveys, feedback and case studies.

We received zero formal complaints this year and recorded zero incidents and accidents.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## Goal 1

**We will ensure that everyone affected by Huntington's disease gets the care and support they need**

Our ambitions under this goal are:

- Anyone affected by Huntington's disease has the best support and is aware of the Huntington's Disease Association
- Everyone can access high quality care, including a multi-disciplinary team
- People are able to make an informed choice about genetic testing
- People know what advice and support are available

This year, we:

- Ensured the best support through our Specialist Huntington's Disease Advisory service
- Helped children and young people to thrive through our Huntington's Disease Youth Engagement Service (HDYES)
- Raised awareness through our *Mindful of Huntington's* campaign
- Championed high quality care through Quality Assured care home accreditation scheme
- Provided trusted information and advice

## **We ensured the best support through our Specialist Huntington's Disease Advisory service**

Our Specialist Huntington's Disease Advisory service is our core service and remains in high demand. Our team of 21 Specialist Advisers support people across all regions of England and Wales by:

- Providing a dedicated point of contact through telephone and video calls, home visits and care home visits. People can also call our national helpline for advice and support.
- Sharing trusted information and advice through our information resources and webinars
- Helping people to access specialist support, including clinics and multi-disciplinary teams
- Providing information, advice and training to health and social care professionals
- Connecting children and young people with our Youth Engagement service
- Connecting people with our online psychological support, webinars and courses
- Working with local volunteers, including our branches and support groups
- Helping people to get support with the cost of living, for example through our welfare grants programme

This year, we have supported **5,111** people through our Advisory service and Youth Engagement service, including **2,416** people with the disease, **556** people at risk of having the disease, and **1,169** carers. We welcomed **1,232** new people to our support this year and are pleased to share one journey below.

### **Chris – working with our Adviser to navigate change**

Chris turned to his Specialist Adviser when the symptoms of Huntington's disease affected his job. Chris loved his job as a support worker, visiting children's centres and hostels, organising events and providing pastoral support to residents and staff. When his symptoms started, Chris noticed an impact on his work. He told us: "I was trying to plan visits to all these locations and organise events. This is when I felt my Huntington's affected my planning and I was becoming distant and removed."

Chris asked his Adviser to support him as he faced these issues with his manager. We worked with Chris and his employer to help him stay in his job as long as possible. Chris said: "My manager and my Adviser had an honest and frank discussion about Huntington's disease. My Adviser was able to speak in a way that didn't come from a medical or scientific point of view, but rather the practicalities and human cost and change in me."

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

Chris had a workplace assessment at a local hospital and our Adviser worked with his employer around reasonable adjustments so that Chris could keep working for as long as possible. His employer funded his job for an additional six months so that Chris could carry on without pressure or expectation and say goodbye to the people he had supported during his time in the role.

Chris told us about the impact of his Adviser's support: "I know that she always acted with my best interest at heart and her advocacy gave me a voice. She was impartial with work and the realities of how to cope with and understand the ups and downs of having me as a member of staff. The whole process was very open and my Adviser's support went beyond what I thought. She was spoken of so highly by my employer – both on a personal and professional level. I owe her a debt of thanks that I don't think I'll be able to repay."

## **We helped children and young people to thrive through HDYES**

HDYES is our Huntington's Disease Youth Engagement service. Through HDYES, we support children and young people aged 8 – 25 who are impacted by Huntington's disease. We also support parents and guardians. We help professionals to understand Huntington's disease so that they can provide better support to children and young people who are affected.

In June 2023, we received a major funding boost from The National Lottery Community Fund, securing a grant of £418,360 over three years. This, along with the funds raised last year through Jingle Jam 2022 and a commitment from our reserves, is helping us to develop and grow HDYES. This year, we have doubled our HDYES team from two to four Youth Workers and created a new role of HDYES Project Officer. **211** children and young people had one or more support session with a Youth Worker this year.

Based on what young people have told us they want and need, we have delivered activity days, including watersports, bowling, mini-golf and a circus workshop. We are grateful for the support of our volunteer-led branches in delivering some of these events.

Working with our Advisory team, we have delivered online and in-person events for young adults. Together, we discussed physical and psychological wellbeing and the transition from HDYES into adult services.

***"I feel less desperately alone after this."*** A young adult who took part in one of our events

We have supported parents and guardians through online sessions and courses, including our new *Navigating Huntington's* course for people with children under the age of 18.

***"I started off with very low benchmark scores in terms of confidence and found myself learning a huge amount about how to deal with the emerging challenges. Just seeing and hearing other families and their experiences made it all feel less overwhelming and frightening and helped to ease some loneliness. I really appreciate the team's kindness and patience."*** A parent who took part in our *Navigating Huntington's* course.

We have trained and educated professionals including teachers, pastoral care professionals, special educational needs coordinators, school governors, genetics teams, children's psychologists and therapists. A full report, *HDYES Our Year One Story*, is available on our [website](#).

## **We raised awareness through our *Mindful of Huntington's* campaign**

Huntington's Disease Awareness Month takes place in May each year. This year, we ran our ***Mindful of Huntington's*** campaign during Awareness Month. We wanted to help people understand the cognitive impact of Huntington's disease and to campaign for better services and support.

Our community played a huge role in shaping our key messages with 109 people responding to our survey about how cognitive impairment and access to mental health services affected them. We found that although 85% of respondents had tried to access community mental health services, 56% felt they had been denied access because of their Huntington's disease status.

In our survey of professionals, 92% of 83 respondents reported that their patients' mental health deteriorated, with 12% of patients ultimately admitted to hospital or reaching crisis point and an alarming 11% being sectioned.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

We hosted a parliamentary drop-in event with the support of Hilary Benn MP, which was part-funded by an independent donation from Roche Products Ltd. Roche had no editorial influence over the content. 79 people attended the event, including 32 MPs who had the opportunity to learn about the challenges faced by people living with Huntington's disease and what needs to be done to improve services. Many of those attending signed pledge cards saying they would support our key policy asks, which include the introduction of NICE guidelines for Huntington's disease.

In June 2023, NICE decided not to prioritise guidelines for Huntington's disease, however we continue to campaign on this issue.

***"We are calling for improved access to mental health services, specific guidelines to ensure consistent care, and additional financial support to offset unavoidable costs such as higher energy usage associated with symptoms of the condition because the current level of provision is simply unacceptable."*** Hilary Benn MP

Our campaign film featured Holly, who has Juvenile Huntington's disease and Jen, who is at risk of having the disease. The film has been viewed over 8,800 times on YouTube.

We secured significant media coverage for our ***Mindful of Huntington's*** campaign, featuring in national and specialist publications, and across national and local radio.

## **We championed high quality care through Quality Assured**

Choosing a care home that meets both current and future care needs is one of the most challenging decisions that people with Huntington's disease, their families and carers can face. We want to make choosing a care home a more positive experience for families affected by Huntington's disease.

Through Quality Assured, we have identified the behaviours, cultures and specialist services required for a care home to specialise in caring for people with Huntington's disease. Homes must go through a rigorous accreditation programme to receive Quality Assured status. Only then are they included in our Quality Assured directory, a trusted resource for people with Huntington's disease and their families. Nine homes are now Quality Assured, including four homes newly accredited this year and one home that sustained its status this year by going through reaccreditation.

***"Everyone at Amber Lodge is delighted that we can continue to support people with Huntington's disease, their loved ones and their families. Going through the accreditation process has enabled us to strengthen our links in the community and continue to be adaptive, so we can provide the best possible standard of care that people with Huntington's Disease deserve, and help them to live longer, healthier, happier lives."*** Chiqui Sunga, Amber Lodge, Colonia Court – a Quality Assured care home

## **We provided trusted information and advice**

Our website is a trusted source of information and advice for our community and the professionals who support them. We continued to develop our website this year and 491,000 people visited the site. Our most popular web pages were:

- What is Huntington's disease?
- Information and support
- Genetic testing
- Awareness month 2023 – ***Mindful of Huntington's***

We shared blogs and stories from our community through the website. We shared stories, webinar recordings, and campaign films through our YouTube channel. Our films had 136,000 total views this year.

4,500 people are signed up to receive our monthly e-newsletter. This year, we developed e-newsletters for professionals, and for people specifically interested in research and campaigns.

We have an active social media presence across Facebook, Instagram, X, LinkedIn, and TikTok. This year, we established a dedicated Instagram channel for our Youth Engagement service and members of HD Youth Voice our youth leadership and co-production group hosted social media takeovers.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## Goal 2

***We will help make each day with Huntington's disease the best possible day***

Our ambitions under this goal are:

- People understand the choices they can make to live with Huntington's disease
- People have the best quality of life available
- People have access to tools that can make life easier

This year, we:

- Brought families together at our JHD Weekend
- Helped people with the cost of living
- Provided psychological support through online courses

### **We brought families together at our JHD Weekend**

Our annual Juvenile Huntington's Disease Weekend gives families the opportunities to come together, relax and have fun. It creates connections between people who are going through similar challenges and teaches coping strategies. 39 people from our community took part this year, with three families joining us for the first time.

The event took place at Calvert Lakes, an accessible adventure activity centre in the Lake District. Activities included canoeing, rock climbing, swimming, a trip to a wildlife park, and a trail walk suitable for wheelchair users. Everyone could get involved, including those in the more advanced and most disabling stages of the disease. Children and young people went home with a sense of achievement and families made lasting memories.

Parents and carers attended a session about managing changes in behaviour, with guidance around handling stress responses and creating meaningful activities to help manage behaviour. Parents and carers also enjoyed a bush craft session on a lakeside beach and walked to a local café.

Children, young people and family members shared their feedback through evaluation forms and conversations during the weekend. Everyone who completed an evaluation form rated the weekend as good or excellent and would recommend the weekend to others in a similar situation.

*Some of the children, young people and families who have attended the weekend for a number of years have made deep, sustaining friendships. One person described the weekend as "a highlight of our year."*

### **Paramjit and Sheenam – making treasured memories at our JHD Weekend**

*Paramjit lost her husband to Huntington's disease in 2002. In the same year, her daughter Sheenam was diagnosed with Juvenile Huntington's disease. Paramjit and Sheenam have regularly attended our JHD Weekend over many years.*

Paramjit told us: "Attending for the first time was the most incredible experience ever and it has left an indelible mark on my heart. I had not seen any other young person with the disease besides my own daughter Sheenam. I remember my heart being so very full of joy seeing Sheenam canoeing, climbing the climbing wall and going on the indoor zip wire. She truly loved the adrenaline rush and capturing her beaming smile is a moment I will treasure forever."

"Spending quality time with the parents away from the young people where we could share and learn in a totally unconditional and non-judgemental space was reassuring. People were so generous with sharing their experiences and what was helpful in coping."

"As soon as we leave the weekend we are looking forward to receiving an email giving us the dates of the next weekend. What Sheenam gets from the weekend is a sense of adventure, being around other young people whom she can relate to – even though she can no longer speak she still feels totally included. It's like a big family reunion. It's something that keeps Sheenam going and something to look forward to. The photos give us a talking point to reminisce about the good times. Events like this are so very important for our community because out of 365 days a year we are able to spend a weekend together in a place where we and our loved ones are making memories."

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## **We helped people with the cost of living**

People with Huntington's disease can be financially vulnerable. Many people have to give up their jobs earlier than planned. People with the disease can spend hours at home, need to keep warm and need a high calorie diet – meaning higher costs for fuel and food. Carers may also have to give up their jobs and many families struggle to survive on lower incomes and benefits.

With the cost of living crisis getting worse, we wanted to understand the impact on our community. 116 people responded to our Cost of Living survey. Our findings showed that:

- 62% were receiving welfare benefits
- 91% were using higher levels of energy in their home because of symptoms
- 90% had higher living costs because of symptoms - 38% had higher costs because of specialist food and a high calorie diet, 18% because of specialist equipment and adaptations, and 11% because of forgetfulness and compulsive behaviour
- 65% were very worried about the current price of household energy bills and 27% were fairly worried
- 67% were worried about the general cost of living and 25% were fairly worried
- 

With the end of the energy price cap predicted to cause a 20% increase in bills, we joined Martin Lewis and MoneySavingExperts's campaign to cap energy bills. We campaigned with over 100 other charities and succeeded in stopping the rise.

We also set up our *Cost of Living Hub*, a dedicated area on our website where people can access information, advice and signposting to other organisations that can help.

Our welfare grants programme continued to provide small grants of up to £350 to people affected by Huntington's disease or Juvenile Huntington's disease. These grants help people to reduce risk and improve quality of life, for example by purchasing a new washing machine or voice banking. This year, we received 53 welfare grant applications and awarded 47 grants with a total value of £15,412. We saw an 18% increase in applications, up from 45 last year. We gave 18% more grants, up from 40 last year.

***"This grant will support communication with ease and clarity in the future. I see this as an achievement and a means to a healthy lifestyle and continued involvement with others."*** Person who received a welfare grant for voice banking

## **We provided psychological support through online courses**

This year we expanded our provision of specialist psychological support for people affected by Huntington's disease. We launched ***Keeping Yourself in Mind***, running four courses - two for family carers, one for parent carers of young people with Juvenile Huntington's disease, and one for people who have tested positive for Huntington's disease but are not yet showing symptoms.

Based on *Acceptance and Commitment Therapy* (ACT), these eight - week courses are designed to help people accept and live with challenges while respecting their values and goals. Led by Dr Sarah Gunn, Lecturer in Clinical Psychology at the University of Leicester, and supported by our Advisory team, the programme is part of a University of Leicester study looking at the effectiveness of ACT as an education and coping strategy tool for carers in our community. This is important because there is limited research evidence for psychological interventions in Huntington's disease. The courses included theory, discussion, practical application and mindfulness exercises.

***"I know that if I had had access to such a course eleven years ago when I was diagnosed, I believe it would have completely changed my journey with Huntington's disease."*** Person who took part in our *Keeping Yourself in Mind* course

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

We delivered two **Narrative Therapy** sessions, one for family carers and one for parents of adult children at risk of Huntington's disease. In Narrative Therapy, participants explore their identity through values, beliefs and support systems. Led by clinical psychologist Mariangels Ferrer Duch, and supported by our Advisory team, these sessions helped people to identify and focus on the many small things that are important in life but which can often be overlooked in times of stress.

***"The use of the metaphor of a tree was a really good way of bringing the 'stuff' of our lives into perspective. Interaction with other course participants was very positive and helpful."*** Person who took part in a Narrative Therapy session

We delivered our five-week **Parents of Adult Children at Risk** online course, with 12 people attending. This course is designed to increase knowledge and awareness whilst creating a space for people to share their experiences with others going through similar challenges. It covers the support we offer, guidance on genetic testing, a research update, and advice on planning ahead. The course also included a Narrative Therapy session.

We delivered our new four-week course, **Navigating Huntington's**, to ten parents of children under 18 who are at risk of Huntington's disease. The course covers the support we offer, how to talk about Huntington's disease as a family, positive activities for families, and a research update. This course is delivered through our Youth Engagement service.

***"I was extremely anxious about how to tell my children about my mother's diagnosis. However, the course gave me the courage to start the process of telling my children."*** Person who took part in our Navigating Huntington's course

**Goal 3**

***We will make sure the voices of people affected by Huntington's disease are heard and at the heart of everything we do***

Our ambitions under this goal are:

- Our work is driven by people affected by Huntington's disease
- We will understand and advocate the needs of everyone affected by Huntington's disease
- We will increase our reach and work with all communities affected by Huntington's disease
- We will increase people's skills to enable them to support people living with Huntington's disease

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

This year, we:

- Put community voice at the heart of research through HD Voice
- Co-produced our Youth Engagement service with HD Youth Voice
- Launched HD Ambassadors – sharing stories to inspire others
- Trained and educated health and social care professionals

## **We put community voice at the heart of research through HD Voice**

HD Voice is our Patient and Public Involvement group, giving people a voice in Huntington's disease research and our work as a charity. 48 people were part of HD Voice this year, getting involved by commenting on proposed research, attending focus groups or reviewing patient information sheets. Members also sit on our Quality Assured care home accreditation panel.

## **Kemi – raising awareness and campaigning for change through HD Voice**

Kemi is a valued member of HD Voice. She told us what motivates her: "I had never heard of Huntington's disease until my sister-in-law was diagnosed about ten years ago. It's been devastating to see a loved one change so much and feel so helpless. One of my friends undertook an amazing challenge to raise funds for the Huntington's Disease Association, running as many 10ks as possible in 24 hours. I thought that if he could do that, I should do something! I looked on the website and found out about HD Voice. I've been part of care home assessment panels, helping to determine their suitability to support Huntington's disease patients. I reviewed documents for pharmaceutical companies and I've been interviewed by researchers looking into various possible Huntington's disease interventions."

As part of our *Mindful of Huntington's* campaign, Kemi joined our parliamentary event this year. She told us: "This was a great day. It was humbling to meet so many people and hear candid life experiences. It ramped up my willingness to do more. It's vital for the Huntington's community to have a presence at such events to advocate for change. There's so much basic support missing that people might not realise, such as the lack of NICE guidelines."

Kemi plans to stay involved with HD Voice, saying: "I'll keep putting my hand up for opportunities to get involved. I'd like to play a part in raising the profile of the work that HD Voice does as well as raise awareness in other countries. There's so much to do, especially as there's currently no cure for Huntington's disease. There are improvements that might not be available for my sister-in-law to benefit from, but if I can support the next generation, I'll do what I can. Representation matters. As a black female, I feel an obligation to highlight that this condition can affect people who look like me as well as other marginalised groups."

## **We co-produced our Youth Engagement service with HD Youth Voice**

HD Youth Voice is our youth leadership and co-production group of 13 inspiring young leaders aged 16-27. A member of HD Youth Voice is also a trustee for the Huntington's Disease Association. Another member is also a Young Adult Executive Committee member for the European HD Network.

Playing a lead role in co-producing our youth service, HD Youth Voice members are changing the landscape for children and young people in our community. This year, the group co-produced our **You are not alone** film, which has been viewed more than 1,400 times on YouTube. They have also played a huge role in producing our social media and online content, including social media takeovers and blogs.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

HD Youth Voice meets online monthly and came together for a 2-night residential this year. This was an opportunity for peer support, co-production of projects, community activities and spending time together.

***“HD Youth Voice has a huge impact and helps me feel less alone, which means I can combat everyday life with Huntington’s disease head on.” Charlotte***

***“HD Youth Voice has taught me that just because someone may be quiet doesn’t mean they’re alright. HD Youth Voice has given us a space to talk about similar experiences we all have.” Joe***

## **We launched HD Ambassadors – sharing stories to inspire others**

We launched our HD Ambassadors programme this year for anyone affected by Huntington’s disease who wants to share their story to inspire others. 55 people signed up and this hugely supportive group has taken every opportunity to spread the word this year. Our HD Ambassadors have helped to secure major press coverage, spoken at events, and helped judge our annual Fundraising awards. They are helping us to embed a story-led approach in our communications by writing blogs and sharing videos about their personal experiences of Huntington’s disease.

***“Reading other people’s stories makes me feel less alone.” A person who recently discovered that Huntington’s disease is in their family***

## **We trained and educated health and social care professionals**

This year, we established a new role of Education Lead, which is helping us to develop and grow our training, education and webinars programme.

We delivered 15 webinars this year, open to anyone affected by Huntington’s disease and the health and social care professionals who support them. Topics ranged from Continuing Health Care to keeping active with Huntington’s disease. We had 456 webinar attendances and our webinar recordings have been viewed 7,893 times on YouTube.

Because Huntington’s disease is rare and complex, many health and social care professionals may not understand the disease or how best to care for someone who is affected. We ran our *Understanding Huntington’s: a certificated course for professionals’* course twice this year. 100 delegates attended the three-day online course, which covers all aspects of the disease. We also delivered 200 training and information sessions for professionals with 1,960 attendances and nine drop-in sessions for professionals with 595 attendances.

We ran our new *HD Champions* training twice this year with 17 delegates graduating. This course is for social care professionals who support people with Huntington’s disease. It is an opportunity for them to develop their understanding and deepen their practice. The course includes self-directed online study, a reflective exercise, consideration of case studies, and discussions with one of our Specialist Huntington’s Disease Advisers.

Working with Specialist Occupational Therapist Alex Fisher, we held a Mental Health online study day this year, with 58 delegates attending. The event was designed to increase understanding of the mental health issues that affect people with Huntington’s disease, so that health and social care professionals can provide better support. A range of guest speakers covered communication, cognition, mental health – with real world practice examples, and psychological support.

***“I have been working with someone with Huntington’s disease for a while now and this course has made me look at and understand some of his psychological difficulties very differently and with so much more knowledge about Huntington’s.” Person who attended our Mental Health online study day***

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## Goal 4

### ***We will not rest until everyone with Huntington's disease has access to treatments***

Our ambitions under this goal are:

- We will continue to support the community in accessing any new treatments
- We will advocate for equity of access to research opportunities
- We will support our partners in the global Huntington's disease community to find treatments for the disease

This year, we:

- Shared research updates and opportunities
- Worked with Pharmaceutical partners
- Developed new resources with research partners

### **We shared research updates and opportunities**

We know that research and the opportunity to take part in trials and access potential treatments, is hugely important to people in our community. We shared research updates and promote opportunities to take part in clinical trials through our website, webinars, and social media. This year, we developed an e-newsletter specifically for people who want to be informed about research opportunities.

People in our community can also access clinical trials through participation in HD Voice and through Enroll-HD, the world's largest observational study for Huntington's disease. Enroll-HD provides data to drive research into potential treatments and access to clinical trials.

We continue to contribute funding to HD Buzz. HD Buzz delivers research news in plain language, written by scientists for the Huntington's disease community.

### **We worked with Pharmaceutical companies**

We have developed close working relationships with pharmaceutical companies who are leading the way towards developing a treatment for the disease.

Our Chief Executive currently sits on the advisory board for a study into Pre-Motor Burden of Illness. Her input has meant a major redesign of the study to make it more likely that people will want to participate. The advisory board consists of global representation and representatives from the UK.

Sage, Prilenia, Roche and uniQure supported us with sponsorship for events. The development of our new website was supported by uniQure.

***"Diseases are never cured by any individual or even a single company, it requires this really complicated ecosystem and you need as many shots on goals as you possibly can."*** Ricardo Dolmetsch, uniQure

### **We developed new resources with researchers**

Our funded research looks at how we can help people affected by Huntington's disease now, with a focus on learning about the disease and treating symptoms.

This year, we shared resources on keeping active with Huntington's disease. These resources were developed by Dr Una Jones and researchers at Cardiff University with the Huntington's Disease Association, Carers' Trust Wales, carers and people with Huntington's disease. They provide a how-to guide to developing a physical activity plan for people with Huntington's disease.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## Goal 5

### *We will be a resilient charity*

Our ambitions under this goal are:

- Everyone feels valued and welcome
- The charity is financially stable, well governed and with a clear plan for managed growth
- Our staff and volunteers are invested in and supported
- The charity is well connected through partnerships
- The Huntington's disease community has active champions

This year, we:

- Launched our Strategy 2023-2027
- Invested in new roles and infrastructure
- Worked in partnership to support our community
- Worked with our community and partners to fundraise
- Advocated for Huntington's disease through our celebrity champions

### **We launched our Strategy 2023-2027**

This year, we launched our Strategy 2023-27. Developed with and for our community, our strategy sets out what we want to achieve over the next five years. Our strategy has five goals:

1. We will ensure that everyone affected by Huntington's disease gets the care and support they need
6. We will help make each day with Huntington's disease the best possible day
7. We will make sure the voices of people affected by Huntington's disease are heard and at the heart of everything we do
8. We will not rest until everyone with Huntington's disease has access to treatments
9. We will be a resilient charity

### **We invested in new roles and infrastructure**

This year, we launched our *Volunteer Hub*, a dedicated resource on our website that supports volunteers, branches and support groups. The Volunteer Hub includes policies, guidelines and risk assessments plus access to a design centre where volunteers can create promotional material.

We established new roles, including our Education Lead, which is helping us to develop and grow our training, education and webinars programme. We created a new Team Leader role for the Advisory service, bringing additional capacity to the team. We created the role of Executive Support Officer to support the smooth running of the charity, including supporting the Chief Executive Office and trustees.

With the significant investment in our Youth Engagement service, we appointed a HDYES Project Officer and two new Youth Workers, providing more intensive, tailored support for young people.

We streamlined a new job pack that gives applicants more information about the charity and how new starters are welcomed. We used the BreatheHR platform to create a more consistent and user-friendly job application process.

We develop staff skills through training. Ensuring that our Advisers can best support our community, they attended training on Mental Capacity, Safeguarding, Compassion in Dying, Non-Abusive Psychological and Physical Intervention (NAPPI), and Deaf Awareness. Managers took part in Neurodiversity, Safer Recruitment training and three members of staff began a management and strategic leadership qualification.

A remuneration review, benchmarked our current charity salaries against those in other similar sized charities across the sector, taking into account specific roles and responsibilities and making changes as relevant to ensure the charity is a competitor in the sector.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

Necessary equipment upgrades included new mobile phones for all staff and upgrades of a number of laptops providing the team with the tools they needed to carry out their work.

## **We worked in partnership to support our community**

We have continued to work with Genetic Alliance UK and the Neurological Alliance to champion the needs of the Huntington's community and influence decision makers.

This year we supported the Neurological Alliance's '#BackThe1'in6' campaign . Giving a voice to people living with a neurological condition, the campaign called on the government to create a Neuro Taskforce to improve services for people with neurological conditions, including access to mental health and wellbeing support.

On Mental Health day in October 2023, we joined forces with 50 charities to write to the Secretary of State for the Department of Health and Social Care about how people affected by a neurological condition struggle to access mental health services.

Working with The Genetic Alliance, a member of our community did a social media takeover for the day, raising awareness of Huntington's disease on a global platform.

Our Chief Executive, Cath Stanley, has co-authored several publications examining the availability of services for people with Huntington's disease and the burden of illness. Published research that we contributed to, included:

- The Huntington's Disease Quality of Life Battery for Carers (HDQoL-Cs): evidence from the Huntington's Disease Burden of Illness (HDBOI) study for Europe, co-authored with global representation and representatives from across the UK. Published in the Journal of Neurology, Neurosurgery and Psychiatry
- Caregiver PRO: The Huntington's Disease Quality of Life Battery for Carers (HDQoL-Cs): evidence from the Huntington's Disease Burden of Illness (HDBOI) study for Europe and US
- Caregiver Burden: Caregiver Burden: evidence from the Huntington's Disease Burden of Illness (HDBOI) study for Europe and US
- ISPOR EU 2023: Work Productivity and Activity Impairment of caregivers of Huntington's Disease patients in the US and EU5: Evidence from the Huntington's Disease Burden of Illness Study (HDBOI)

As part of our work in campaigning for NICE guidelines, we met with Sir Stephen Powis. All NHS Mental Health Trusts were subsequently advised that people with Huntington's disease must be included in their service if they have a mental health symptom.

Our Education Lead spoke at the European Huntington Association conference in Belgium about HD Champions, in partnership with the Swedish Huntington Association.

We raised awareness of our Youth Engagement service by presenting to the UK Huntington's Disease Network, the Predictive Testing Consortium, and at a Neurogenetics Calman training day. Our HDYES team met up with colleagues from the Scottish Huntington's Association Youth Service to discuss ways of working that best support children and young people in our community.

Our celebrity champions helped to raise awareness and advocated for our community. Our patron, Actor George Rainsford generously raised the profile of our *Mindful of Huntington's* campaign, featuring in media coverage across print, online and radio. Comedian and actor Jess Robinson, who has a personal connection to Huntington's disease, also took part in broadcast media interviews and increased our engagement on social media.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## **We worked with our community and partners to fundraise**

Once again, our amazing community played a huge and highly valued role in raising funds to sustain our lifeline services. We raised an outstanding **£517,417** through community fundraising and events. Our '#TeamHDA' runners, including our patron George Rainsford, raised **£68,682** through the TCS London Marathon. Our runners also took to the streets from Newcastle to South Shields, raising **£20,241** through the Great North Run.

Our '#HD8000' series raised over **£12,000** through our '#HDMove', '#HDHike' and '#HDBike' challenges.

Our community raised over £10,000 through our first *Odds And Socks Day* by sporting odd socks and raising awareness of Huntington's disease. This was our most inclusive fundraising campaign to date, and we loved seeing so many people wearing their odd socks in care homes, schools and other settings.

Community members took on some incredible fundraising challenges. William Parkes completed the TransAmerica Cycle Challenge, Conor Toland completed a 24-hour solo cycle challenge. Charlotte Conn completed her CrossFit challenge and Philip Bull took on the Three Peaks and a cycle challenge. The Hadjikkou family continued their highly valued fundraising, donating more than £7,000 from their Golf Day. Gemma Rae Dale and her family organised a charity ball and Otterburn Care Home organised a zip wire event. Our friends at Do It For Dom donated a wonderful £25,000 through their ongoing fundraising activities. Sales of *One Shilling*, the story of John Elvin and the golden era of football programme design, raised over £5,000.

We were delighted to be chosen as Charity Partner for the Club Triumph Round Britain Reliability Run, which took place in October. Over 48 hours, over 100 teams drove almost 2,000 miles from Knebworth House to John O'Groats and Lands End, before arriving back at Knebworth House. This fantastic event raised a wonderful **£79,846**.

We experienced a **26%** increase in individual giving this year, raising **£442,871** from our generous supporters. We raised **£13,160** through the Big Give Kind2Mind campaign and **£16,926** through the Big Give Christmas Challenge. These funds helped us to provide specialist psychological support to people in our community and deliver the JHD Weekend. We value the support of our Big Give match funders, including a major donor and the Hospital Saturday Fund.

We launched a Memory Wall in partnership with MuchLoved and received 27 special dedications to loved ones on this page. Through our partnership with MuchLoved, people in our community can now use the Grief Chat bereavement counselling service.

Our regular donors donated an amazing **£93,163** over the year. Our charity lottery goes from strength to strength. We attracted **141** new lottery players this year and raised **£22,203**.

Legacy giving continues to grow and we received **£634,091** from legacy donations this year. 81 people accessed the National Free Wills Network; 6 people went on to write their will for free with 5 people pledging a gift to the charity.

In July, we were thrilled to welcome everyone back to the Radisson Blu Liverpool for the **Huntington's Disease Association Awards**. Following nominations and hundreds of votes from our community, this year's winners were announced as:

- Fundraiser of the Year - Jess Webb
- Young Fundraiser of the Year - Kara-Mai Oliver
- Fundraising Group of the Year - HD Support Squad
- Excellence in Health or Social Care Winners - Fiona Chaabane
- Founders Award - The Branches and Support Groups of the Association

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

We were delighted to be selected as FutureHeads Recruitment's Charity Partner of the Year. We received valuable support from corporate partners, including Novuna Mitsubishi, RWD, Yorkshire Car Parts and Recovery Clinic, Johnson's Workwear and KME. Three Brothers Brewery developed a new beer in our name, raising £500. We received support from many others in the world of business either through matched funding or charity committees.

We value the continued support of our trusts and foundations partners, many of whom have supported us over many years. In an increasingly competitive fundraising environment, their continued generosity and kindness is more valuable than ever.

A grant of **£418,360** over three years from The National Lottery Community Fund Reaching Communities programme is making a huge difference to how we support children and young people affected by Huntington's disease. This funding is helping us to develop and grow our Youth Engagement service.

Our partnerships with several Integrated Care Boards and Integrated Care Systems have continued over the year.

We introduced new methods of gathering feedback on our fundraising, including surveys. We received zero complaints about our fundraising this year. We monitor return on investment on all our fundraising activities.

We meet or exceed all statutory and regulatory obligations. We are members of the Fundraising Regulator and the Chartered Institute of Fundraising, following their best practice guidance and the Charity Commission guidance for Charity Trustees (CC20). We comply with the Privacy and Electronic Communications Regulations (PECR). We work with people who are vulnerable and follow the Chartered Institute of Fundraising's guidance Treating Donors Fairly – responding to the needs of people in vulnerable circumstances.

### ***George and Scott – pushing themselves to the limit***

Brothers George and Scott are pushing themselves to the limit by taking on a range of fundraising challenges. Their dad was initially misdiagnosed with Alzheimer's disease before they found out he had Huntington's disease.

George told us: "When we first learned that our dad had Alzheimer's disease we wanted to help in our own way. We planned to complete 12 challenges in 2020 - one challenge every month. We completed the first one in January 2020, which was a half marathon in under two hours – an amazing achievement for me personally as I had never run more than 10k in a timed event. Unfortunately, the rest of the challenges were postponed due to the Covid-19 pandemic. A matter of months later we learned that our dad had been misdiagnosed and he in fact had Huntington's disease. We decided that when everything returned back to normal the Huntington's Disease Association was the charity that we would raise money for. It wasn't something that we had heard much about, unlike Dementia and Alzheimer's. This was one of the reasons we agreed that whatever our results, we would help to raise as much awareness and money for Huntington's disease as we could."

"So far, we have completed a skydive, a Total Warrior 12.5km event, a half marathon, a marathon and a 35-mile walk along the Gritstone Trail. Personally, I found the skydive the most enjoyable so far. Mainly because it helped me overcome a fear of heights and experience something truly amazing and out of this world."

"Three of the remaining challenges really stick out for us. The 60-mile bike ride, the 62 miles (100k) Jurassic Coast walk over two days and the 56-mile (90k) walk under 24 hours. These will continue to push our limits and our determination. The crazy thing for me is that we have to complete the 90k walking challenge in one full day without stopping or sleeping – something which blows our minds."

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**Our year in numbers**

**5,111** people supported through our Advisory service and Youth service, including:

**2,416** people with the disease

**556** people at risk of having the disease

**1,169** carers

We welcomed **1,232** new people to our support this year

**8** online courses for our community with **73** attendances

**15** webinars with **456** attendances

Webinar recordings viewed **7,893** times on YouTube

**48** HD Voice members

**13** HD Youth Voice members

**55** Ambassadors

**17** branches

**17** support groups

**2** Certificated courses for Professionals with **101** delegates

**2** HD Champions courses with **17** delegates

**1** Mental Health online study day with **58** delegates

**200** training and information sessions for professionals with **1,960** attendances

**9** drop-in sessions for professionals with **595** attendances

**4** new members of our Quality Assured scheme for care homes

A total of **9** homes now accredited through the scheme

**53** welfare grant applications – **up 18%** on last year

**47** welfare grants awarded with a total value of **£15,112**

**98%** of 718 respondents rated the activity or service as excellent or good

**93%** of 955 respondents have a better knowledge and understanding of the disease

**87%** of 217 respondents feel less isolated

**80%** of 283 respondents feel more resilient and better able to cope with challenges

**83%** of 299 respondents feel more prepared for the future

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## Financial review

The results for the year show an overall deficit of £41,492 (2023: deficit £104,651) made up of a surplus on the general fund of £34,951 (2023: deficit £247,578) and a deficit on the restricted funds of £76,443 (2023: surplus £142,927). The overall performance was boosted by income from legacies and fund raising centrally, in branches and by our supporters throughout England and Wales. Details of particular activities and sources of funds are given elsewhere in the Trustees Report.

At the year end the restricted funds balance amounted to £149,534 (2023: £225,977). Details are given in note 23 of the specific conditions applicable to these funds. The designated funds which have been set aside for specific purposes accounted to £301,835 (2023: £391,424) are detailed in note 24 and show their application during the year.

In order to match our reserves target, the Trustees continued their policy of budgeting for deficits over the next three years and are therefore content with the results shown in the accounts.

## Reserves Policy

The reserve requirement of the charity is to enable the salaries of staff members and running costs to be covered in the event of short-term income fluctuations. As a result of the uncertainties arising increased general cost and inflationary pressures which may impact on income, it was agreed that the target for general reserves needed to be maintained at nine months recurring costs being approximately £1.4m. At the year end, free reserves available excluding designated funds and tangible fixed assets but including fixed asset investments stood at £1,869,548 (2023 £1,746,363) and therefore exceeded target.

We have received several substantial legacies in recent years and recognise the need to reduce reserves. To achieve this, we are committed to investing our own resources in new roles and organisational development over the next two years. These plans will include developing support for volunteers, the development of the policy and public affairs work, and developing the infrastructure of the charity by appointing in house support for finance and human resources, both of which are necessary due to the charity's growth. In addition to developing a robust EDI strategy. This will be financed from the reserves.

## Grant making policy

The charity provides welfare grants to people directly affected by Huntington's disease. The applications for a grant are submitted and supported by a health care professional and a specified criteria needs to be met. There is also a criteria of items we will fund. Applicants can only apply once a year, and the maximum grant is £350. We receive feedback as to what the impact of the grant was to the individual.

When funding is received specifically for research this sits in a specific fund. When sufficient funds are available the charity opens an invitation for submissions for research applications. These are reviewed by the medical advisory panel and ranked and they make recommendations to the trustees about which to fund. Research must be based in England and Wales.

## Investment policy

The charity delegates responsibility for investments to an expert third party, currently Rathbones. They invest in collective, reputable funds that are in line with the charity's objectives. The risk level of the portfolio is set at medium. The finance committee regularly review the performance of Rathbones investments and report back to the trustee board. Rathbones follows environmental, social and governance (ESG) investing practice with all investments screened to reflect responsible and ethical ESG best practice.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**Future plans**

We will continue to deliver on the commitments of our Strategy 2023 – 2027 in the coming year.

A priority for the coming year is development of a care pathway for Huntington's disease to improve quality of care. Following a 2023 decision by NICE not to prioritise guidelines for Huntington's disease, we will work with health and social care professionals to develop a recommended care pathway.

We will continue to develop our Youth Engagement service, with the multiyear funding we secured this year from The National Lottery Community Fund. In Year Two of the project, we will increase the number of activity events for children and young people, including a residential for 8 – 17 year-olds. We'll continue to provide support for parents and guardians, delivering our online courses and new webinars. We'll continue to train, educate and engage professionals.

HD Youth Voice will continue to meet monthly and their residential will run over three nights, based on feedback from the group that they want to spend more time together. Following specialist training, the group will deliver peer support to other children and young people in our community.

We'll continue to develop our support for young adults, running a residential event in 2024.

We'll continue to provide psychological support to people in our community. Through HDYES, we'll roll out a new approach called LOHA Digital Systemic Therapy. Through LOHA, parents and guardians work through a digital toolkit with their children. This empowers parents and guardians to help their children identify and understand their feelings, emotions and behaviours.

We will attend the EHDN 2024 conference in September to continue to learn and share knowledge about Huntington's disease. Our staff will meet with and contribute to the working groups, which are:

- Genetic Counseling and Testing
- Health Economics
- HEATED TF (Huntington's Equal Access to Effective Drugs)
- Multidisciplinary Treatment and Care
- Paediatric HD
- Physiotherapy
- Psychological Interventions and Approaches

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

For this year's Awareness Month campaign, we will target people who have little understanding of Huntington's disease with a call to action to **Learn in 5 minutes**. We will develop a factsheet that describes the disease and how we can help. Although Huntington's disease is complex, the **Learn in 5 minutes** message will improve people's understanding of the condition by presenting complex information in an easy to understand way.

We will bring our community together for the first in-person family conference and AGM since the Covid-19 pandemic. The event will take place at the prestigious Crewe Hall Hotel in Cheshire in October 2024.

We will extend our HD Ambassadors with new members and seek more opportunities to speak. We will continue to work with HD Voice and encourage more members of the community to have an active voice. We will work with HD Youth Voice as we develop website content for young people.

People's stories will continue to be at the heart of all our communications, including our Awareness Month campaign. Covering all aspects of the disease, each month we will focus on a dedicated topic such as genetic testing, starting a family, and mental health. We will work with the community to capture and share their experiences through our website and social media.

We will continue to work with Enroll-HD to accelerate progress toward effective treatments. We will continue to support HD Buzz, who help us understand the progress being made in research for Huntington's disease.

We will continue our work alongside pharmaceutical companies as they develop drugs that could delay symptoms, improve symptoms, and hopefully find a cure. Our attendance at EHDN 2024 will keep us current with the latest research news. The conference also gives us an opportunity to hear from Huntington's disease associations from across the world on best practice in managing the symptoms of Huntington's disease.

Building on our effective engagement with policy makers, we will establish a new role of Head of Policy and Public Affairs. This appointment will ensure we have a stronger voice in parliament and support our campaign for Care Coordinators across England and Wales to ensure that everyone affected by Huntington's disease gets the care and support they need.

A new Volunteer Manager will support our current volunteers, branches and support groups and develop new opportunities for people to get involved. Supporting our financial resilience, we will recruit a new role of Community Fundraiser Co-ordinator.

As the charity continues to develop and grow, we want to ensure the health and wellbeing of our team and provide support, training and development opportunities. We will create a new HR Manager role to support this.

In April 2024, actor Alison Steadman will present our BBC Lifeline appeal to raise awareness of Huntington's disease and appeal for donations. The appeal will be broadcast on BBC One and BBC Two and subsequently be available on our website.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

---

## Structure, governance and management

### Governing document

The company is a registered charity founded in 1971 and incorporated on 21 May 1986. The charity is governed by the Memorandum and Articles of Association.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Ms S Barker  
Mr S Duckett  
Dr G El-Nimr  
Mr N M Heath (Hon Treasurer)  
Ms C K Holmes  
Ms H Hubberstey  
Ms C Lyon  
Professor H Rickards (Chair)  
Mr D R Thomas  
Dr N Swales  
Ms B E Waters (Resigned 4 November 2023)

### Recruitment and appointment of trustees

The Trustees are elected to serve a term of three years at the Annual General Meeting by the voting members of the Association who are the Guarantors.

### Organisational structure

The charity is managed by an Executive Council made up of the trustees, which met on seven occasions during the year.

The Executive Council members focus on the strategic decisions required for the overall governance of the Huntington's Disease Association and devolve operational running to the management team.

The Chief Executive and senior managers oversee the operational management of the Huntington's Disease Association within the policies and guidelines approved by the Executive Council. Prior to board meetings, the Chief Executive provides a written update report to the Executive Council on the operational management of the charity, which all senior managers have an input into. These reports provide the Executive Council with a detailed overview of the operational progress of the Association. The Chief Executive attends board meetings to discuss the management reports further and answer any questions the trustees may have.

### Trustee induction and training

Most trustees are already familiar with the work of the charity and their training involves briefings on their duties and liabilities. Additionally, new trustees receive an induction pack covering:

- The duties of charity trustees;
- An induction pack outlining duties and responsibilities;
- The Association's Memorandum and Articles of Association, strategic plan, latest published annual report and accounts, financial projections and budgets, project and programme plans and publications;
- Trustee details and staff structure;
- *The Essential Trustee: what you need to know* (Charity Commission);
- Minutes and reports submitted to the previous three meetings of the board of trustees.

### Remuneration policy

The trustees have responsibility for setting the pay and remuneration of the charity's key personnel and this is done on an annual basis, including a formal cost of living review. Salaries are benchmarked with other similar organisations across the sector.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**Auditor**

In accordance with the company's articles, a resolution proposing that DSG be reappointed as auditor of the company will be put at a General Meeting.

**Disclosure of information to auditor**

Each of the trustees has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

**Small company provisions**

This report has been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The trustees' report was approved by the Board of Trustees.

*N M Heath*

**Mr N M Heath (Hon Treasurer)**

Dated: 28 August 2024

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF TRUSTEES' RESPONSIBILITIES  
FOR THE YEAR ENDED 31 MARCH 2024**

---

The trustees, who are also the directors of Huntington's Disease Association for the purpose of company law, are responsible for preparing the Trustees' Report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law requires the trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these accounts, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT

## TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

---

### Opinion

We have audited the financial statements of Huntington's Disease Association (the 'charity') for the year ended 31 March 2024 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2024 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

### Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the trustees' report has been prepared in accordance with applicable legal requirements.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
INDEPENDENT AUDITOR'S REPORT (CONTINUED)  
TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION**

---

**Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

**Responsibilities of trustees**

As explained more fully in the statement of trustees' responsibilities, the trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

**Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT (CONTINUED) TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

---

## Capability of the audit in detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

Based on our discussions with the charity's management and the Trustees, we identified that the following laws and regulations are significant to the entity:

- Those laws and regulations considered to have a direct effect on the financial statements include UK financial reporting standards and Charity Law.
- Those laws and regulations for which non-compliance may be fundamental to the operating aspects of the charity and therefore may have a material effect on the financial statements include compliance with the charitable objectives, public benefit, fundraising regulations, safeguarding and health and safety legislation.

These matters were discussed amongst the engagement team at the planning stage and the team remained alert to non-compliance throughout the audit.

Audit procedures undertaken in response to the potential risks relating to irregularities (which include fraud and non-compliance with laws and regulations) comprised of: inquiries of management and the Trustees as to whether the entity complies with such laws and regulations; enquiries with the same concerning any actual or potential litigation or claims; inspection of relevant legal correspondence; review of Trustee meeting minutes; testing the appropriateness of journal entries; and the performance of analytical review to identify unexpected movements in account balances which may be indicative of fraud.

No instances of material non-compliance were identified. However, the likelihood of detecting irregularities, including fraud, is limited by the inherent difficulty in detecting irregularities, the effectiveness of the entity's controls, and the nature, timing and extent of the audit procedures performed. Irregularities that result from fraud might be inherently more difficult to detect than irregularities that result from error. As explained above, there is an unavoidable risk that material misstatements may not be detected, even though the audit has been planned and performed in accordance with ISAs (UK).

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

## Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



**Andrew Moss BA FCA (Senior Statutory Auditor)**  
for and on behalf of DSG

28 August 2024

**Chartered Accountants**  
**Statutory Auditor**

Castle Chambers  
43 Castle Street  
Liverpool  
L2 9TL

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF FINANCIAL ACTIVITIES  
INCLUDING INCOME AND EXPENDITURE ACCOUNT**

**FOR THE YEAR ENDED 31 MARCH 2024**

		Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
	<b>Notes</b>						
<b>Income from</b>							
Donations and legacies	<b>3</b>	1,673,330	95,106	1,768,436	1,298,518	74,311	1,372,829
Charitable activities	<b>4</b>	40,404	296,735	337,139	28,354	542,026	570,380
Other trading activities	<b>5</b>	83,709	-	83,709	18,367	-	18,367
Investments	<b>6</b>	77,533	-	77,533	36,267	-	36,267
Other income	<b>7</b>	-	-	-	5,735	-	5,735
<b>Total income</b>		<u>1,874,976</u>	<u>391,841</u>	<u>2,266,817</u>	<u>1,387,241</u>	<u>616,337</u>	<u>2,003,578</u>
<b>Expenditure on:</b>							
Raising funds	<b>8</b>	293,933	-	293,933	292,650	-	292,650
Charitable activities	<b>9</b>	1,610,508	468,284	2,078,792	1,268,506	473,410	1,741,916
<b>Total expenditure</b>		<u>1,904,441</u>	<u>468,284</u>	<u>2,372,725</u>	<u>1,561,156</u>	<u>473,410</u>	<u>2,034,566</u>
Net gains/(losses) on investments	<b>14</b>	64,416	-	64,416	(73,663)	-	(73,663)
<b>Net movement in funds</b>		34,951	(76,443)	(41,492)	(247,578)	142,927	(104,651)
<b>Reconciliation of funds</b>							
Fund balances at 1 April 2023		2,158,146	225,977	2,384,123	2,405,724	83,050	2,488,774
<b>Fund balances at 31 March 2024</b>		<u>2,193,097</u>	<u>149,534</u>	<u>2,342,631</u>	<u>2,158,146</u>	<u>225,977</u>	<u>2,384,123</u>

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
BALANCE SHEET**

**AS AT 31 MARCH 2024**

	Notes	2024		2023	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	16		21,714		20,359
Investments	17		1,039,563		875,147
			<u>1,061,277</u>		<u>895,506</u>
<b>Current assets</b>					
Stocks	19	8,175		9,007	
Debtors	20	440,245		390,793	
Cash at bank and in hand		987,706		1,243,672	
		<u>1,436,126</u>		<u>1,643,472</u>	
<b>Creditors: amounts falling due within one year</b>	21	(154,772)		(154,855)	
Net current assets			<u>1,281,354</u>		<u>1,488,617</u>
<b>Total assets less current liabilities</b>			<u><u>2,342,631</u></u>		<u><u>2,384,123</u></u>
<b>Income funds</b>					
Restricted funds	23		149,534		225,977
<u>Unrestricted funds</u>					
Designated funds	24	301,835		391,424	
General unrestricted funds		1,891,262		1,766,722	
		<u>2,193,097</u>		<u>2,158,146</u>	
			<u><u>2,342,631</u></u>		<u><u>2,384,123</u></u>

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the Trustees on 28 August 2024

*N M Heath*

Mr N M Heath (Hon Treasurer)  
**Trustee**

**Company registration number 02021975**

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF CASH FLOWS**

**FOR THE YEAR ENDED 31 MARCH 2024**

	Notes	2024 £	£	2023 £	£
<b>Cash flows from operating activities</b>					
Cash (absorbed by)/generated from operations	29		(218,868)		254,329
<b>Investing activities</b>					
Purchase of tangible fixed assets		(14,631)		(9,840)	
Purchase of investments		(100,000)		-	
Investment income received		77,533		36,267	
<b>Net cash (used in)/generated from investing activities</b>			(37,098)		26,427
<b>Net cash used in financing activities</b>			-		-
<b>Net (decrease)/increase in cash and cash equivalents</b>			(255,966)		280,756
Cash and cash equivalents at beginning of year			1,243,672		962,916
<b>Cash and cash equivalents at end of year</b>			987,706		1,243,672

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

---

## 1 Accounting policies

### Charity information

Huntington's Disease Association is a private company limited by guarantee incorporated in England and Wales. The registered office is Suite 24 Liverpool Science Park, Innovation Centre, 131 Mount Pleasant, Liverpool, L3 5TF.

### 1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)". The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention except for the revaluation of fixed asset investments in accordance with the Charities SORP.

### 1.2 Going concern

The Trustees have considered the potential effects of current inflationary pressures and general economic uncertainty on the charity.

At the time of approving the accounts the Trustees consider that the charity has adequate reserves and diverse revenue streams to continue in operational existence for the foreseeable future taking account of economic uncertainties caused by the pandemic. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the accounts.

### 1.3 Charitable funds

*Unrestricted funds* are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

*Designated funds* comprise funds which have been set aside at the discretion of the trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the accounts.

*Restricted funds* are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the accounts.

### 1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Investment income consists of interest and dividends received and receivable.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is disclosed as a contingent asset.

No amounts are included in the financial statements for services donated by volunteers.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**1 Accounting policies**

**(Continued)**

Grants, including grants for the purchase of fixed assets, are recognised in full in the statement of financial activities in the year in which they are receivable.

Deferred income represents grants received in advance of the expenditure to which it is allocated to support.

No amounts are included in these financial statements for goods donated to charity shops or services donated by volunteers.

Income from merchandise sales and fundraising income is recognised as earned (that is, as the related goods or services are provided).

**1.5 Expenditure**

All expenditure has been accounted for on an accruals basis and includes irrecoverable VAT where applicable. Expenditure is allocated to relevant activity categories on a basis that is consistent with the use of that resource. Support costs have been attributable to charitable activity in accordance with best estimates.

Research grants are made each year after approval and recommendation by the Medical Advisory Panel. The amount charged to the profit and loss account represents the cost of projects approved during the year.

**1.6 Tangible fixed assets**

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% straight line
-----------------------	-------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year..

**1.7 Fixed asset investments**

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

**1.8 Impairment of fixed assets**

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

**1.9 Stocks**

Stocks are valued at the lower of cost or selling price less selling costs, after making due allowance for obsolete and slow-moving items. Cost is calculated using the first-in first-out basis of valuation.

**1.10 Cash and cash equivalents**

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**1 Accounting policies**

**(Continued)**

**1.11 Financial instruments**

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

***Basic financial assets***

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

***Impairment of financial assets***

Financial assets, other than those held at fair value through income and expenditure, are assessed for indicators of impairment at each reporting date. Financial assets are impaired where there is objective evidence that, as a result of one or more events that occurred after the initial recognition of the financial asset, the estimated future cash flows have been affected.

If an asset is impaired, the impairment loss is the difference between the carrying amount and the present value of the estimated cash flows discounted at the asset's original effective interest rate. The impairment loss is recognised in net income/(expenditure) for the year.

If there is a decrease in the impairment loss arising from an event occurring after the impairment was recognised, the impairment is reversed. The reversal is such that the current carrying amount does not exceed what the carrying amount would have been, had the impairment not previously been recognised. The impairment reversal is recognised in net income/(expenditure) for the year.

***Derecognition of financial assets***

Financial assets are derecognised only when the contractual rights to the cash flows from the asset expire or are settled, or when the charity transfers the financial asset and substantially all the risks and rewards of ownership to another entity, or if some significant risks and rewards of ownership are retained but control of the asset has transferred to another party that is able to sell the asset in its entirety to an unrelated third party.

***Basic financial liabilities***

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

***Derecognition of financial liabilities***

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

**1 Accounting policies (Continued)**

**1.12 Employee benefits**

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

**1.13 Retirement benefits**

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

**1.14 Branch funds**

The funds of the Association's branches have been consolidated in the accounts.

**2 Critical accounting estimates and judgements**

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

**3 Donations and legacies**

	<b>Unrestricted funds</b>	<b>Restricted funds</b>	<b>Total</b>	Unrestricted funds	Restricted funds	Total
	<b>2024</b>	<b>2024</b>	<b>2024</b>	2023	2023	2023
	£	£	£	£	£	£
Donations and gifts	996,636	87,273	1,083,909	968,144	70,121	1,038,265
Legacies receivable	626,258	7,833	634,091	297,406	-	297,406
Branch income	50,436	-	50,436	32,968	4,190	37,158
	<u>1,673,330</u>	<u>95,106</u>	<u>1,768,436</u>	<u>1,298,518</u>	<u>74,311</u>	<u>1,372,829</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2024**

**4 Income from charitable activities**

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Grants received	3,500	296,735	300,235	6,000	542,026	548,026
Merchandise	14,808	-	14,808	15,708	-	15,708
Other income	22,096	-	22,096	6,646	-	6,646
	<u>40,404</u>	<u>296,735</u>	<u>337,139</u>	<u>28,354</u>	<u>542,026</u>	<u>570,380</u>

**5 Income from other trading activities**

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Company sponsorships	51,876	600
Consultancy	31,833	17,767
Other trading activities	<u>83,709</u>	<u>18,367</u>

**6 Income from investments**

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Income from listed investments	29,469	25,241
Interest receivable	48,064	11,026
	<u>77,533</u>	<u>36,267</u>

**7 Other income**

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Miscellaneous income	-	5,735
	<u>-</u>	<u>5,735</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**8 Raising funds**

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2024</b>	2023
	<b>£</b>	£
<u>Fundraising and publicity</u>		
Fundraising events	26,675	24,195
Other fundraising costs	57,435	94,196
Staff costs	209,823	174,259
	<u>          </u>	<u>          </u>
Fundraising and publicity	<u>293,933</u>	<u>292,650</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**

**FOR THE YEAR ENDED 31 MARCH 2024**

**9 Charitable activities**

	Specialist HD Advisory Service	Welfare and Respite Care	Communication and Policy and Public Affairs	Youth Workers & Juvenile	Branch	Total 2024	Total 2023
	£	£	£	£	£	£	£
Staff costs	916,084	929	163,624	181,620	19,720	1,281,977	1,006,266
Welfare grants	-	15,112	-	-	16,940	32,052	20,792
Research	-	-	-	-	-	-	20,180
Recruitment	3,471	-	1,549	2,595	320	7,935	3,407
Travel and training	48,842	-	4,173	15,335	1,081	69,431	48,860
Telephone and internet	42,052	-	1,340	1,946	350	45,688	20,566
Other costs	46,733	76	20,419	38,534	29,582	135,344	150,587
Website	-	-	17,727	-	-	17,727	23,945
Marketing	-	-	74,467	-	-	74,467	24,669
Event costs	1,429	-	2,497	33,515	-	37,441	32,077
	<u>1,058,611</u>	<u>16,117</u>	<u>285,796</u>	<u>273,545</u>	<u>67,993</u>	<u>1,702,062</u>	<u>1,351,349</u>
Share of support costs (see note 10)	197,571	18,202	72,808	39,054	36,404	364,039	378,514
Share of governance costs (see note 10)	12,691	-	-	-	-	12,691	12,053
	<u>1,268,873</u>	<u>34,319</u>	<u>358,604</u>	<u>312,599</u>	<u>104,397</u>	<u>2,078,792</u>	<u>1,741,916</u>
<b>Analysis by fund</b>							
Unrestricted funds	1,011,062	26,851	155,599	312,599	104,397	1,610,508	1,268,506
Restricted funds	257,811	7,468	203,005	-	-	468,284	473,410
	<u>1,268,873</u>	<u>34,319</u>	<u>358,604</u>	<u>312,599</u>	<u>104,397</u>	<u>2,078,792</u>	<u>1,741,916</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2024**

**9 Charitable activities**

**(Continued)**

For the year ended 31 March 2023

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication and Policy and Public Affairs	Youth Workers & Juvenile	Branch	Total 2023
	£	£	£	£	£	£	£
Staff costs	793,743	882	882	120,739	72,432	17,588	1,006,266
Welfare grants	-	12,734	-	-	-	8,058	20,792
Research	-	-	20,180	-	-	-	20,180
Recruitment	2,386	-	-	257	764	-	3,407
Travel and training	37,722	-	-	2,490	7,961	687	48,860
Telephone and internet	18,965	-	-	690	675	236	20,566
Other costs	49,406	63	63	54,925	25,143	20,987	150,587
Website	-	-	-	23,945	-	-	23,945
Marketing	-	-	-	24,669	-	-	24,669
Event costs	7,712	-	-	706	23,659	-	32,077
	<u>909,934</u>	<u>13,679</u>	<u>21,125</u>	<u>228,421</u>	<u>130,634</u>	<u>47,556</u>	<u>1,351,349</u>
Share of support costs (see note 10)	204,472	19,338	-	77,352	38,676	38,676	378,514
Share of governance costs (see note 10)	12,053	-	-	-	-	-	12,053
	<u>1,126,459</u>	<u>33,017</u>	<u>21,125</u>	<u>305,773</u>	<u>169,310</u>	<u>86,232</u>	<u>1,741,916</u>
<b>Analysis by fund</b>							
Unrestricted funds	779,438	24,100	1,125	297,715	79,896	86,232	1,268,506
Restricted funds	347,021	8,917	20,000	8,058	89,414	-	473,410
	<u>1,126,459</u>	<u>33,017</u>	<u>21,125</u>	<u>305,773</u>	<u>169,310</u>	<u>86,232</u>	<u>1,741,916</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2024**

**10 Support costs allocated to activities**

	<b>2024</b>	<b>2023</b>
	£	£
Staff costs	208,524	215,284
Depreciation	13,276	9,618
Head office costs	142,239	153,612
Governance costs	12,691	12,053
	<u>376,730</u>	<u>390,567</u>

**Analysed between:**

Specialist HD Advisory Service	210,262	216,525
Welfare and Respite Care	18,202	19,338
Communication, policy and public affairs	72,808	77,352
Youth workers and juvenile	39,054	38,676
Branch	36,404	38,676
	<u>376,730</u>	<u>390,567</u>

**Governance costs comprise:**

	<b>2024</b>	<b>2023</b>
	£	£
Audit fees	8,874	8,250
EC meeting costs	3,817	3,803
	<u>12,691</u>	<u>12,053</u>

Support costs are allocated on the basis of time spent.

**11 Net movement in funds**

	<b>2024</b>	<b>2023</b>
	£	£
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	8,874	8,250
Depreciation of owned tangible fixed assets	13,276	9,618
	<u>22,150</u>	<u>17,868</u>

**12 Trustees**

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year (2023: £nil) and no trustees were reimbursed expenses (2023: two trustees were reimbursed £179).

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

**13 Employees**

The average monthly number of employees during the year was:

	<b>2024</b>	<b>2023</b>
	<b>Number</b>	<b>Number</b>
Specialist HD Advisors	25	22
Management	1	1
Fundraising	5	5
Youth Worker	5	2
Administration	6	8
Communications	3	3
	<u>45</u>	<u>41</u>

**Employment costs**

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Wages and salaries	1,501,293	1,240,304
Social security costs	156,408	121,121
Other pension costs	42,623	34,384
	<u>1,700,324</u>	<u>1,395,809</u>

The number of employees whose annual remuneration was more than £60,000 is as follows:

	<b>2024</b>	<b>2023</b>
	<b>Number</b>	<b>Number</b>
£70,001 - £80,000	-	1
£80,001 - £90,000	1	-
	<u>1</u>	<u>1</u>

**Remuneration of key management personnel**

The remuneration of key management personnel, which consists of the Chief Executive and the heads of departments, is as shown below.

	<b>2024</b>	<b>2023</b>
	<b>£</b>	<b>£</b>
Aggregate compensation	<u>315,348</u>	<u>298,495</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**14 Gains and losses on investments**

	<b>Unrestricted funds 2024 £</b>	<b>Unrestricted funds 2023 £</b>
Gains/(losses) arising on:		
Revaluation of investments	64,416	(73,663)
	<u>64,416</u>	<u>(73,663)</u>

**15 Taxation**

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

**16 Tangible fixed assets**

	<b>Fixtures and fittings £</b>
<b>Cost</b>	
At 1 April 2023	46,149
Additions	14,631
At 31 March 2024	<u>60,780</u>
<b>Depreciation</b>	
At 1 April 2023	25,790
Depreciation charged in the year	13,276
At 31 March 2024	<u>39,066</u>
<b>Carrying amount</b>	
At 31 March 2024	<u>21,714</u>
At 31 March 2023	<u>20,359</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2024**

**17 Fixed asset investments**

	<b>Listed investments £</b>
<b>Valuation</b>	
At 1 April 2023	875,147
Additions	100,000
Valuation changes	64,416
	<hr/>
At 31 March 2024	1,039,563
	<hr/>
<b>Carrying amount</b>	
At 31 March 2024	1,039,563
	<hr/> <hr/>
At 31 March 2023	875,147
	<hr/> <hr/>

**18 Financial instruments**

	<b>2024 £</b>	<b>2023 £</b>
<b>Carrying amount of financial assets</b>		
Instruments measured at fair value through profit or loss	1,039,556	875,143
	<hr/> <hr/>	<hr/> <hr/>

**19 Stocks**

	<b>2024 £</b>	<b>2023 £</b>
Merchandise	8,175	9,007
	<hr/> <hr/>	<hr/> <hr/>

**20 Debtors**

	<b>2024 £</b>	<b>2023 £</b>
<b>Amounts falling due within one year:</b>		
Trade debtors	15,338	3,309
Other debtors	355,844	297,298
Prepayments	69,063	90,186
	<hr/> <hr/>	<hr/> <hr/>
	440,245	390,793
	<hr/> <hr/>	<hr/> <hr/>

Other debtors include £307,978 (2023: £252,932) of legacies receivable.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

**21 Creditors: amounts falling due within one year**

	<b>2024</b>	<b>2023</b>
	£	£
Other taxation and social security	37,190	27,005
Trade creditors	38,709	54,744
Other creditors	20,945	-
Accruals and deferred income	57,928	73,106
	<u>154,772</u>	<u>154,855</u>

Included in accruals and deferred income is deferred income of £41,250 (2023: £58,423) relating to income received for future periods.

**22 Retirement benefit schemes**

	<b>2024</b>	<b>2023</b>
	£	£
<b>Defined contribution schemes</b>		
Charge to profit or loss in respect of defined contribution schemes	42,623	34,384
	<u>42,623</u>	<u>34,384</u>

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

The charge to the statement of financial activities in respect of defined contribution schemes was £42,623 (2023 - £34,384).

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**

**FOR THE YEAR ENDED 31 MARCH 2024**

**23 Restricted funds**

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	Movement in funds			Movement in funds			
	Balance at 1 April 2022 £	Incoming resources £	Resources expended £	Balance at 1 April 2023 £	Incoming resources £	Resources expended £	Balance at 31 March 2024 £
Research	26,404	7,980	(20,000)	14,384	47,595	-	61,979
The National Lottery Community Fund	-	-	-	-	136,452	(90,168)	46,284
Specialist HD Advisory Service (SHDA)	-	347,021	(347,021)	-	171,944	(164,944)	7,000
Children in Need	4,757	-	(4,757)	-	-	-	-
Lancashire Training Events	4,849	-	-	4,849	-	-	4,849
The Big Give - JHD weekend	-	-	-	-	16,926	-	16,926
The Big Give - Kind2mind	-	1,500	(1,500)	-	13,160	(3,664)	9,496
JHD Weekend	25,472	-	(25,472)	-	3,000	-	3,000
Youth Services	18,241	1,524	(19,765)	-	-	-	-
B & Q Foundation	467	5,000	(2,768)	2,699	-	(2,699)	-
Welfare Fund	2,860	4,329	(6,149)	1,040	2,764	(3,804)	-
Website	-	8,058	(8,058)	-	-	-	-
Jingle Jam	-	240,925	(37,920)	203,005	-	(203,005)	-
	<u>83,050</u>	<u>616,337</u>	<u>(473,410)</u>	<u>225,977</u>	<u>391,841</u>	<u>(468,284)</u>	<u>149,534</u>

**Research**

Research funds are raised to promote medical and social/ therapeutic research of direct significance to Huntington's Disease sufferers and their families. Our Medical Advisory Board reviews all applications on an annual basis before a decision is taken by our Executive Council. Funds were received from individuals, organisations and Branches requesting their donation be spent on this activity.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**23 Restricted funds**

**(Continued)**

**The National Lottery Community Fund**

Multiyear funding through The National Lottery Community Fund Reaching Communities programme to support the development of our Huntington's Disease Youth Engagement Service (HDYES).

**Specialist HD Advisory Service (SHDA)**

The network of Specialist HD Advisers was maintained during the year. Restricted funding relating purely to this service and for each geographical area was received from numerous sources in the period.

**Children in Need**

This grant is to fund a youth worker.

**Lancashire Training Events**

Money raised towards an awareness/training event in the Fylde Coast area.

**The Big Give - JHD Weekend**

Restricted funding to support our annual JHD Weekend for families impacted by Juvenile Huntington's Disease.

**The Big Give - Kind2Mind**

Restricted funding to support our psychological support programmes.

**JHD Weekend**

These relate to individual donations and grants that have been or are to be spent on the JHD weekend.

**Youth Services**

This relates to Trusts funding received to fund the work of our Youth Worker

**B&Q Foundation**

Funding received from B&Q Foundation for enhancing quality of life and helping to reduce risks by providing financial assistance to maintain, repair or improve housing

**Welfare Fund**

Funding received towards welfare grants.

**Website**

A development grant was received from Uniqure to develop our website.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**

**FOR THE YEAR ENDED 31 MARCH 2024**

**23 Restricted funds**

**(Continued)**

**Jingle Jam**

Jingle Jam is the World's largest gaming event which took place in December 2022. We were one of 12 charities that benefited from the event and secured funding of £240,925 towards our Youth Engagement Services.

**24 Unrestricted funds**

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	<b>At 1 April 2023</b>	<b>Incoming resources</b>	<b>Resources expended</b>	<b>Transfers</b>	<b>Gains and losses</b>	<b>At 31 March 2024</b>
	£	£	£	£	£	£
<b>Designated funds</b>						
Special projects fund	142,890	-	-	(17,890)	-	125,000
Branch funds	65,002	37,844	(45,288)	-	-	57,558
Huntington's Disease Youth Engagement Service	183,532	-	-	(64,255)	-	119,277
<b>General funds</b>	1,766,722	1,837,132	(1,859,153)	82,145	64,416	1,891,262
	<u>2,158,146</u>	<u>1,874,976</u>	<u>(1,904,441)</u>	<u>-</u>	<u>64,416</u>	<u>2,193,097</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**

**FOR THE YEAR ENDED 31 MARCH 2024**

<b>24 Unrestricted funds</b>	<b>(Continued)</b>					
<b>Previous year:</b>	<b>At 1 April 2022</b>	<b>Incoming resources</b>	<b>Resources expended</b>	<b>Transfers</b>	<b>Gains and losses</b>	<b>At 31 March 2023</b>
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
<b>Designated funds</b>						
Special projects fund	184,000	-	(41,110)	-	-	142,890
Branch funds	65,722	26,276	(26,996)	-	-	65,002
Huntington's Disease Youth Engagement Service	207,000	-	(23,468)	-	-	183,532
<b>General funds</b>	<b>1,949,002</b>	<b>1,360,965</b>	<b>(1,469,582)</b>	<b>-</b>	<b>(73,663)</b>	<b>1,766,722</b>
	<u>2,405,724</u>	<u>1,387,241</u>	<u>(1,561,156)</u>	<u>-</u>	<u>(73,663)</u>	<u>2,158,146</u>

A designated special projects fund of £400,000 was established as a result of generous legacies received during 2013. It is intended that the fund be used for special projects, which, once instituted, may be developed in accordance with the long-term objectives of the charity. During 2015 and 2016 £130,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support. A further £40,000 of the fund was used to support the new communication initiative in 2017/18 and £16,000 was used in 2018/19 to complete the Care Home Accreditation project. In 2021/22, £30,000 was released to cover costs associated with changes necessitated by the pandemic including reducing the office size, software improvement and project development. The balance of the fund amounting to £184,000 at 1 April 2023 has been allocated in 2023 and 2024 to cover the establishment of new posts covering National Support, Policy and Public Affairs, Data Management and Volunteer Support.

The Huntington's Disease Youth Engagement Service (Youth Project) designated fund was established to cover the commitment to spend £183,532 of our own resources in addition to 3 years of funding from the National Lottery for the project.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

**25 Analysis of net assets between funds**

	<b>Unrestricted funds 2024 £</b>	<b>Restricted funds 2024 £</b>	<b>Total 2024 £</b>
<b>At 31 March 2024:</b>			
Tangible assets	21,714	-	21,714
Investments	1,039,563	-	1,039,563
Current assets/(liabilities)	1,131,820	149,534	1,281,354
	<u>2,193,097</u>	<u>149,534</u>	<u>2,342,631</u>
	<u><u>2,193,097</u></u>	<u><u>149,534</u></u>	<u><u>2,342,631</u></u>
	<b>Unrestricted funds 2023 £</b>	<b>Restricted funds 2023 £</b>	<b>Total 2023 £</b>
<b>At 31 March 2023:</b>			
Tangible assets	20,359	-	20,359
Investments	875,147	-	875,147
Current assets/(liabilities)	1,262,640	225,977	1,488,617
	<u>2,158,146</u>	<u>225,977</u>	<u>2,384,123</u>
	<u><u>2,158,146</u></u>	<u><u>225,977</u></u>	<u><u>2,384,123</u></u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2024**

---

**26 Operating lease commitments**

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	<b>2024</b>	<b>2023</b>
	£	£
Within one year	31,104	34,627
Between two and five years	39,058	70,926
	<u>70,162</u>	<u>105,553</u>

**27 Related party transactions**

**Remuneration of key management personnel**

The remuneration of key management personnel, which consists of the Chief Executive and the heads of departments, is as shown below.

	<b>2024</b>	<b>2023</b>
	£	£
Aggregate remuneration	<u>315,348</u>	<u>298,495</u>

**Transactions with related parties**

During the year, one trustee donated £120 (2023: £116).

Mr Nick Heath, a trustee, is chair of Victoria Convalescent Trust which made grants totalling £2,544 (2023: £2,129) to the charity in the year.

Ms Catherine Lyon, a trustee, received a grant from the charity of £2,000 (2023: £Nil) towards funding for her PhD on end of life care and Huntington's Disease.

There were no other related party transactions in the year.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

**28 Branch funds**

Reports received from branches are set out below and incorporated into the accounts.

	<b>2024</b>	<b>2023</b>
	£	£
<b>Cash balances</b>		
At 1 April 2023	65,002	65,722
Receipts in year	50,483	37,158
Less :		
Local welfare grants	(16,640)	(8,058)
Sent to head office	(12,639)	(10,882)
Branch activities, local newsletters, equipment, research etc	(28,648)	(18,938)
	<u>57,558</u>	<u>65,002</u>
At 31 March 2024	<u>57,558</u>	<u>65,002</u>

**29 Cash generated from operations**

	<b>2024</b>	<b>2023</b>
	£	£
Deficit for the year	(41,492)	(104,651)
Adjustments for:		
Investment income recognised in statement of financial activities	(77,533)	(36,267)
Fair value gains and losses on investments	(64,416)	73,663
Depreciation and impairment of tangible fixed assets	13,276	9,618
Movements in working capital:		
Decrease in stocks	832	1,167
(Increase)/decrease in debtors	(49,452)	286,710
(Decrease)/increase in creditors	(83)	24,089
	<u>(218,868)</u>	<u>254,329</u>
<b>Cash (absorbed by)/generated from operations</b>	<u>(218,868)</u>	<u>254,329</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**30 Acknowledgements**

We would like to thank the following grant makers for their support:

The 29th May 1961 Charity

Belron Ronnie Lubner Charitable Foundation

The Adint Charitable Trust

The Alice Ellen Cooper Dean Charitable Foundation

The Ardwick Trust

The Barbour Foundation

Chapman Charitable Trust

The Christopher Laing Foundation

Chrysalis Trust

The Drapers' Company

The Dyers' Company Charitable Trust

Ethel and Gwynne Morgan Trust

The Florence Turner Trust

Fowler Smith & Jones Trust

The Goldcrest Charitable Trust

Hadrian Trust

The Hospital Saturday Fund

The Ian Askew Charitable Trust

The Inter-Church Caring Trust

The J Reginald Corah Foundation Fund

The John Avins Trust

The Joseph and Lena Randall Charitable Trust

The Lord Cozens-Hardy Trust

May Hearnshaw Charitable Trust

The Michael and Anna/ Wix Charitable Trust

The Miss Pannett Charitable Trust

The National Lottery Community Fund

The Oakdale Trust

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2024**

---

**30 Acknowledgements continued**

P F Charitable Trust

The Paul Bassham Charitable Trust

Pilkington Charities Fund

The Proven Family Trust

The Roger and Jean Jefcoate Trust

The Roger De Haan Charitable Trust

Sandra Charitable Trust

The Sir James Knott Trust

The Sir James Reckitt Charity

The Sir James Roll Charitable Trust

The Sylvia and Colin Shepherd Charitable Trust

Tesco Charity Trust

The Sunrise (Sidmouth) Charitable Trust

The Thomas Sivewright Catto Charitable Settlement

**Statutory**

Birmingham City Council

Cambridgeshire and Peterborough Integrated Care System

Dorset HealthCare University NHS Foundation Trust

NHS Cornwall and Isles of Scilly Integrated Care Board

NHS Devon Integrated Care Board

NHS Lancashire and South Cumbria Integrated Care Board

NHS North East and North Cumbria Integrated Care Board

**HUNTINGTONS DISEASE ASSOCIATION**

England & Wales - Charity number 296453

---

# Accounts

---

Charity registration number 296453

Company registration number 02021975 (England and Wales)

**HUNTINGTON'S DISEASE ASSOCIATION**  
**COMPANY LIMITED BY GUARANTEE**  
**ANNUAL REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2023**

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE LEGAL AND ADMINISTRATIVE INFORMATION

---

<b>Patrons</b>	Tony Hadley Shane Richie George Rainsford
<b>Trustees</b>	Dr G El-Nimr Mr N M Heath (Hon Treasurer) Professor H Rickards (Chair) Ms C Lyon Ms S Barker Mr S Duckett Dr N Swales Ms B E Waters Ms H Hubberstey (Appointed 20 October 2022) Ms C K Holmes (Appointed 20 October 2022) Mr D R Thomas (Appointed 20 October 2022)
<b>Chief executive</b>	Mrs C Stanley BSc (Hons)
<b>Charity number</b>	296453
<b>Company number</b>	02021975
<b>Registered office</b>	Suite 24 Liverpool Science Park Innovation Centre 131 Mount Pleasant Liverpool L3 5TF
<b>Auditor</b>	DSG Castle Chambers 43 Castle Street Liverpool L2 9TL
<b>Bankers</b>	National Westminster Bank Plc 66/68 St John's Road Battersea London SW11 1PB

---

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE CONTENTS

---

	<b>Page</b>
Trustees' report	1 - 16
Statement of trustees' responsibilities	17
Independent auditor's report	18 - 20
Statement of financial activities	21
Balance sheet	22
Statement of cash flows	23
Notes to the financial statements	24 - 42

---

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2023

---

The trustees present their annual report and financial statements for the year ended 31 March 2023.

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 charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)".

## Objectives and activities

### Charity objects

The Huntington's Disease Association's objects are the relief and treatment of those suffering from or believed to be suffering from Huntington's disease and to provide financial support for such persons and their families in need and for research and the dissemination of the results of such research for the public benefit into the cause and possible cures whether partial or complete and possible prevention of the said disease.

### Huntington's disease, a brief overview

Huntington's disease is a rare neurological disorder that is caused by a faulty gene passed down through families. Each child of a parent with Huntington's has a 50% chance of inheriting the faulty gene. The disease affects the central nervous system, the network of nerve tissues in the brain and spinal cord that co-ordinate the body's activities. It is a progressive condition that causes changes in movement, thinking, emotions, eating and speech that worsen over time. Symptoms usually begin between the ages of 30 and 50, though they can also develop much earlier or later. If someone begins to show symptoms before the age of 20, this is known as Juvenile Huntington's disease. It is estimated that around 8,000 people are living with Huntington's and 32,000 are at risk of developing it in the United Kingdom.

2022 saw the end of the Huntington Disease Association's five year strategy. Throughout 2021 and 2022 we were reflecting on what we had achieved as we planned for the next strategy for 2023 to 2027.

### Our Vision

A better life for anyone affected by Huntington's disease.

### Mission

To enable everyone affected by Huntington's disease to live life to their full potential by:

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community and influencing policymakers

At the end of the five-year strategy, we undertook an impact report to see what difference we had made.

" We thought no one understood us until we met you"

### Values

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive

### Who we are

The charity was founded in 1971 after a family who had been given a diagnosis of Huntington's sent a letter to a local paper asking if anyone knew of any other families in a similar situation. It began as a support group with 76 members and was known initially as the 'Association to Combat Huntington's Chorea', later becoming the Huntington's Disease Association.

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023**

---

Feedback from families that they would benefit from professionals with knowledge and understanding of the illness led to a 1993 project known as CASE – Care, Advice, Support and Education. This project saw the birth of our Specialist Huntington's Disease Advisory service that continues to be a valued resource and focus for development to this day.

The Huntington's Disease Association provides support to anyone affected by Huntington's or anyone involved in their care and support across England and Wales. We also work closely with other Huntington's disease charities across the UK and Ireland. We now have 36 staff members from a wide range of backgrounds. From nursing and social care to fundraising and administration, all united in our dedication to supporting people living with and affected by Huntington's.

## **What we do**

### **Specialist Advisory Service**

The Specialist Huntington's disease Advisory service provides practical information, advice and emotional support to people with Huntington's and their families across England and Wales. Our advisers promote local services, assist with the organisation of care packages and answer crisis calls to ensure people affected by Huntington's receive the best possible care and support available. They also offer training, advice and support to professionals involved in the care of people with Huntington's to improve quality of care.

### **Juvenile Huntington's disease support**

We are the only Huntington's disease charity with a dedicated Specialist Juvenile Huntington's Adviser in the world, supporting people affected by the juvenile form of the disease and their families across England and Wales.

### **Youth Services**

We have a Huntington's Disease Youth Engagement service (HDYES) providing support to young people aged 8-25 living in families affected by Huntington's. HDYES is co-ordinated by a Youth Engagement Co-ordinator currently covering the whole of England and Wales.

### **Membership**

We have a membership of over 5,000 people, made up of both families living with Huntington's disease and health and social care professionals caring for people with Huntington's.

### **Branches and Support Groups**

We are linked to a number of local Huntington's Disease Association branches and support groups, all led by dedicated volunteers. These groups provide invaluable peer support on a local level. They support many aspects of the Huntington's Disease Association's work.

### **Partnership working**

We are a charity with limited resources, so we work closely with other organisations for maximum impact and influence. Organisations we regularly work with include the Neurological Alliance, Genetic Alliance UK and Rare Disease UK. We also work with other Huntington's disease charities including the European and International Huntington's Associations. We are part of an alliance with the Scottish Huntington Association, Huntington's Disease Alliance Northern Ireland, and the Huntington's Disease Association of Ireland.

### **Research projects**

We work with scientific, clinical and social researchers and experts in the field of Huntington's in their search for ways to improve care and treatment. One day, we hope for a cure for the disease.

### **Supporters**

We have an army of committed supporters who dedicate their time and energy to raising awareness, supporting those affected by the disease and fundraising to help ensure we can continue supporting those who need our help.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

## Achievements and performance

### Highlights 2022/23

As we begin our new five-year strategy, this year's annual report is a reflection on our key achievements over the past year. This year we consulted with the community on what they wanted our priorities to be.

After an increase in fundraising last year investment has been made into the charity infrastructure this year, so we can continue our ambitious aims whilst continuing to offer support to the Huntington's disease community.

Key investment achievements included:

- The Helpline Advisor role quickly made an impact enabling people accessing the services the ability to speak to a person sooner.
- The Policy and Public Affairs Manager established positive relationships with Parliament, with Hilary Benn agreeing to be a Parliamentary Champion for us, leading to a Westminster Hall Debate in November 2022. To have a role that can help people advocate for Huntington's disease is an exciting time, we want to be able to create change for people affected by Huntington's disease.
- A new youth worker means we can support more young people and new advisers meaning we can directly support more young people.

Our campaign for Huntington's Disease Awareness Month in 2022 was called Huntington's in Mind, its objective was to raise awareness of mental health and Huntington's disease.

The three main target audiences the campaign wants to engage with:

1. Huntington's community; those with symptoms, those at risk, those who are gene-positive, carers and family members
2. Policy makers and parliamentarians
3. Health care professionals

The campaign was used as a call to action across the year, raising the understanding that mental health is an important part of people affected by Huntington's disease.

We celebrated two Award wins this year:

1. Charitable Campaign of the Year Award at the Communiqué Awards 2022
2. Best Campaign Award at the Gene People Awards 2022

This was for a campaign involving the Alliance Partnership for the 'My Family Matters' campaign which took place in May 2021.

As we came to the end of our five year strategy, we began consultation on how people had found their support from our charity. The consultation included a questionnaire and a number of focus group sessions, all conducted by an external agency to prevent bias.

The results were positive with the charity receiving a Net Promoter Score ( a customer satisfaction score) of 75, meaning people are highly likely to recommend us.

As said by one participant

"Facing this extremely difficult illness with an uncertain future ahead, we are confident in the knowledge that the Huntington's Disease Association is beside us for this journey."

The respondents used a mix of services showing the variety of ways people access our services.

- 87% of respondents had used the service by telephone or in person
- 78% had used our services digitally
- 43% had engaged through in person events, branches and support groups

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023**

---

Comments where people thought we could improve have been taken into consideration for the next strategy. This included an online chat or email service and difficulty in accessing the service for those for whom English is not their first language. Other feedback was the loss of face-to-face contact that many felt was needed, at the time of the survey some of the comments were made at times when we couldn't risk face-to-face situations due to Covid. However, it is good to understand how people would like to access our services when planning for the future.

Using information gained in this report, consulting with staff and trustees led to the creation of our new five-year strategy, our promise on how we will support anyone affected by Huntington's disease.

## **Summary of Huntington's Disease Association Annual Report:**

### **Goal 1: Improved Quality Care and Support**

- The advisory service has provided crucial support, education, and help for families affected by Huntington's disease.
- Quality Assured accreditation ensures better care in care homes, with several homes receiving recognition.
- In-person events like the JHD Weekend resumed in June 2022, fostering connections among families facing Huntington's disease.

### **Goal 2: Better Knowledge and Understanding of Huntington's disease**

- Professionals attended courses and webinars, enhancing their knowledge of Huntington's disease.
- Support for professionals, training sessions, and attendance at professional meetings significantly increased.
- Webinars for families covered various topics, and a Family Voices webinar series featured lived experiences.
- The HD Champions Pilot program expanded knowledge-sharing through online learning.

### **Goal 3: Greater Opportunity for Peer Support and Community Involvement**

- The AGM and Family Conference adapted to online formats, engaging the community and featuring key speakers.
- A new Volunteer Manager role was introduced to support branches and support groups.
- In-person family events returned, strengthening connections among community members.
- Peer support groups and Narrative Therapy sessions offered valuable support.

### **Goal 4: Improved Understanding of Huntington's and the Association's Role with the General Public**

- The '#HuntingtonsInMind' campaign raised awareness about the mental health impact of the disease.
- Collaboration with the BBC showcased Huntington's disease on prime-time TV.
- An Early Day Motion in Parliament furthered awareness and support.
- The website was updated for better community navigation, and social media engagement increased significantly.

### **Goal 5: A Strong Charity to Better Champion the Needs of Our Community**

- New roles, including a Helpline Adviser, Policy and Public Affairs Manager, and Youth Team Worker, increased the charity's effectiveness.
- Income from community fundraising and events grew significantly.
- Individual giving and regular donations also increased, ensuring stable funding.
- Trusts, foundations, and corporate supporters contributed to the charity's growth.

### **Goal 6: Supporting Huntington's Research**

- The Association continued to support research studies and drug trials, keeping the community informed.
- HD Voice provided valuable feedback on research projects and played a role in communication and fundraising.
- Attendance at the European Huntingtons Disease Network (EHDN) conference facilitated international collaboration.
- Fundraising efforts, including the Christmas Appeal, and Jingle Jam, contributed to funding.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

In conclusion, the Huntington's Disease Association achieved its goals of providing support and education, fostering community involvement, and contributing to research. The report highlights the dedication and impact of the Association in improving the lives of those affected by Huntington's disease.

The following pages show in detail what we have achieved in relation to our strategic aims:

## **Our Impact**

### **Goal one - Improved quality care and support**

Camilla talks about how the advisory service has helped her,

*"I learnt about the Huntington's Disease Association after a few years of looking after her (sister). The Specialist Adviser for Cornwall was amazing. He ran sessions in the nursing homes to provide information on Huntington's disease and how best to help patients and he provided help with continuing healthcare (CHC). My great auntie wasn't even given a Huntington's consultant or specialist Huntington's nurse due to non-compliance. Our adviser helped me to learn about the disease and give me advice at various stages when needed."*

The expertise of the advisers and the understanding of Huntington's disease that they have demonstrate the difference that knowledge can make in improving care and support.

This quote from a service user shows the difference our services make,

*"Our family has had the support of the Huntington's Disease Association at a time of severe emotional stress. It was the only place that could possibly understand the complexities of a family member being diagnosed with Huntington's disease and the impact of that on all concerned. Though one or two family members are accessing the service, it has a trickle effect which enables you to support others in the best way possible."*

Our services continue to be in demand, with our advisers working to support families across England and Wales. We offer support in a number of ways and will attend clinics to ensure all health and social care professionals are supported in providing the right care for someone with Huntington's disease.

### **In numbers**

Support: 8,012 people

Family visits ( virtual and in person): 989

Clinic Attendance: 250

### **HDA Quality Assured**

The Quality Assured accreditation is a mark of assurance to make choosing a care home more of a positive experience for families affected by Huntington's disease. The scheme improves choice and provides people with reassurance that core standards of care will be provided and more information to help them make a decision about the best care home for their needs.

Accreditation is a rigorous process and HDA Quality Assured was this year awarded to

- Exemplar homes - Dearnevale in Barnsley and Kavanagh Place in Liverpool.
- Fieldbay homes - Yr Ysgol and Pen Y Bont.
- Elysium Health Care - Stanley House in Herefordshire.

### **Juvenile Huntington's Disease (JHD) and Young People**

This year saw a return to in-person events. We were delighted to be able to hold the JHD Weekend in June 2022. The first in three years.

*"We made new friends who are in the same situation as ourselves, people who can understand and empathise with us."* - Weekend attendee.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

## **Youth Engagement Service - HDYES**

Due to its hereditary nature Huntington's disease affects all generations. Working with children and young people is key to offering people with Huntington's disease the generational support they need. This year we have been working and consulting with young people to see how services can be designed to meet their needs. We worked with an external agency to consult with young people to prevent bias. The lockdown in the previous year had a huge impact on young children and how they accessed our services. Understanding we needed a fresh approach to engage with young people we worked with an external company to consult with young service users. From this, the Huntington's Disease Youth Voice was created - a group of young people who will help us develop the services, programmes and resources that we create so that we can provide the best possible support for young people impacted by Huntington's disease. The group started in January 2023 with a residential meeting of ten young people accompanied by our Youth Coordinators. This group continue to meet and influence the way our HDYES service has transformed.

## **HDYES in numbers**

Support by the youth service: 704  
Family visits (virtual and in person): 429  
New contacts: 84

## **Welfare Grant**

Offering direct financial support through welfare grants improves people's quality of life, and independence and reduces risks. £10,022.75 was awarded in 40 grants during 22/23. All of these grants were for people symptomatic with Huntington's disease. Research found that the grant improved quality of life in 93% of cases, and in 81% of cases, risk had been reduced.

## **Communication**

Understanding the importance of the website as a source of information for the community, we aim to continually improve the website. Working with the community allowed us to improve the navigation of the website and understand what information they looked for when visiting [www.hda.org.uk](http://www.hda.org.uk).

Through consultation a new website was designed with an easier-to-manage content system, this meant website updates could be made more timely and the design reflected what the community told us they wanted. For example, the 'How we support you' area of the website now includes all information by area including all details of the local adviser, branches and support group information.

Over the year the website had 284,000 views. The most popular pages visited were 'What is Huntington's disease', 'News' and 'Support near you'.

## **Goal two - Better knowledge and understanding of Huntington's disease**

We work with families and professionals to inform and educate them about Huntington's disease.

Educating professionals about Huntington's disease is key to increasing knowledge and understanding making it easier when families are visiting professionals as they have a better understanding of the disease. This includes offering:

Understanding Huntington's disease - course for professionals. This three day certified course was attended by 60 attendees this year.

*"I believe the training was excellent. Huntington's is such a complex disease, so I do not believe I will ever become an expert or feel confident explaining it to my colleagues. However, my knowledge of the disease has improved significantly and I believe I stand a greater chance of connecting with families suffering from Huntington's" - Course attendee.*

A series of education webinars across the year, covered various topics as requested by professionals we worked with.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

As commented by an attendee at a session targeting care homes,

*"Staff gained more confidence to provide a high quality of care to residents with Huntington's disease. Some of us were reluctant and some were scared to provide care however, after the training the staff have now different views about it."*

## **Working with professionals**

In numbers:

Support to professionals ( email and phone): 16,720

Training sessions delivered by the advisory service: 135 sessions with 1,368 attendees

Attending professional meetings: 656

Attending HDYES professional meetings: 60

HDYES information sessions for professionals: 19 sessions delivered

We offer a number of webinars for families covering topics that the community have raised as queries, these include subjects such as voice banking, insurance, genetic testing, seating and posture, eating and drinking plus many more. Nine webinars organised attracted 285 attendees, and the YouTube version of the webinars has been watched many more times.

This year we launched the Family Voices webinar series, four webinars sharing lived experiences from well-respected people in the community. The webinars were a partnership between the Huntington's Disease Alliance UK and Ireland. This was a positive experience of working together with people from all over the UK attending the live sessions, the webinars are now available to watch on our YouTube channel and have been viewed over 1,000 times.

With a return to more in-person events, highlights included a study afternoon in Dorset and a successful event on the Isle of Man.

The Isle of Man event was supported by Specialist Huntington's disease Advisers, Anita Daly and Theresa Westhead and was attended by 100 professionals. They also offered one to one family support sessions with a total of ten family members. *"We are just realising what we have actually achieved, it's just truly amazing. I am so proud of the hard work and commitment from our small committee. Teamwork makes the dream work, we support and care together"* Helen Martin (Support Group Leader – Isle of Man)

## **Mental health study afternoon**

We ran a course on mental health and Huntington's disease as part of the '#HuntingtonsInMind' campaign attended by 80 professionals. Due to its popularity, a second session was organised and attended by 400 professionals. It was a fantastic success to reach this number of people working in an area of such importance to the charity.

•96% of attendees said that their knowledge and understanding of Huntington's disease had increased as a result of the course

•97% of poll responders said that the webinar would help them provide better quality care and 99% said that the webinar had improved their knowledge.

## **HD Champions Pilot**

Working with the European Huntington's Disease Network (EHDN) we piloted an online learning program with six care homes. The program was developed by the Swedish Association and was successfully trialled in five care homes that are part of the Quality Assured Scheme. The course will be run 3-4 times a year. We have been invited to give a talk, alongside the Swedish Huntington's Association who developed the online programme

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

## Goal three - Greater opportunity for peer support and community involvement

### AGM and Family Conference

The decision on whether the conference had to be held in person or online had to be made earlier in the year, due to the uncertainty of Covid. The online conference was well attended and the speakers were recorded to be shared as online webinars. We were pleased to have our patron George Rainsford join us. Nicci Robertson shared an update on Enroll HD, Chloe Holmes shared her journey with HDYES and Jenny Townhill gave a Clinical Trials update. At the conference, we premiered our new co created animation that explains 'What is Huntington's disease?' Feedback about the animation included:

*"This is great"  
"When can we see this on TV?"*

We asked attendees what they wanted for the next AGM through online polls, making sure the community's opinions were at the heart of our decision-making for next year's conference.

### Volunteer Manager

We were delighted to create a new post this year, the new Volunteer Manager whose responsibilities include supporting Branches and support groups. Branches and support groups play a big part in our community and we now need to do more to ensure these groups are supported. The role also includes supporting the wider volunteer network.

### JHD weekend 3 - 5 June

This year we were excited to return to the Calvert Trust for our first in-person family event in three years! The weekend was packed full of activities for those affected with Juvenile Huntington's disease and their families. It is always very powerful to see the families all together and see them relax together as the weekend progresses. Some of the young people as well as some of the parents have made some really deep friendships which have continued outside of the weekend. A comment which regularly comes up on the evaluation forms is that this is the one environment where they feel they can completely relax.

*"A welcoming and informative weekend where there is no shortage of chat and laughter as well as the opportunity to make new friends." - Weekend attendee*

The year also saw a return to family days, as mentioned previously the Isle of Man held a successful event with over 100 professionals attending. Other family events included Brockenhurst and Hampshire family days. It was fantastic to see people from the community connect again.

We continued to offer online support through a mix of peer support groups for carers and families affected by JHD. These events are well-attended and offer an easy way for people to stay connected.

We trialled Narrative Therapy a respectful, non-blaming approach to counselling and community work which centres people as the experts in their own lives. The sessions were received extremely positively and narrative therapy as a tool to support people will continue to be a feature on the events calendar

*"Made me realise I have a lot of skills, people, beliefs and hopes to help me when facing challenges. I felt lighter, less burdened and able to cope with difficulties in a more positive way" - Narrative therapy attendee.*

### Policy and Public Affairs

With a new Policy and Public Affairs Manager recruited we could begin work on our policy asks. Our top five policy asks are:

1. Access to community mental health services when psychiatric symptoms are present
2. A named care coordinator in each area to ensure people can navigate the many professionals they need and those professionals have knowledge and understanding of this disease
3. Specific NICE guidelines for Huntington's disease to ensure there is consistent care for this complex illness
4. A review of the blanket refusal to entry to the armed forces unless there has been a negative predictive test
5. Uplifting of benefits to reflect inflation as many people with Huntington's disease have higher energy and nutritional need.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

Key successes already include:

- Increased awareness of the problem of mental health in people affected by Huntington's disease
- Agreement by Hilary Benn MP to become a parliamentary champion for the Huntington's Disease Association - it an honour to have such a well respected MP supporting our cause. Hilary Benn organised a Westminster Hall debate in the Autumn of 2022, to engage MPs on the issue of Huntington's disease and raise awareness of the issues members of the community were facing with the government. Ahead of the debate, HDA staff briefed Hilary Benn, ministerial advisors and MPs. A briefing was sent to all politicians about Huntington's disease, the main issues and our policy asks. A dozen MPs attended the debate, with a good spread of MPs from across the country and different political parties. MPs eloquently raised the big issues facing those with Huntington's disease at present - from the postcode lottery of services, the need for NICE guidelines, to the exclusion to mental health services that so many are experiencing. Helen Whately, the Social Care Minister attended the debate on behalf of the government and agreed to take away several actions: looking into NICE guidelines for Huntington's, the exclusions to mental health services and the possibility of having a named care coordinator for Huntington's disease in every part of the country. While these issues were being looked into by the minister behind the scenes, the public affairs work switched to building a stronger base of support with more MPs, Lords and Baronesses.

## **Goal four - Improved understanding of Huntington's and the Huntington's Disease Association's role with the general public.**

We worked with the BBC on the continuing storyline of Dr Ethan Hardy who found out he was positive for the Huntington's disease gene. The actor George Rainsford who plays the character is now a patron of the Huntington's Disease Association. The community were delighted to see Huntington's disease mentioned on prime-time TV. Working with the BBC helps us to ensure the disease is portrayed in the correct way.

### **Huntington's Disease Awareness Month May**

For Huntington's disease awareness month, we highlighted the impact that Huntington's disease has on mental health with the campaign, '#HuntingtonsInMind'. The campaign raised awareness about the mental health impact that a diagnosis of Huntington's disease has on individuals and their families. We asked people from the Huntington's community if they would like to share their stories, we were so thankful to the community who were so willing to do so.

The campaign '#HuntingtonsInMind' has a dual meaning, both looking at mental health and Huntington's being in the forefront of people's minds.

Three videos were released during the month of May capturing the lived experience of people in the Huntington's community and discussing the difficulties they had with mental health and accessing support.

A project group was set up across the charity to drive the campaign. We were delighted when George Rainsford agreed to be a spokesperson for the campaign, the timing of the campaign was a key moment in Casualty's storyline meaning George spoke about the campaign on ITV's Loose Women and BBC Morning Live. This gave the campaign in TV terms alone a reach of over two million people. Additional press coverage included Metro papers, The Independent, Daily Express, Pick Me Up magazine an opinion piece in the Yorkshire Times and features in press aimed at professionals including The Carer, NR Times and Practice Nurse. The estimated total reach of all the press coverage was over 10.8 million people. It is an honour to be able to share people's stories as the cornerstone of the campaign. Our heartfelt thanks to everyone who contributed. The legacy of the campaign continues in the videos hosted on our YouTube channel which have been watched over 35,000 times.

During the month of May, we organised webinars about mental health as part of the '#HuntingtonsInMind' campaign. The momentum of the campaign became a call to action for the community. Working in partnership with the Scottish Huntington's Disease Association, and Northern Ireland Association over 100 signatures were gathered for an Early Day Motion in Parliament, to look at:

*"Calls on health and social care providers throughout the UK to expand specialist Huntington's disease services and access to mental health and other essential support in order to help those living with Huntington's disease and their families in the community."*

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

## Website

Thanks to funding from UniQure a pharmaceutical company, we were able to update our website, aligning it with the community's needs and preferences. The new look website was launched in April, with initial feedback positive. The new website also allows us to update information easily meaning our updates can be quicker allowing us to keep the community informed.

## Social Media

With the appointment of a Social Media Officer, we were able to improve how we communicated digitally. This enabled us to develop new strategies for each social media platform. Key achievements include:

- Increased engagement - people commenting, and sharing our information
- Specific messages developed for each platform
- Development of TikTok - working with young people via the Huntington's Disease Youth Voice enabled us to reach a new audience

YouTube - Our channel continued to grow giving members of the community a chance to view webinars they were unable to attend. The platform has been used to share people's stories, the content has really resonated with the community. Through the power of sharing stories, we have been able to reach new people. Becki's story sharing her experience of living with Huntington's disease and how her Specialist Adviser has supported her has been viewed over 25,000 times. Total views for the year on our YouTube channel is over 35,000 times. With 339 subscribers and 50,632 views on our YouTube channel, social media plays a key role in increasing people's understanding of Huntington's disease.

## Goal five - A strong charity to better champion the needs of our community

### New roles

As the charity reported an increase in income in the previous year, we were able to recruit to new roles to increase the effectiveness of the service we offer.

Helpline Adviser - this is a responsive role. The Adviser Kim, is often the first point of contact for people who ring the helpline. Kim is a listening ear, provides emotional support and general advice/guidance and signposts/links to relevant wider services.

Policy and Public Affairs Manager - this important role has allowed us to have a voice in parliament to help fulfil our vision of 'A better life for anyone affected by Huntington's disease' Having a dedicated person to fulfil this role has meant our influence as a charity has a greater reach.

New youth team worker - due to the hereditary nature of Huntington's disease and its impact on children and young people we were delighted to be able to recruit a new youth worker further enabling the reach of the work we do. Jack has quickly established himself working with young people and has allowed the youth service to start its ambitious growth plan.

The operations team continues to support the charity to enable it to operate effectively. Their work includes HR, systems management, supporting staff, safeguarding policy and procedure management.

## Goal six - Supporting Huntington's research

We continue to do all we can to continue in the fight for a cure for Huntington's disease. We have been closely working with pharmaceutical companies communicating research studies, and drug trials, and keeping the community up to date with the latest results from research studies.

We continue to fund HDBUZZ Huntington's disease research news. In plain language. Written by scientists. For the global Huntington's community

HD Voice continues to grow. HD Voice is an initiative by the Huntington's Disease Association that gives families a voice in Huntington's disease research and the internal work of the charity. They have been involved in many research projects giving valuable feedback on research. The group were also involved with supporting the communication and fundraising team. One of the HD Voice members was successfully appointed to the Clinical Research Network Kent, Surrey and Sussex (CRN KSS) as a Patient and Public Representative to the Partnership Board.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

Attendance at the EHDN conference in September allowed us to meet with Huntington's disease Associations across the world as well as meet with various pharmaceutical companies. Together we work to inform the community of all developments in the drug world with the potential to help people affected by Huntington's disease.

## **Fundraising**

In 2022/2023 our income from Community Fundraising and Events saw a huge boost bringing in £511,334.68 an increase of 16.2% on the previous year. Our largest event in the calendar year is the TCS London marathon which returned to the streets of London in October 2022 with our runners in '#TeamHDA' raising a brilliant £104,593.37. We expanded our offer to our TCS London Marathon '#TeamHDA' runners with activities over the weekend of the marathon including a pre and post-event meet up in central London. Thank you to everyone who took part and cheered '#TeamHDA' on whether it was on the TV or in person. At the other end of the country we were also thrilled to see our '#TeamHDA' take to the streets from Newcastle to South Shields in the Great North Run raising £13,805.92 towards our work.

As ever, our supporters showed imagination and ingenuity when it comes to organising their own fundraising challenges to raise funds. The fabulous Ladies Who Dare who took part in a skydive, Jess Webb not only organised a charity ball but also organised a collection at the Goodwood Super Car Day and was also the star of the BBC One Show, "One Big Thank You" in recognition of her amazing fundraising achievements for the Huntington's Disease Association. We have an energetic lot of supporters who trained and ran for various challenge events including climbing Kilimanjaro, the Yorkshire 3 Peaks, the Rustbox Rally, the South West Coast Path Challenge and the Peaky Ramblers who covered the distance from Alnwick Castle to Bamburgh Castle.

Individual giving saw a 6.5% increase on the previous year with all donations in this area hitting £351,276. We now have over 534 regular donors who donated a total of £79,711 in the year. Donating to our work in this way is a cost-effective way for the charity to receive donations and helps the charity to plan our work. We have carried out a lot of work across individual giving across the year including an improved stewardship process for in memory donors and new fundraising products. It can be a nervous time for a charity when introducing a new fundraising product; we are conscious that we do not want to overload our supporter base, but we also want to be able to offer fundraising products which will engage and attract funding to support our work. We took the decision to introduce a charity lottery, working with Sterling Management and being part of their Unity Lottery. Our players have helped to raise £17,732 in its first full year. Thank you to everyone who has taken part in the lottery.

We would also like to thank those who invite the charity to be a part of their life celebrations, to the numerous brides and grooms and those celebrating wedding anniversaries raising funds for our work, thank you for allowing us to be a part of your special day.

Big thanks go to the community groups who supported our work. St George's Golf Club in Surrey raised over £30,000 at their Captain's Golf Day, Helston Cober Valley Rotary Group raised £3,000, and the Harvel Pedigree Whippet Racing Club raised over £1,000 from their pedigree whippet racing day. Our thanks go to all the choirs, churches and schools who raise funds and awareness of our work.

Our '#HD8000' challenge series continued raising over £10,000 over the course of the year. Our huge thanks to everyone who took part in '#HDMove', '#HDHike' or '#HDBike'.

In May 2022 we were thrilled to welcome people back to the Liverpool Blu Radisson for the Huntington's Disease Association Awards, ably hosted by our friend, Charles Sabine. We introduced two new categories for this year, the Excellence in Health or Social Care to recognise the fantastic efforts of professionals who take the time to understand the complexities of Huntington's disease to ensure that those in their care receive the best support was awarded to Alex Fisher. The Recognition award was presented to Maureen Jones and Doreen Spiers in honour of their hard work in the earlier days of the charity. Our congratulations to everyone who was nominated and our winners. It was wonderful to see you all there on the day.

Our first Christmas Appeal took place in December 2022 raising a wonderful £11,509 to support our work. Our thanks go to members of HDVoice, who helped us to shape our appeal letter and share their own stories of how to celebrate Christmas whilst living with Huntington's.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

We were delighted to continue our work with the Westerleigh Group and our thanks go to their many employees who took to the skies, ran or baked cakes raising over £40,000 towards our work. Our thanks go to other corporate supporters over the year including Strategic Dimensions who donated £2,000, Wixroyd Group who donated £3,700 in support of a ball organised by a supporter, the Phoenix Life who matched their employee's fundraising efforts with a donation of over £1,100 for the charity, the Ice Co who donated £650 following their annual family fun day, Lewis and Cooper in Northallerton continued their support with instore fundraising activities raising over £500, and Pyramid Steel whose monthly support of our work helped, to raise over £600 in the year. In total our corporate income increased 34.9% on the previous year.

## Trusts and Foundations

Over the course of the year we saw a 64% increase on the previous year on income from Trusts and Foundations and Statutory. We are grateful to those Trusts and Foundations and Statutory partners whose support helps us to provide vital advice, information and support for people affected by Huntington's disease.

In August 2022, we were delighted to be selected as one of 12 charities to benefit from the 2022 Jingle Jam Charity gaming event. Jingle Jam is the largest charity gaming event in the world and is driven by a community of volunteers, content creators, games companies, and charities all coming together over a two-week period between 1 December – 14 December 2022 to raise money. The charity was awarded £240,924.52 in support of our continued support and development of the Huntington's Disease Association Youth Engagement Service (HDYES).

In February 2023 a full proposal worth £418,360 was submitted to the National Lottery Community Fund. This funding is to support the continued development of HDYES over the next three years.

2023 saw big changes as Clinical Commissioning Groups evolved into Integrated Care Boards/Systems. However, despite this we maintained our grant agreements for all our contracts as well as with Birmingham City Council and Dorset Healthcare University NHS Foundation. In addition, we received cost of living uplifts for three of our grant agreements as well as being successful in applying for a grant award of £31,275 from Liverpool City Council for our work support Clinically Extremely Vulnerable community members.

In 2022-23 we hosted our inaugural online Trusts and Foundations Engagement event. This virtual event brought Trust and Foundation grant-makers and funders closer to the people who their funding supports. Three speakers shared their different perspectives of Huntington's disease and the work of the Huntington's Disease Association. We look forward to planning more of these events in the future.

Putting people with Huntington's disease at the heart of our work is key to letting the world know about Huntington's disease and its effect upon individuals, families and communities. We will continue to work collaboratively with staff and supporters to share their stories and powerful messages.

We monitor return on investment on all our fundraising activities and meet or exceed all statutory and regulatory obligations.

We are members of the Fundraising Regulator and the Chartered Institute of Fundraising following best practice guidance laid down by them as well as the Charity Commission guidance for Charity Trustees (CC20). We comply with the Privacy and Electronic Communications Regulations (PECR). The Huntington's Disease Association recognises that we may work with people in vulnerable circumstances so protection of vulnerable people is something we take seriously. We adhere to the Chartered Institute of Fundraising's guidance – 'Treating Donors Fairly – responding to the needs of people in vulnerable circumstances'.

For the year 2022/2023 we did not receive any complaints about our fundraising practices/approaches.

## Financial review

### Financial review

The results for the year show an overall deficit of £104,651 (2022: surplus £742,867) made up of a deficit on the general fund of £247,758 (2022: surplus £715,699) and a surplus on the restricted funds of £142,927 (2022:surplus £27,168). The overall performance produced a deficit less than the 2022/2023 budgeted figure but the continued development of our services are anticipated to utilise reserves over the next two years to bring them in line with the Reserves Policy target.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

## Reserves Policy

The reserve requirement of the charity is to enable the salaries of staff members and running costs to be covered in the event of short-term income fluctuations. As a result of the uncertainties arising from the pandemic and inflationary pressures which may impact on income, it was agreed that the target for general reserves needed to be maintained at nine months recurring costs being approximately £1m.

At the year end, free reserves available excluding designated funds and tangible fixed assets stood at £1,746,363 (2022: £1,928,865) and therefore comfortably exceeded target. As noted in the Financial Review, the Trustees have agreed to utilise surplus reserves to develop the Association for the benefit of those impacted by Huntington's disease and this is budgeted to continue over the next two years.

## Risk Policy

The Trustees have assessed the major risks to which the Charity is exposed and are satisfied that systems are in place to mitigate exposure to major risks. The impact of the Coronavirus pandemic has been closely monitored by the Trustees and the Finance Committee. The success of the Reserves Policy means that the charity is well placed to make considered decisions on measures that may need to be taken as the current inflationary crisis unfolds.

Whilst working on the new strategy we looked at external and internal risks for the charity. Using two well-known strategy planning models, PESTLE and SWOT we have been able to identify potential risks to the charity. These include the rise in Cyberattacks, we have been working with our IT providers on a prevention strategy. All staff undergo mandatory training including, cyber security, data protection and Safeguarding.

## The Future

We began the new financial year with the launch of our strategy. An animation was created to launch the strategy, sharing how we will make a difference.

The promises in this strategy will shape our future work. We looked at our Vision as a charity, working with the community in partnership has brought many benefits and we wanted to include this element in our updated vision by including the word 'Together', acknowledging that it is only by working with others we will achieve our vision.

*"Together we will build a better life for anyone affected by Huntington's disease."*

Our mission includes our commitment to advocating for change through campaigning, our continued commitment to providing education and support and demonstrating our commitment to working with the community to shape our mission:

To enable everyone affected by Huntington's disease to live life to their full potential by:

1. Improving care and support
2. Educating families and the professionals who work with them
3. Championing the needs of the Huntington's community by working together
4. Influencing decision makers to tackle discrimination and secure equity of access to services

During this time of reflection, we looked at our values, on what drives us as an organisation, again taking feedback from the community we updated and added a new value, Inspirational

Our values are:

- Tenacious
- Experienced
- Compassionate
- Inclusive
- Inspirational

Throughout the consultation process and throughout our work we often commented how it was the community that drove us, we reflected this with our new strapline to launch the strategy.

*"Inspired by our community"*

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023**

---

Our five goals for the next five years are:

1. We will ensure everyone affected by Huntington's disease gets the care and support they need
2. We will help make each day with Huntington's disease the best possible day
3. We will make sure the voices of people affected by Huntington's disease are heard and are at the heart of everything we do
4. We will not rest until everyone with Huntington's disease has access to treatments
5. We will be a resilient charity

## **Plans for 2023/24**

We have recently submitted a bid to the lottery service to improve the expansion of the Huntington Disease Association Youth Service (HDYES), following on from the success of last year's Jingle Jam fundraising we have big plans for the development of the service that includes:

- Developing co-production services
- Develop psychological support sessions with children and young people, including drawing and talking therapy and narrative therapy sessions
- Deliver HD Youth Voice co-production sessions, embedding our youth leadership and collaboration programme and producing new information resources for HDYES

We will continue to develop our resources adding new content using co production principles so our information is developed with the voices of people with Huntington's.

We will work to increase the reach of all communication through all relevant social media, the website and online communications. Whilst increasing reach we will increase awareness of Huntington's disease. We will continue to develop our Ambassadors scheme so that people with Huntington's can share their stories. We will continue to fight for a better future, making every day the best possible day with our campaign work. We will prioritise mental health and NICE guidelines and work with our parliamentary champion to gain more support in Parliament and the House of Lords.

We will continue working with other charities to ensure we have a louder voice and work to influence policymakers to address concerns of the community on concerns such as the increase in cost of living, access to appropriate treatment at the right time and access to mental health services.

Our development of the Advisory service remains a top priority, ensuring we have the right people to offer services throughout England and Wales. Understanding the complexity of Huntington's disease and working with multiple agencies to ensure consistent care will remain a top priority of the Advisory Service. The team will expand its educational offering through the recruitment of an Education Lead, as we seek to improve professionals understanding of Huntington's disease.

We will continue to offer in-person events where we can, although as are many other companies these can be affected by external factors such as train strikes, and adverse weather events. We have already booked our AGM and Community Conference to be held at the Radisson Blu Hotel, Derby and we are looking forward to an inspiring weekend of talks and events.

We plan to embrace the power of fundraising this year by introducing creative ways to fundraise, through gaming (after the success of this year's Jingle Jam) and have partnered with Run for Charity to be able to offer a wider selection of events for people. We want to ensure giving is easy for people to do and are working with GOODPAYE to streamline payroll giving. We are developing the website to simplify the donation process.

As we continue to work with researchers and pharmaceutical companies to help find a cure and access to drugs to help treat the symptoms of Huntington's disease we are driven by the resilience of the people we work with. We can not thank the community enough who tirelessly campaign with us and fundraise for us.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

---

## Structure, governance and management

### Governing document

The company is a registered charity founded in 1971 and incorporated on 21 May 1986. The charity is governed by the Memorandum and Articles of Association.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Dr G El-Nimr	
Mr N M Heath (Hon Treasurer)	
Dr E M Howard (Vice-Chairperson)	(Resigned 15 October 2022)
Professor H Rickards (Chair)	
Dr A Fryer	(Resigned 15 October 2022)
Ms C Lyon	
Ms S Barker	
Mr S Duckett	
Dr N Swales	
Ms B E Waters	
Ms H Hubberstey	(Appointed 20 October 2022)
Ms C K Holmes	(Appointed 20 October 2022)
Mr D R Thomas	(Appointed 20 October 2022)

### Recruitment and appointment of trustees

The Trustees are elected to serve a term of three years at the Annual General Meeting by the voting members of the Association who are the Guarantors.

### Organisational structure

The charity is managed by an Executive Council made up of the trustees which met on five occasions during the year.

The trustees have considered the Charity Commission's general guidance on public benefit in relation to the objectives of the charity. This report sets out those objectives and describes how they have been met in the current year.

The Executive Council members focus on the strategic decisions required for the overall governance of the Huntingtons Disease Association and devolve operational running to the management team.

The Chief Executive and senior managers oversee the operational management of the Huntingtons Disease Association within the policies and guidelines approved by the Executive Council. Prior to board meetings, the Chief Executive provides a written update report to the Executive Council on the operational management of the charity which all senior managers have an input into. The reports provide the Executive Council with a detailed overview of the operational progress of the Association. The Chief Executive attends board meetings to discuss the management reports further and answer any questions trustees may have.

### Trustee induction and training

Most trustees are already familiar with the work of the charity and their training involves briefings on their duties and liabilities. Additionally, new trustees receive an induction pack covering:

- The duties of charity trustees;
- An induction pack outlining duties and responsibilities;
- The Association's Memorandum and Articles of Association, strategic plan, latest published annual report and accounts, financial projections and budgets, and project and programme plans and publications;
- Trustee details and staff structure;
- 'The Essential Trustee: what you need to know' (Charity Commission);
- Minutes and reports submitted to the previous three meetings of the board of trustees.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

---

**Remuneration policy**

The Trustees have responsibility for setting the pay and remuneration of the charity's key personnel and this is done on an annual basis, including a formal cost of living review. Salaries are benchmarked with other similar organisations across the sector.

**Auditor**

In accordance with the company's articles, a resolution proposing that DSG be reappointed as auditor of the company will be put at a General Meeting.

**Disclosure of information to auditor**

Each of the trustees has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

**Small company provisions**

This report has been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The trustees' report was approved by the Board of Trustees.



**Mr N M Heath (Hon Treasurer)**

Dated: 18 October 2023

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF TRUSTEES' RESPONSIBILITIES  
FOR THE YEAR ENDED 31 MARCH 2023**

---

The trustees, who are also the directors of Huntington's Disease Association for the purpose of company law, are responsible for preparing the Trustees' Report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law requires the trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these accounts, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT

## TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

---

### Opinion

We have audited the financial statements of Huntington's Disease Association (the 'charity') for the year ended 31 March 2023 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

### Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the trustees' report has been prepared in accordance with applicable legal requirements.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
INDEPENDENT AUDITOR'S REPORT (CONTINUED)  
TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION**

---

**Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

**Responsibilities of trustees**

As explained more fully in the statement of trustees' responsibilities, the trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

**Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT (CONTINUED) TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

---

## Capability of the audit in detecting irregularities, including fraud

Based on our discussions with the charity's management and the Trustees, we identified that the following laws and regulations are significant to the entity:

- Those laws and regulations considered to have a direct effect on the financial statements include UK financial reporting standards and Charity Law.
- Those laws and regulations for which non-compliance may be fundamental to the operating aspects of the charity and therefore may have a material effect on the financial statements include compliance with the charitable objectives, public benefit, fundraising regulations, safeguarding and health and safety legislation.

These matters were discussed amongst the engagement team at the planning stage and the team remained alert to non-compliance throughout the audit.

Audit procedures undertaken in response to the potential risks relating to irregularities (which include fraud and non-compliance with laws and regulations) comprised of: inquiries of management and the Trustees as to whether the entity complies with such laws and regulations; enquiries with the same concerning any actual or potential litigation or claims; inspection of relevant legal correspondence; review of Trustee meeting minutes; testing the appropriateness of journal entries; and the performance of analytical review to identify unexpected movements in account balances which may be indicative of fraud.

No instances of material non-compliance were identified. However, the likelihood of detecting irregularities, including fraud, is limited by the inherent difficulty in detecting irregularities, the effectiveness of the entity's controls, and the nature, timing and extent of the audit procedures performed. Irregularities that result from fraud might be inherently more difficult to detect than irregularities that result from error. As explained above, there is an unavoidable risk that material misstatements may not be detected, even though the audit has been planned and performed in accordance with ISAs (UK).

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

## Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



**Andrew Moss BA FCA (Senior Statutory Auditor)**  
for and on behalf of DSG

18 October 2023

**Chartered Accountants**  
**Statutory Auditor**

Castle Chambers  
43 Castle Street  
Liverpool  
L2 9TL

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF FINANCIAL ACTIVITIES  
INCLUDING INCOME AND EXPENDITURE ACCOUNT**

**FOR THE YEAR ENDED 31 MARCH 2023**

		Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
	Notes						
<b>Income from</b>							
Donations and legacies	2	1,298,518	74,311	1,372,829	1,723,498	27,981	1,751,479
Charitable activities	3	28,354	542,026	570,380	55,853	319,533	375,386
Other trading activities	4	18,367	-	18,367	24,975	-	24,975
Investments	5	36,267	-	36,267	12,941	-	12,941
Other income	6	5,735	-	5,735	1,544	-	1,544
<b>Total income</b>		<b>1,387,241</b>	<b>616,337</b>	<b>2,003,578</b>	<b>1,818,811</b>	<b>347,514</b>	<b>2,166,325</b>
<b>Expenditure on:</b>							
Raising funds	7	292,650	-	292,650	219,774	-	219,774
Charitable activities	8	1,268,506	473,410	1,741,916	879,401	320,346	1,199,747
<b>Total expenditure</b>		<b>1,561,156</b>	<b>473,410</b>	<b>2,034,566</b>	<b>1,099,175</b>	<b>320,346</b>	<b>1,419,521</b>
Net gains/(losses) on investments	12	(73,663)	-	(73,663)	(3,937)	-	(3,937)
<b>Net movement in funds</b>		<b>(247,578)</b>	<b>142,927</b>	<b>(104,651)</b>	<b>715,699</b>	<b>27,168</b>	<b>742,867</b>
<b>Reconciliation of funds</b>							
Fund balances at 1 April 2022		2,405,724	83,050	2,488,774	1,690,025	55,882	1,745,907
<b>Fund balances at 31 March 2023</b>		<b>2,158,146</b>	<b>225,977</b>	<b>2,384,123</b>	<b>2,405,724</b>	<b>83,050</b>	<b>2,488,774</b>

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
BALANCE SHEET**

**AS AT 31 MARCH 2023**

	Notes	2023		2022	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	14		20,359		20,137
Investments	15		875,147		948,810
			<u>895,506</u>		<u>968,947</u>
<b>Current assets</b>					
Stocks	16	9,007		10,174	
Debtors	17	390,793		677,503	
Cash at bank and in hand		1,243,672		962,916	
		<u>1,643,472</u>		<u>1,650,593</u>	
<b>Creditors: amounts falling due within one year</b>	18	(154,855)		(130,766)	
Net current assets			<u>1,488,617</u>		<u>1,519,827</u>
<b>Total assets less current liabilities</b>			<u><u>2,384,123</u></u>		<u><u>2,488,774</u></u>
<b>Income funds</b>					
Restricted funds	20		225,977		83,050
<u>Unrestricted funds</u>					
Designated funds	21	391,424		456,722	
General unrestricted funds		1,766,722		1,949,002	
		<u>2,158,146</u>		<u>2,405,724</u>	
			<u><u>2,384,123</u></u>		<u><u>2,488,774</u></u>

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the Trustees on 18 October 2023

*N M Heath*

Mr N M Heath (Hon Treasurer)  
Trustee

Company registration number 02021975

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF CASH FLOWS**

**FOR THE YEAR ENDED 31 MARCH 2023**

	Notes	2023 £	£	2022 £	£
<b>Cash flows from operating activities</b>					
Cash generated from operations	26		254,329		473,153
<b>Investing activities</b>					
Purchase of tangible fixed assets		(9,840)		(23,289)	
Purchase of investments		-		(501,462)	
Proceeds from disposal of investments		-		1,462	
Investment income received		36,267		12,941	
<b>Net cash generated from/(used in) investing activities</b>			26,427		(510,348)
<b>Net cash used in financing activities</b>			-		-
<b>Net increase/(decrease) in cash and cash equivalents</b>			280,756		(37,195)
Cash and cash equivalents at beginning of year			962,916		1,000,111
<b>Cash and cash equivalents at end of year</b>			<u>1,243,672</u>		<u>962,916</u>

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

---

## 1 Accounting policies

### Charity information

Huntington's Disease Association is a private company limited by guarantee incorporated in England and Wales. The registered office is Suite 24 Liverpool Science Park, Innovation Centre, 131 Mount Pleasant, Liverpool, L3 5TF.

### 1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)". The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention except for the revaluation of fixed asset investments in accordance with the Charities SORP.

### 1.2 Going concern

The Trustees have considered the potential effects of current inflationary pressures and general economic uncertainty on the charity.

At the time of approving the accounts the Trustees consider that the charity has adequate reserves and diverse revenue streams to continue in operational existence for the foreseeable future taking account of economic uncertainties caused by the pandemic. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the accounts.

### 1.3 Charitable funds

*Unrestricted funds* are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

*Designated funds* comprise funds which have been set aside at the discretion of the trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the accounts.

*Restricted funds* are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the accounts.

### 1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Investment income consists of interest and dividends received and receivable.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is disclosed as a contingent asset.

No amounts are included in the financial statements for services donated by volunteers.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

---

**1 Accounting policies**

**(Continued)**

Grants, including grants for the purchase of fixed assets, are recognised in full in the statement of financial activities in the year in which they are receivable.

Deferred income represents grants received in advance of the expenditure to which it is allocated to support.

No amounts are included in these financial statements for goods donated to charity shops or services donated by volunteers.

Income from merchandise sales and fundraising income is recognised as earned (that is, as the related goods or services are provided).

**1.5 Expenditure**

All expenditure has been accounted for on an accruals basis and includes irrecoverable VAT where applicable. Expenditure is allocated to relevant activity categories on a basis that is consistent with the use of that resource. Support costs have been attributable to charitable activity in accordance with best estimates.

Research grants are made each year after approval and recommendation by the Medical Advisory Panel. The amount charged to the profit and loss account represents the cost of projects approved during the year.

**1.6 Tangible fixed assets**

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% straight line
-----------------------	-------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year..

**1.7 Fixed asset investments**

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

**1.8 Impairment of fixed assets**

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

**1.9 Stocks**

Stocks are valued at the lower of cost or selling price less selling costs, after making due allowance for obsolete and slow-moving items. Cost is calculated using the first-in first-out basis of valuation.

**1.10 Cash and cash equivalents**

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

---

**1 Accounting policies**

**(Continued)**

**1.11 Financial instruments**

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

***Basic financial assets***

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

***Impairment of financial assets***

Financial assets, other than those held at fair value through income and expenditure, are assessed for indicators of impairment at each reporting date. Financial assets are impaired where there is objective evidence that, as a result of one or more events that occurred after the initial recognition of the financial asset, the estimated future cash flows have been affected.

If an asset is impaired, the impairment loss is the difference between the carrying amount and the present value of the estimated cash flows discounted at the asset's original effective interest rate. The impairment loss is recognised in net income/(expenditure) for the year.

If there is a decrease in the impairment loss arising from an event occurring after the impairment was recognised, the impairment is reversed. The reversal is such that the current carrying amount does not exceed what the carrying amount would have been, had the impairment not previously been recognised. The impairment reversal is recognised in net income/(expenditure) for the year.

***Derecognition of financial assets***

Financial assets are derecognised only when the contractual rights to the cash flows from the asset expire or are settled, or when the charity transfers the financial asset and substantially all the risks and rewards of ownership to another entity, or if some significant risks and rewards of ownership are retained but control of the asset has transferred to another party that is able to sell the asset in its entirety to an unrelated third party.

***Basic financial liabilities***

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

***Derecognition of financial liabilities***

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

**1 Accounting policies (Continued)**

**1.12 Employee benefits**

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

**1.13 Retirement benefits**

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

**1.14 Branch funds**

The funds of the Association's branches have been consolidated in the accounts.

**2 Donations and legacies**

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2023	2023	2023	2022	2022	2022
	£	£	£	£	£	£
Donations and gifts	968,144	70,121	1,038,265	888,814	23,381	912,195
Legacies receivable	297,406	-	297,406	805,537	3,000	808,537
Branch income	32,968	4,190	37,158	29,147	1,600	30,747
	<u>1,298,518</u>	<u>74,311</u>	<u>1,372,829</u>	<u>1,723,498</u>	<u>27,981</u>	<u>1,751,479</u>

**3 Charitable activities**

	2023	2022
	£	£
Grants received	548,026	345,633
Merchandise	15,708	19,812
Other income	6,646	9,941
	<u>570,380</u>	<u>375,386</u>
<b>Analysis by fund</b>		
Unrestricted funds	28,354	55,853
Restricted funds	542,026	319,533
	<u>570,380</u>	<u>375,386</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2023**

**4 Other trading activities**

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
Consultancy	18,367	24,975

**5 Investments**

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
Income from listed investments	25,241	12,615
Interest receivable	11,026	326
	<u>36,267</u>	<u>12,941</u>

**6 Other income**

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
Miscellaneous income	5,735	1,544

**7 Raising funds**

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
<u>Fundraising and publicity</u>		
Fundraising events	24,195	4,683
Other fundraising costs	94,196	43,830
Staff costs	174,259	171,261
	<u>292,650</u>	<u>219,774</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**

**FOR THE YEAR ENDED 31 MARCH 2023**

**8 Charitable activities**

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication - Policy & Public Affairs	Youth Workers & Juvenile	Branch	Total 2023	Total 2022
	£	£	£	£	£	£	£	£
Staff costs	793,743	882	882	120,739	72,432	17,588	1,006,266	783,674
Welfare grants	-	12,734	-	-	-	8,058	20,792	19,551
Research	-	-	20,180	-	-	-	20,180	91
Recruitment	2,386	-	-	257	764	-	3,407	1,028
Travel and training	37,722	-	-	2,490	7,961	687	48,860	14,623
Telephone and internet	18,965	-	-	690	675	236	20,566	20,862
Other costs	49,406	63	63	54,925	25,143	20,987	150,587	65,098
Newsletter	-	-	-	24,669	-	-	24,669	5,334
Website	-	-	-	23,945	-	-	23,945	15,379
Event costs	7,712	-	-	706	23,659	-	32,077	4,855
	<u>909,934</u>	<u>13,679</u>	<u>21,125</u>	<u>228,421</u>	<u>130,634</u>	<u>47,556</u>	<u>1,351,349</u>	<u>930,495</u>
Share of support costs (see note 9)	204,472	19,338	-	77,352	38,676	38,676	378,514	257,598
Share of governance costs (see note 9)	12,053	-	-	-	-	-	12,053	11,654
	<u>1,126,459</u>	<u>33,017</u>	<u>21,125</u>	<u>305,773</u>	<u>169,310</u>	<u>86,232</u>	<u>1,741,916</u>	<u>1,199,747</u>
<b>Analysis by fund</b>								
Unrestricted funds	779,438	24,100	1,125	297,715	79,896	86,232	1,268,506	879,401
Restricted funds	347,021	8,917	20,000	8,058	89,414	-	473,410	320,346
	<u>1,126,459</u>	<u>33,017</u>	<u>21,125</u>	<u>305,773</u>	<u>169,310</u>	<u>86,232</u>	<u>1,741,916</u>	<u>1,199,747</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2023**

**8 Charitable activities**

**(Continued)**

For the year ended 31 March 2022

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication - Policy & Public Affairs	Youth Workers & Juvenile	Branch	Total 2022
	£	£	£	£	£	£	£
Staff costs	604,237	2,608	795	79,203	86,831	10,000	783,674
Welfare grants	-	11,536	-	-	-	8,015	19,551
Research	-	-	91	-	-	-	91
Recruitment	593	-	-	435	-	-	1,028
Travel and training	14,332	-	-	160	131	-	14,623
Telephone and internet	19,949	-	1	504	408	-	20,862
Other costs	23,954	38	38	16,366	4,635	20,067	65,098
Newsletter	-	-	-	5,334	-	-	5,334
Website	-	-	-	15,379	-	-	15,379
Event costs	4,504	-	-	-	351	-	4,855
	<u>667,569</u>	<u>14,182</u>	<u>925</u>	<u>117,381</u>	<u>92,356</u>	<u>38,082</u>	<u>930,495</u>
Share of support costs (see note 9)	141,678	12,880	-	30,912	20,608	51,520	257,598
Share of governance costs (see note 9)	11,654	-	-	-	-	-	11,654
	<u>820,901</u>	<u>27,062</u>	<u>925</u>	<u>148,293</u>	<u>112,964</u>	<u>89,602</u>	<u>1,199,747</u>
<b>Analysis by fund</b>							
Unrestricted funds	547,694	17,608	834	148,293	75,370	89,602	879,401
Restricted funds	273,207	9,454	91	-	37,594	-	320,346
	<u>820,901</u>	<u>27,062</u>	<u>925</u>	<u>148,293</u>	<u>112,964</u>	<u>89,602</u>	<u>1,199,747</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2023**

**9 Support costs**

	Support costs	Governance costs	2023	Support costs	Governance costs	2022
	£	£	£	£	£	£
Staff costs	215,284	-	215,284	124,021	-	124,021
Depreciation	9,618	-	9,618	7,771	-	7,771
Head office costs	153,612	-	153,612	125,806	-	125,806
Audit fees	-	8,250	8,250	-	8,000	8,000
EC meeting costs	-	3,803	3,803	-	3,654	3,654
	<u>378,514</u>	<u>12,053</u>	<u>390,567</u>	<u>257,598</u>	<u>11,654</u>	<u>269,252</u>
Analysed between Charitable activities	<u>378,514</u>	<u>12,053</u>	<u>390,567</u>	<u>257,598</u>	<u>11,654</u>	<u>269,252</u>

Support costs are allocated on the basis of time spent.

**10 Trustees**

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year (2022: £nil). Two trustees were reimbursed expenses totalling £179 for a subscription and part payment of a training course (2022: two trustees were reimbursed £112).

**11 Employees**

The average monthly number of employees during the year was:

	2023 Number	2022 Number
Specialist HD Advisors	22	19
Management	1	1
Fundraising	5	5
Youth Worker	2	1
Administration	8	5
Communications	3	2
Total	<u>41</u>	<u>33</u>

**Employment costs**

	2023 £	2022 £
Wages and salaries	1,240,304	963,553
Social security costs	121,121	89,010
Other pension costs	34,384	26,393
	<u>1,395,809</u>	<u>1,078,956</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2023**

**11 Employees** **(Continued)**

The number of employees whose annual remuneration was more than £60,000 is as follows:

	<b>2023 Number</b>	<b>2022 Number</b>
£60,001 - £70,000	-	1
£70,001 - £80,000	1	-
	<u>          </u>	<u>          </u>

**12 Net gains/(losses) on investments**

	<b>Unrestricted funds 2023 £</b>	<b>Unrestricted funds 2022 £</b>
Revaluation of investments	(73,663)	(3,937)
	<u>          </u>	<u>          </u>

**13 Taxation**

The charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

**14 Tangible fixed assets**

	<b>Fixtures and fittings £</b>
<b>Cost</b>	
At 1 April 2022	96,747
Additions	9,840
Disposals	(60,438)
	<u>          </u>
At 31 March 2023	46,149
	<u>          </u>
<b>Depreciation</b>	
At 1 April 2022	76,610
Depreciation charged in the year	9,618
Eliminated in respect of disposals	(60,438)
	<u>          </u>
At 31 March 2023	25,790
	<u>          </u>
<b>Carrying amount</b>	
At 31 March 2023	20,359
	<u>          </u>
At 31 March 2022	20,137
	<u>          </u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2023**

**15 Fixed asset investments**

	<b>Listed investments £</b>
<b>Valuation</b>	
At 1 April 2022	948,810
Valuation changes	(73,663)
At 31 March 2023	<u>875,147</u>
<b>Carrying amount</b>	
At 31 March 2023	<u>875,147</u>
At 31 March 2022	<u>948,810</u>

<b>16 Stocks</b>	<b>2023 £</b>	<b>2022 £</b>
Merchandise	<u>9,007</u>	<u>10,174</u>

<b>17 Debtors</b>	<b>2023 £</b>	<b>2022 £</b>
<b>Amounts falling due within one year:</b>		
Trade debtors	3,309	15,455
Other debtors	297,298	608,214
Prepayments	90,186	53,834
	<u>390,793</u>	<u>677,503</u>

Other debtors include £252,932 (2022: £575,845) of legacies receivable.

<b>18 Creditors: amounts falling due within one year</b>	<b>2023 £</b>	<b>2022 £</b>
Other taxation and social security	27,005	25,512
Trade creditors	54,744	48,286
Accruals and deferred income	73,106	56,968
	<u>154,855</u>	<u>130,766</u>

Included in accruals and deferred income is deferred income of £58,423 (2022: £37,600) relating to income received for future periods.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

---

**19 Retirement benefit schemes**

**Defined contribution schemes**

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

The charge to the statement of financial activities in respect of defined contribution schemes was £34,384 (2022 - £26,393).

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**

**FOR THE YEAR ENDED 31 MARCH 2023**

**20 Restricted funds**

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds			Movement in funds			Balance at 31 March 2023 £
	Balance at 1 April 2021 £	Incoming resources £	Resources expended £	Balance at 1 April 2022 £	Incoming resources £	Resources expended £	
Research	16,700	9,795	(91)	26,404	7,980	(20,000)	14,384
Specialist HD Advisory Service (SHDA)	-	268,674	(268,674)	-	347,021	(347,021)	-
Children in Need	4,757	-	-	4,757	-	(4,757)	-
Lancashire Training Events	4,849	-	-	4,849	-	-	4,849
Juvenile Huntingtons Disease	-	135	(135)	-	1,500	(1,500)	-
JHD Weekend	24,624	1,000	(152)	25,472	-	(25,472)	-
Youth Services	3,048	52,500	(37,307)	18,241	1,524	(19,765)	-
BUPA Old Carers	1,904	-	(1,904)	-	-	-	-
B & Q Foundation	-	5,000	(4,533)	467	5,000	(2,768)	2,699
Welfare Fund	-	10,410	(7,550)	2,860	4,329	(6,149)	1,040
Website	-	-	-	-	8,058	(8,058)	-
Jingle Jam	-	-	-	-	240,925	(37,920)	203,005
	<u>55,882</u>	<u>347,514</u>	<u>(320,346)</u>	<u>83,050</u>	<u>616,337</u>	<u>(473,410)</u>	<u>225,977</u>

**Research**

Research funds are raised to promote medical and social/ therapeutic research of direct significance to Huntington's Disease sufferers and their families. Our Medical Advisory Board reviews all applications on an annual basis before a decision is taken by our Executive Council. Funds were received from individuals, organisations and Branches requesting their donation be spent on this activity.

**Specialist HD Advisory Service (SHDA)**

The network of Specialist HD Advisers was maintained during the year. Restricted funding relating purely to this service and for each geographical area was received from numerous sources in the period.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

---

**20 Restricted funds**

**(Continued)**

**Children in Need**

This grant is to fund a youth worker.

**Lancashire Training Events**

Money raised towards an awareness/training event in the Fylde Coast area.

**Juvenile HD**

This fund relates to income raised by a supporter who requested the funds be used to raise awareness of Juvenile Huntingtons Disease.

**JHD Weekend**

These relate to individual donations and grants that have been or are to be spent on the JHD weekend.

**Youth Services**

This relates to Trusts funding received to fund the work of our Youth Worker

**Bupa Old Carers**

We were awarded funding by BUPA UK Foundation to create an online area to support older carers aged 65+.

**B&Q Foundation**

Funding received from B&Q Foundation for enhancing quality of life and helping to reduce risks by providing financial assistance to maintain, repair or improve housing

**Welfare Fund**

Funding received from B&Q Foundation for enhancing quality of life and helping to reduce risks by providing financial assistance to maintain, repair or improve housing.

**Website**

A development grant was received from Uniqure to develop our website.

**Jingle Jam**

Jingle Jam is the World's largest gaming event which took place in December 2022. We were one of 12 charities that benefited from the event and secured funding of £240,925 towards our Youth Engagement Services.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

**21 Designated funds**

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

	Movement in funds				Movement in funds			
	Balance at 1 April 2021 £	Incoming resources £	Resources expended £	Transfers £	Balance at 1 April 2022 £	Incoming resources £	Resources expended £	Balance at 31 March 2023 £
Special projects fund	214,000	-	-	(30,000)	184,000	-	(41,110)	142,890
Branch funds	72,265	20,992	(27,535)	-	65,722	26,276	(26,996)	65,002
Huntington's Disease Youth Engagement Service	-	-	-	207,000	207,000	-	(23,468)	183,532
	<u>286,265</u>	<u>20,992</u>	<u>(27,535)</u>	<u>177,000</u>	<u>456,722</u>	<u>26,276</u>	<u>(91,574)</u>	<u>391,424</u>

A designated special projects fund of £400,000 was established as a result of generous legacies received during 2013. It is intended that the fund be used for special projects, which, once instituted, may be developed in accordance with the long-term objectives of the charity. During 2015 and 2016 £130,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support. A further £40,000 of the fund was used to support the new communication initiative in 2017/18 and £16,000 was used in 2018/19 to complete the Care Home Accreditation project. In 2021/22, £30,000 was released to cover costs associated with changes necessitated by the pandemic including reducing the office size, software improvement and project development. The balance of the fund amounting to £184,000 has been allocated in part to cover a substantial portion of the 2022/23 budget deficit arising from new posts covering National Support, Policy and Public Affairs, Data Management and Volunteer Support.

We have been successful in obtaining funding from the National Lottery for a 3 year project for the expansion of the Huntington's Disease Youth Engagement Service (Youth Project). The project began on 1 June 2023 and as part of the project we have committed to spending £183,532 of our own resources over the 3 years.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2023**

**22 Analysis of net assets between funds**

	Unrestricted funds	Restricted funds	Total Unrestricted funds		Restricted funds	Total
	2023	2023	2023	2022	2022	2022
	£	£	£	£	£	£
Fund balances at 31 March 2023 are represented by:						
Tangible assets	20,359	-	20,359	20,137	-	20,137
Investments	875,147	-	875,147	948,810	-	948,810
Current assets/(liabilities)	1,262,640	225,977	1,488,617	1,436,777	83,050	1,519,827
	<u>2,158,146</u>	<u>225,977</u>	<u>2,384,123</u>	<u>2,405,724</u>	<u>83,050</u>	<u>2,488,774</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

**23 Operating lease commitments**

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	<b>2023</b>	<b>2022</b>
	£	£
Within one year	34,627	28,580
Between two and five years	70,926	96,233
	<u>105,553</u>	<u>124,813</u>

**24 Related party transactions**

**Remuneration of key management personnel**

The remuneration of key management personnel, which consists of the Chief Executive and the heads of departments, is as shown below.

	<b>2023</b>	<b>2022</b>
	£	£
Aggregate remuneration	<u>298,495</u>	<u>217,690</u>

**Transactions with related parties**

During the year, one trustee donated £116 (2022: £120).

There were no other related party transactions in the year.

**25 Branch funds**

Reports received from branches are set out below and incorporated into the accounts.

	<b>2023</b>	<b>2022</b>
	£	£
<b>Cash balances</b>		
At 1 April 2022	65,722	72,265
Receipts in year	37,158	30,747
Less :		
Local welfare grants	(8,058)	(7,468)
Sent to head office	(10,882)	(9,755)
Branch activities, local newsletters, equipment, research etc	(18,938)	(20,067)
	<u>65,002</u>	<u>65,722</u>
At 31 March 2023	<u>65,002</u>	<u>65,722</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2023**

<b>26 Cash generated from operations</b>	<b>2023</b>	<b>2022</b>
	<b>£</b>	<b>£</b>
(Deficit)/surplus for the year	(104,651)	742,867
Adjustments for:		
Investment income recognised in statement of financial activities	(36,267)	(12,941)
Fair value gains and losses on investments	73,663	3,937
Depreciation and impairment of tangible fixed assets	9,618	7,771
Movements in working capital:		
Decrease/(increase) in stocks	1,167	(615)
Decrease/(increase) in debtors	286,710	(293,777)
Increase in creditors	24,089	25,911
	<u>          </u>	<u>          </u>
<b>Cash generated from operations</b>	<b>254,329</b>	<b>473,153</b>
	<u>          </u>	<u>          </u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

---

**27 Acknowledgements**

B&Q Foundation  
Baron Davenport Charitable Trust  
Birmingham City Council  
Chapman Charitable Trust  
Cheshire Community Foundation  
Chrysalis Trust  
Dorset Healthcare University NHS Foundation  
Douglas Arter Foundation  
Dryden Family Foundation  
Edith Murphy Foundation  
Edward Cadbury Charitable Trust  
Elizabeth L Rathbone Charitable Trust  
Fowler Smith and Jones Trust  
Garfield Weston Foundation  
Gay and Peter Hillard Hartley Charitable Trust  
Hampshire and the Isle of Wight Community Foundation  
Jingle Jam  
John James Bristol Foundation  
Liverpool City Council  
Lord Leverhulmes Charitable Trust  
Milles Charitable Foundation  
Mrs Gladys Lancaster Will Trust  
NHS Cambridgeshire & Peterborough Integrated Care Board  
NHS Cornwall and Isles of Scilly Integrated Care Board  
NHS Devon Integrated Care Board  
NHS Lancashire and South Cumbria Integrated Care Board  
North East and North Cumbria Integrated Care Board  
PF Charitable Trust  
PH Holt Foundation  
PIB Community Trust  
ShareGift (Orr Mackintosh Foundation)  
Sovereign Healthcare  
The Alan Higgs Charity  
The Barbour Foundation  
The Barratt Foundation  
The Benham Charitable Settlement  
The Charles Jacob Charitable Trust  
The Charles Littlewood Charitable Trust  
The Cumber Family Charitable Trust  
The D'Oyly Carte Charitable Trust  
The Dyers' Company Charitable Trust  
The Earmark Trust  
The Eveson Charitable Trust  
The Februrary Foundation  
The Florence Turner Trust  
The Frederick and Phyllis Cann Trust  
The George A Moore Foundation  
The Goldcrest Charitable Trust  
The Grace Trust  
The Hadfield Charitable Trust  
The Hadrian Trust  
The Hull and East Riding Charitable Trust  
The J Reginald Corah Foundation Fund  
The Jeniffer & Jonathan Charitable Trust  
The Joseph and Lena Randall Charitable Trust  
The Lawson Trust

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2023**

---

**27 Acknowledgements continued**

The Sir James Knott  
The Sir James Reckitt Charity  
The Sir James Roll Charitable Trust  
The Strangwards Trust  
The Sunrise (sidmouth) Charitable Trust  
The Sylvia and Colin Shepherd Charitable Trust  
The Thomas Sivewright Catto Charitable Settlement  
The Ursula Keys Trust  
The William Leech Charity  
The Wixamtree Trust  
The WO Street Charitable Foundation  
The Lord Cozens-Hardy Trust  
The Maud Elkington Charitable Trust  
The May 1961 Charitable Trust  
The Michael and Anna Wix Charitable Trust  
The Miss Pannett Charitable Trust  
The Mollie Croysdale Charitable Trust  
The Norman Family Charitable Trust  
The Paul Bassham Charitable Trust  
The Peter Stebbing Memorial Charity  
The Proven Family Trust  
The Roger De Haan Charitable Trust  
The Simon and Philip Cohen Charitable Trust

**HUNTINGTONS DISEASE ASSOCIATION**

England & Wales - Charity number 296453

---

# Accounts

---

Charity registration number 296453

Company registration number 02021975 (England and Wales)

**HUNTINGTON'S DISEASE ASSOCIATION**  
**COMPANY LIMITED BY GUARANTEE**  
**ANNUAL REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2022**

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE LEGAL AND ADMINISTRATIVE INFORMATION

---

<b>Patrons</b>	Tony Hadley Shane Richie George Rainsford
<b>Trustees</b>	Dr G El-Nimr Mr N M Heath (Hon Treasurer) Dr E M Howard (Vice-Chairperson) Professor H Rickards (Chair) Dr A Fryer Ms C Lyon Ms S Barker Mr S Duckett Dr N Swales Ms B E Waters
<b>Chief executive</b>	Mrs C Stanley BSc (Hons)
<b>Charity number</b>	296453
<b>Company number</b>	02021975
<b>Registered office</b>	Suite 24 Liverpool Science Park Innovation Centre 131 Mount Pleasant Liverpool L3 5TF
<b>Auditor</b>	DSG Castle Chambers 43 Castle Street Liverpool L2 9TL
<b>Bankers</b>	National Westminster Bank Plc 66/68 St John's Road Battersea London SW11 1PB

---

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE CONTENTS

---

	<b>Page</b>
Trustees' report	1 - 12
Statement of trustees' responsibilities	13
Independent auditor's report	14 - 16
Statement of financial activities	17
Balance sheet	18
Statement of cash flows	19
Notes to the financial statements	20 - 36

---

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2022**

---

The trustees present their annual report and financial statements for the year ended 31 March 2022.

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 charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)".

## **Objectives and activities**

### **Charity objects**

The Huntington's Disease Association's objects are the relief and treatment of those suffering from or believed to be suffering from Huntington's disease and to provide financial support for such persons and their families in need and for research and the dissemination of the results of such research for the public benefit into the cause and possible cures whether partial or complete and possible prevention of the said disease.

### **Huntington's disease, a brief overview**

Huntington's disease is a rare neurological disorder that is caused by a faulty gene passed down through families. Each child of a parent with Huntington's has a 50% chance of inheriting the faulty gene. The disease affects the central nervous system, the network of nerve tissues in the brain and spinal cord that co-ordinate the body's activities. It is a progressive condition that causes changes in movement, thinking, emotions, eating and speech that worsen over time. Symptoms usually begin between the ages of 30 and 50, though they can also develop much earlier or later. If someone begins to show symptoms before the age of 20, this is known as Juvenile Huntington's disease. It is estimated that around 8,000 people are living with Huntington's and 32,000 are at risk of developing it in the United Kingdom.

### **Vision**

A better life for anyone affected by Huntington's disease.

### **Mission**

To enable everyone affected by Huntington's disease to live life to their full potential by:

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community and influencing policymakers

### **Values**

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive

### **Who we are**

The charity was founded in 1971 after a family who had been given a diagnosis of Huntington's sent a letter to a local paper asking if anyone knew of any other families in a similar situation. It began as a support group with 76 members and was known initially as the 'Association to Combat Huntington's Chorea', later becoming the Huntington's Disease Association.

Feedback from families that they would benefit from professionals with knowledge and understanding of the illness led to a 1993 project known as CASE – Care, Advice, Support and Education. This project saw the birth of our Specialist Huntington's Disease Advisory service that continues to be a valued resource and focus for development to this day.

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022**

---

The Huntington's Disease Association provides support to anyone affected by Huntington's or anyone involved in their care and support across England and Wales. We also work closely with other Huntington's disease charities across the UK and Ireland. We now have 36 staff members from a wide range of backgrounds. From nursing and social care to fundraising and administration, all united in our dedication to supporting people living with and affected by Huntington's.

## **What we do**

### **Specialist Advisory Service**

The Specialist Huntington's disease Advisory service provides practical information, advice and emotional support to people with Huntington's and their families across England and Wales. Our advisers promote local services, assist with the organisation of care packages and answer crisis calls to ensure people affected by Huntington's receive the best possible care and support available. They also offer training, advice and support to professionals involved in the care of people with Huntington's to improve quality of care.

### **Juvenile Huntington's disease support**

We are the only Huntington's disease charity with a dedicated Specialist Juvenile Huntington's Adviser in the world, supporting people affected by the juvenile form of the disease and their families across England and Wales.

### **Youth Services**

We have a Huntington's Disease Youth Engagement service (HDYES) providing support to young people aged 8-25 living in families affected by Huntington's. HDYES is co-ordinated by a Youth Engagement Co-ordinator currently covering the whole of England and Wales.

### **Membership**

We have a membership of over 5,000 people, made up of both families living with Huntington's disease and health and social care professionals caring for people with Huntington's.

### **Branches and Support Groups**

We are linked to a number of local Huntington's Disease Association branches and support groups, all led by dedicated volunteers. These groups provide invaluable peer support on a local level. They support many aspects of the Huntington's Disease Association's work.

### **Partnership working**

We are a charity with limited resources, so we work closely with other organisations for maximum impact and influence. Organisations we regularly work with include the Neurological Alliance, Genetic Alliance UK and Rare Disease UK. We also work with other Huntington's disease charities including the European and International Huntington's Associations. We are part of an alliance with the Scottish Huntington Association, Huntington's Disease Alliance Northern Ireland, and the Huntington Disease Association of Ireland.

### **Research projects**

We work with scientific, clinical and social researchers and experts in the field of Huntington's in their search for ways to improve care and treatment. One day, we hope for a cure for the disease.

### **Supporters**

We have an army of committed supporters who dedicate their time and energy to raising awareness, supporting those affected by the disease and fundraising to help ensure we can continue supporting those who need our help.

### **Aims and objectives in 2021/22**

The following goals underpin the Huntington's Disease Association's five-year strategy and were the focus of the charity's work throughout 2021/22:

- Improved quality care and support
- Better knowledge and understanding of Huntington's
- Greater opportunity for peer support and community involvement
- Improved understanding of Huntington's and the Huntington's Disease Association's role with the general public
- A strong charity to better champion the needs of our community
- Supporting Huntington's research

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

---

## Achievements and performance

### Our impact in 2021/2022

#### Improved quality care and support

This year we continued with lessons learned from the pandemic. With in-person contact still not advisable, we carried on offering our services online and, on the phone, to provide the Huntington's disease community with the support it needs. We continued to deliver online webinars, and this year we recorded them to give people the chance to watch on-demand via our YouTube channel.

Our support services were available mainly through phone calls, emails and virtual meetings, although 2021 saw some return to in-person meetings. Our 19 Specialist Huntington's Disease Advisers provided information and advice to 4,060 individuals and we supported 1,026 families. Throughout the year we held 18,740 conversations with families, by email or phone.

*"The Adviser is an incredible part of the Huntington's disease team, I feel blessed to have her support. I'm very thankful for the time she gave me and feel a great rapport has been built. She's thoroughly trustworthy and caring in her manner. A brilliant asset to the Huntington's Disease Association."*

In addition to the support available, online webinars continued to offer support on subjects requested by the community. We were fortunate to hear from well-known people in the Huntington's disease community who shared their expert advice and knowledge on topics including keeping active at home and health. In total, 26 webinars were attended by 612 people, as well as being held live the webinars were also uploaded to our YouTube channel giving everyone in the community the opportunity to watch them. Virtual carers groups continued with a total of 57 meetings, attended by over 300 people. 41 people with Juvenile Huntington's Disease were also supported through nine peer support sessions.

We continued to expand our digital communications and improve our website. The newly developed knowledge area of the website saw 1,823 visitors downloading our resources and guides. Our social media continued to share knowledge and resources resulting in an engagement rate of over 20,000 people reacting to our posts across all platforms.

Our project aimed at older carers funded by BUPA resulted in specific guides and information, additional resources, an older carers area of the website, a number of webinars, ongoing educational and peer events, and long-term peer support.

The Youth Engagement Co-ordinator supported 317 children and young people. Understanding that young people's needs have increased and changed over the last two years, particularly during the pandemic, we worked with a company to consult with young people to see what thought of our current support offer and how we can improve this. The feedback was incredibly positive and the information we gained will help us to shape future services. The children and young people we spoke with told us that they felt supported by the charity and that the Youth Engagement Service was central to this. Securing an additional youth worker to build on the existing support was a clear priority for young people, although a number of other suggestions came from the consultation, including activity days and weekends, as well as more active involvement of young people in developing the charity's services.

*"I truly don't know where I'd be without the support the Youth Co-ordinator has given me over the last year or so. He's educated me on Huntington's disease and been there to listen when no-one in my family was, and just generally been really empowering for me to make choices for myself. My mental health took a big hit last year due to the impacts of being at risk of Huntington's and he was the first person I opened up to about this and he encouraged me to get further support for my mental health. He somehow manages to turn really hard conversations into a positive somewhere and is the friendliest person I know. He truly is an asset to the charity and his support will have a lifelong impact on me."*

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)**

## ***FOR THE YEAR ENDED 31 MARCH 2022***

---

When looking at the data collected about the Advisory Service, 90% of contact made this year was either by phone, text, email or video call. 27% of people contacting us this year hadn't been in contact with us before. When asked how they felt after they had been in touch, 97% of respondents felt it had been useful. 56% felt their understanding of Huntington's disease had increased after contact was made. In terms of emotional well-being, 66% said their well-being had improved and 69% reported feeling less isolated. 68% of people asked felt they had more knowledge about where to turn to for professional help. 49% of contact made was to ask for support in a crisis or potential crisis situations.

Due to the ongoing uncertainty of COVID-19 and continued restrictions in care homes we were only able to open our Care home accreditation scheme, HDA Quality Assured, later on in the year and one care home was accredited. Dearnevale care home has now joined a number of care homes who have demonstrated that they meet a high standard in the care and support they provide for people and families affected by Huntington's disease

Thirty one welfare grants were awarded during the year, totalling £9,000. In addition, we were able to provide an additional £5,000 gifted by B&Q. 100% of recipients reported that the grant had improved their quality of life, and 71% reported that risks had been reduced.

We are delighted that due to partnership with Surrey Heartlands, Kent Surrey Sussex Academic Health Science Network and Roche Products Ltd, we were able to help produce a Service Model and Care Pathway for Huntington's disease. This work also culminated in the commissioning of a Care Co-ordinator in Surrey. We believe this will make a big difference and improve care and support for people with Huntington's disease in the area.

During the year, we worked closely with the Neurological Alliance, with our CEO now a trustee. This has led to a stronger voice for people with Huntington's disease as we have been able to collaborate on projects. The partnership meant we could input into best practice guidelines in neuropsychiatry and advise practices for the forthcoming Integrated Care System (ICS) changes to commissioning.

We also worked with the Rare Disease Industry group during the year who had direct input into NICE who have been reviewing the mechanisms by which new drugs are approved. We are part of the National Neuroscience Advisory Group who reviewed how neurology sits within Integrated Care Systems during the year with a view to ensuring neurological services are a priority within this new structure.

Our website had a record 268,766 visitors over the year with 537,060 pages read. Our top visited pages on the website were 'What is Huntington's disease', 'what is Juvenile Huntington's disease', 'Symptoms' and 'Genetics' suggesting people reached out to the website as a source of information for Huntington's disease. The engagement rates on our social media grew along with the number of followers, demonstrating the need for social media to increase our engagement with the community. Statistics demonstrated that visitors to the website who came from social media were the people who stayed the longest on the website. We changed video platforms, moving from Vimeo to a new YouTube account and all of our online webinars throughout the year were recorded, edited, and uploaded. This gave people who wanted to watch the webinars, but who may not have been able to attend, the ability to watch them at any time they wanted. This led to 74 subscribers to the YouTube channel by year-end and the videos have been watched over 2,500 times.

### **Better knowledge and understanding of Huntington's**

Educating people about Huntington's remained a key priority for the Huntington's Disease Association throughout the year.

Over three days in June we held our first virtual certificated professional course. 'Understanding Huntington's disease - a certificated course for professionals' gave Health and Social Care professionals an opportunity to learn about the disease in-depth. The course covered topics from genetics, behaviour, and therapies to research and all sessions were delivered by experts in their fields. The opportunity to also hear from someone with lived experience of the condition was invaluable for those that attended. Running this course virtually for the first time, made it more accessible to those who might not usually be able to attend. Following the success of the course in June, we ran a further course in November with a total of 84 people attending across the two events.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

---

In addition, we delivered 103 training sessions attended by 891 Health and Social Care professionals and held 102 information sessions attended by 967 people. 82% of training was delivered online. 100% of attendees stated their knowledge of Huntington's disease had changed and the quality of care and support they give will change. All who attended said they would now know where to go to find out more about Huntington's disease.

Our website also saw some improvements, with a professional specific section created containing detailed resources to provide accurate and up-to-date advice for professionals working with people affected by Huntington's. We also set up a 'professional hub' on our messageboard as a secure space for Occupational Therapists to share knowledge, information and resources. It is likely that this will be rolled out to other disciplines in the future.

*"We have all gained lots of knowledge about Huntington's and the different aspects of it. We have a lot of residents with Huntington's disease and this has helped more people gain an understanding."*

**Greater opportunity for peer support and community involvement**

Local branches and support groups continued to provide vital support to the community, and in the year, we had 39 branches and support groups across England and Wales.

Our social media channels continued to grow in popularity, with follower numbers increasing. A more accurate metric demonstrating how the community interacts with our pages is engagement rate. This figure demonstrates the number of interactions on each platform:

<b>Social Media</b>	<b>Followers</b>	<b>Engagement</b>
Facebook	15,286	117,393
Instagram	2,216	78,469
Twitter	3,840	8,812
LinkedIn	1,312	5,310

Our co-production group, HD Voice has consulted on 13 projects this year, lending their lived experience to help shape Huntington's disease services as well as input into research.

During the year we held our Family Conference and AGM online, due to continuing COVID-19 restrictions. 120 people enjoyed the virtual event, during which we were also able to celebrate our 50th year as a charity.

**Improved understanding of Huntington's and the Huntington's Disease Association's role with the general public**

During the year, we worked with the BBC on the script for the TV Show Casualty, which continued its storyline of the character, Ethan Hardy, who has the Huntington's gene and is beginning to show symptoms. The show was a brilliant opportunity for the disease to be talked about on prime-time TV and we received wonderful feedback from the community. We were delighted when the actor who plays Ethan, George Rainsford agreed to become our Patron. George took part in a fundraising challenge helping us raise both awareness of the disease and money through his fundraising. George said of becoming a patron,

*"I am honoured to become a patron and help raise awareness of Huntington's disease so that the public understand not only how devastating the disease can be but also to celebrate the amazing strength and positivity that some families with Huntington's have."*

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)**

## **FOR THE YEAR ENDED 31 MARCH 2022**

---

This year for Huntington's disease awareness month in May we were delighted to work as 'The Huntington's Disease Alliance', a combination of four charities; ourselves, the Scottish Huntington Disease Association, the Huntington's Disease Association for Northern Ireland, and the Huntington Disease Association of Ireland. Established to promote awareness of Huntington's disease and improve support for families across the UK and Ireland, the Alliance has worked together on many projects over the years, but 2020/21 saw incredible strides made. With funding received from Roche, together we created a campaign called 'My Family Matters'. The campaign was designed to show the enormous 'ripple effect' of Huntington's within a family unit, to help the public realise the impact of this disease. It celebrated the resilience of many of the families affected to help inspire and support the community, and to recognise that every family has a different experience. The campaign featured a living wall, on the My Family Matters website, of people's experiences of living with Huntington's disease with hundreds sharing their stories, poems, and art. The campaign is a testament to the community's spirit and dedication to raising awareness of Huntington's disease. It achieved outstanding results. The films alone achieved over 5,297 views and 288 hours in total watch time on YouTube. Media coverage was also extensive across both national and regional outlets. Broadcast coverage netted over six million opportunities to see the campaign, and print and online coverage brought a further 380 million opportunities to see the story. The social media programme reached over 1.5 million people. The month-long campaign resulted in four Huntington's disease questions being tabled in parliament. The campaign has also been nominated for an award and we are looking forward to finding out the result.

This year we launched Right Market, an online design platform, through which our supporters, staff and branch and support group volunteers can develop on-brand materials such as posters and flyers. 50th anniversary templates were also made available for fundraisers to share. The platform will help us establish our branding.

Our website continued to improve with navigation made easier and a number of new blogs and stories featuring people from the community. 5,243 people visited the stories webpage, and one of the stories featured, Mark's Story, was read 5,927 times. Total visits for 2021/22 to the website were 268,766, a 42% increase from the year before.

On social media we introduced a popular giving people the opportunity to share their fundraising stories. This proved to be successful and helped people achieve their fundraising targets. It also gave us the opportunity to get to know more about our supporters and create a successful online community.

We continued to grow our audiences on Facebook, Twitter, Instagram, and LinkedIn, giving us a chance to really connect with our community. We did a soft launch of our TikTok channel, and plan to explore this further as part of next year's strategy.

### **A strong charity to better champion the needs of our community**

During the year we made the decision to downsize our central office, reviewing working practices and opting for a hybrid model. This allowed us to significantly reduce our overheads and redirect these funds back into directly supporting the Huntington's community. In addition, we reviewed several software products and have moved to a cloud-based Human Resources system which has enabled us to operate much more efficiently, as well as significantly reducing our paper usage and carbon footprint.

With staff returning to work after the COVID-19 Job retention scheme finished, we were able to continue to grow as a charity. We were able to strengthen teams with additional people joining during the year. Due to some staff retirement and a period of recruitment, our advisory team finished the year with 19 Specialist Huntington's Disease Advisers. Other new roles in 2021/22 included, Head of Communication and Marketing, Social Media Officer, Data Manager, Operations Assistant and Senior Individual Giving Co-ordinator.

Relevant training was carried out by employees and trustees throughout 2021/22 in line with their individual roles for their continued professional development. Safeguarding and lone working training was introduced for all staff with supporting policies developed.

Our board of trustees met frequently throughout the year to monitor the charity's performance both financially and operationally and ensure compliance with the charity governance code and the charity commission's good practice guidelines.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

---

## Supporting Huntington's research

With confirmation of the withdrawal of the GENERATION-HD1 trial brought disappointment to the community, new analysis released of GENERATION HD1 suggests that the drug tominersen may have potential benefit to some patients. Roche are at the early stages of designing a new Phase 2 clinical trial in younger adult patients with lower disease burden, meaning someone in the earlier stages of the disease. During the year, as results were released, we acted quickly to ensure the community had access to accurate and easy to understand information as updates emerged.

Our volunteer patient and public involvement group, HD Voice, were consulted on a number of research and service development projects throughout the year ensuring that the needs and viewpoints of the Huntington's community remained at the forefront of development and decision-making. Some of the projects they were involved in included:

- Domino-HD – a volunteer-led virtual meeting looking at issues with engagement on this project, which studies how digital technologies, such as wearable fitness trackers, can be used to support people with Huntington's disease.
- BUPA older carers project – ongoing support and consultation for this in-house project to improve support for older carers.
- HD-Drum – trialling a drumming app built specifically for people in early stages of the condition.
- PIVOT-HD – with Cardiff University – working with use of volunteers in exercise promotion in collaboration with Disability Sport Wales.
- Quality Assured - two members of HD Voice were on the panel for the assessment of a care home
- Kim's Friends - assistance given on our resources for those who've tested negative, including a web page, guides and a private Facebook group.

We continued to financially support and promote HD Buzz, a website that explains current Huntington's research in plain English and encourages people to participate in Enroll-HD, the world's largest observational study for Huntington's disease to enable researchers to gain better insight into the condition.

We worked collaboratively throughout the year with HCD Economics, with funding from Roche and UniQure, on a burden of illness study, to try to demonstrate the impact of the disease on individuals affected and their carers. Findings from this study have been presented in poster format at various conferences throughout the world and there is a manuscript planned to formally publish the results. This will help raise awareness of the significant effect the condition has on the families affected.

We have worked with Hugh Rickards, Chair of the board of trustees and Consultant and Honorary Professor in Neuropsychiatry, on developing a collaborative working group of experts in the fields of pharmacology and drug treatment regulation. This group has been created to act in an advisory capacity to enable us to understand how pharmaceutical companies operate and the regulation process new treatments have to take so we can be prepared to act quickly when new treatments emerge to best support the Huntington's community.

It is important for our charity to understand current services for people affected by Huntington's to help us highlight the disparity in the support and care available across the UK. We worked with HCD Economics, in another project funded by Roche, involving the circulation of questionnaires to services that provide care and support for people with Huntington's. This was then followed up by in-depth interviews to get a better understanding of the breadth of service that individual centres provide and any gaps in service. These findings will be published in the year ahead and will be used by the charity as evidence to advocate for and fight for better quality access to services, care and support for the Huntington's community.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

---

## Fundraising

As we moved into the second year of living with COVID-19, we continued with our fundraising to ensure that the charity remained operational, offering information and advice to those who needed it most.

In 2021/2022, our income from Community Fundraising and Events saw a huge boost bringing in a magnificent £440,710. In October 2021, we were thrilled that the majority of '#TeamHDA' were back on the streets of London with the TCS London Marathon as well as the streets around their local towns through the Virtual TCS London Marathon. Although we could not be there in person, our London runners coped amazingly with the new restrictions put in place to ensure the event could go ahead. In total all our TCS London Marathon runners raised an astonishing £113,457. We were also thrilled to see the Great North Run return in 2021 with our team of runners raising £15,935.

As ever, our supporters came through for us in 2021/2022 with many organising and taking on their own challenges, such as Suzanna Mavity who as a part of her 'Do it for Dom' group, spent Christmas 2021 climbing Kilimanjaro raising an amazing £11,487, Ella Doheny who cycled 100 miles from Coventry to Abergavenny raising £1,235, Molly and Isla who raised £2,671 with a marathon walk and our new Patron, George Rainsford took on the three-day ultra-marathon, The Druids Challenge, raising an astonishing £6,185.

'#HD8000', our flagship fundraising challenge series continued into the year with '#HDHike' taking place in May raising £31,100 and '#HDBike' taking place in August raising £5,808. In total '#HD8000', with the first in the series, '#HDMove' in January 2021 raising £13,854, raised over £50,000.

For the first time we had to move our Volunteer Awards online, our event celebrating our fundraisers and supporters, took place on Friday 11 June 2021 and we were delighted to welcome many people to share in their success. Our thanks to everyone who took part and congratulations to the winners on the day.

2021 also saw the 50th anniversary of the founding of the Huntington's Disease Association and our fundraising challenge '#50MyWay' encouraged supporters to take up challenges based around the number 50. We are grateful to everyone who took part and helped to raise over £9,701.

In January 2022, we were delighted to be named 'Charity of the Year' for the Westerleigh Group who kicked off their fundraising with a fantastic donation of £22,000 towards our work. We look forward to continuing to work with the Westerleigh Group into the next year. Our thanks go to other corporate supporters over the year, including Perenco who donated £2,000, Iceland Foods Ltd in Worksop who raised £724, Centre Parcs at Whinfall Forest who donated £1,000, the Maldon Salt Company with their donation of £500, Lewis and Cooper in Northallerton who held an in-store fundraising and awareness event raising £484 and the continued support of Mazars with their donation of £1,000.

As we moved out of the shadow of COVID-19 the support provided by Trusts and Foundations became even more important to continuing our work in 2021/2022. Their support has helped us adapt to the needs of our community throughout the pandemic and continue to provide vital advice, information and support for people affected by Huntington's disease.

All the funding we received was, and continues to be, important; however, we were particularly grateful for the £20,000 funding we received from Garfield Weston Foundation in support of our work across the North West and the Moondance Foundation who provided a grant of £20,000 for our work across South Wales. In addition, we successfully applied to the B&Q Foundation for a £5,000 grant to enable us to provide welfare grants for families. In statutory funding, we continued to deliver services through grant agreements across a number of Clinical Commissioning Group areas including Blackburn with Darwen, Cambridgeshire and Peterborough, Devon, Kernow and Sunderland. In addition, we successfully delivered our two-year contract with Birmingham City Council. We are happy to report that this contract has been extended for a further two years.

In 2021/2022 two incredibly important funding relationships came to an end. First, our six-year relationship with the Clive Richards Foundation came to an end as they revised their funding criteria. Second, our six-year relationship with the Milton Damerel Trust was paused. We are incredibly thankful for their support that has enabled us to establish our services for adults and children and young people affected by Huntington's disease.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

---

Putting people with Huntington's disease at the heart of our work is key to letting the world know about Huntington's disease and its effect upon individuals, families and communities. We will continue to work collaboratively with staff and supporters to share their stories and powerful messages.

We monitor return on investment on all our fundraising activities and meet or exceed all statutory and regulatory obligations.

We are members of the Fundraising Regulator and the Chartered Institute of Fundraising following best practice guidance laid down by them as well as the Charity Commission guidance for Charity Trustees (CC20). We comply with the Privacy and Electronic Communications Regulations (PECR). The Huntington's Disease Association recognises that we may work with people in vulnerable circumstances so protection of vulnerable people is something we take seriously. We adhere to the Chartered Institute of Fundraising's guidance – 'Treating Donors Fairly - Fundraising with people in vulnerable circumstances'.

For the year 2021/2022 we did not receive any complaints about our fundraising practices or approaches.

## Financial review

The results for the year show an overall surplus of £742,867 (2021: £656,775) made up of a surplus on the general fund of £715,699 (2021: £630,030) and a surplus on the restricted funds of £27,168 (2021: £26,745).

As discussed elsewhere in the Trustees' Report, the pandemic continued to cause disruption to our service delivery and a reduction in costs continued due to restrictions imposed. However, as a result of a substantial increase in legacies, income rose to over £2m from £1.88m despite the absence of furlough support and specific pandemic recovery grants.

The Trustees, through the Finance Committee, have monitored developments closely and considered how the surplus should be utilised taking account of the uncertainties arising from the pandemic and the consequent need to boost reserves. Budgeted expenditure has been increased by boosting the number of Specialist Huntington's Advisors and strengthening the data management, impact assessment and policy and communications operations. The Trustees have also committed to a major expansion of the Youth Engagement Service for which funds have been designated. As a result of the continuing impact of the pandemic and the exceptional legacy income, the anticipated deficit for 2021/22 did not arise. However, in the absence of generous bequests, the budget anticipates a deficit of £300,000 in 2022/23 and the subsequent two years.

## Reserves Policy

The reserve requirement of the charity is to enable the salaries of staff members and running costs to be covered in the event of short-term income fluctuations. As a result of the uncertainties arising from the pandemic and inflationary pressures which may impact on income, it was agreed that the target for general reserves needed to be maintained at nine months recurring costs being approximately £1m.

At the year end, free reserves available excluding designated funds and tangible fixed assets stood at £1,928,865 (2021: £1,399,141) and therefore comfortably exceeded target. As noted in the Financial Review, the Trustees have agreed a policy to utilise surplus reserves over the next two years to develop the Association for the benefit of those impacted by Huntington's Disease.

## Risk Policy

The Trustees have assessed the major risks to which the Charity is exposed and are satisfied that systems are in place to mitigate exposure to major risks. The impact of the Coronavirus pandemic has been closely monitored by the Trustees and the Finance Committee. The success of the Reserves Policy means that the charity is well placed to make considered decisions on measures that may need to be taken as the current inflationary crisis unfolds.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

---

## Future plans 2022/23

As a charity, we emerged stronger than ever after the pandemic, due to our incredible fundraisers, and successful grant bids we are now looking forward to how we can grow in 2022/23 to enable us to offer more to our community.

Early indicators from the mapping project demonstrate a lack of service provision for people's mental health with Huntington's. Our plans for Huntington's disease awareness month in May 2022 will be about mental health and Huntington's. The campaign will feature people's lived experiences as we continue to put people at the heart of our charity.

We will make a difference to national policy with plans for a new role of Policy and Public Affairs Manager, that will help us make our campaigns really make a difference to those whose life is affected by Huntington's disease.

The team will continue to grow with a number of new roles planned. We hope to recruit a Volunteer Manager to assist with our growing number of volunteers and branch and support groups, and a Helpline Adviser to become the first point of contact for people calling or emailing us for advice and support. The communication team is also looking to expand with one new post.

We have plans to extend our Huntington's Disease Youth Engagement Service (HDYES) over the forthcoming year. The recent consultation report with young people has given us some fantastic information on how we can develop this service. We hope to employ a further youth worker to help us as we design this new service with children and young people, and their views and ideas, at the heart of its development.

This year our JHD weekend will return as an in-person event for the first time since the pandemic. This is an invaluable opportunity for families affected by the Juvenile form of the condition, to meet and enjoy activities together.

Due to the success of this year's training for professionals, we will continue in the year ahead to offer both in-person and online training, including bespoke presentations, informative webinars, our flagship certified course for professionals, and a new online information event specifically for mental health teams.

We will extend our reach into digital fundraising and are looking at how we can get involved in the Gaming for Good campaign. We are keen to celebrate our fundraisers at in-person events and plan to support our London marathon runners this year as the event returns live.

We plan to further improve our social media presence, developing different targeting strategies for each digital platform. We will also include paid advertising in our social media.

We will expand and develop our TikTok channel to engage with a new audience. The website will continue to evolve and we will use data and consultation to ensure we are communicating with people in the way they want. We will continue with our monthly email newsletter but also explore other ways of engaging with our community. We will continue to use our Google Ad grant to expand our website reach.

We look forward to our Family conference and AGM this year in which we have invited our patron, George Rainsford, to speak, this will be held virtually giving people the opportunity to attend from across England and Wales.

As we enter the final year of our strategic plan, our Board of trustees are looking ahead to develop our strategy for the next five years. Staff consultation events will be held to see where our strengths and weaknesses have been over the last five years. We will also work with our community to ask them how we can best support them on their Huntington's journey. Their voice will help us reflect on what we as a charity have achieved and identify the key priorities for the Huntington's community to enable us to build our strategy around them.

As we plan and develop our new strategy, we will make sure our Board of trustees have the skills and expertise to guide the charity through the years ahead, fulfilling relevant training needs and recruiting trustees with particular expertise to fill any skill gaps identified. The board of trustees supported by the Finance and Audit subcommittee will meet throughout 2022/23 to ensure the strong governance of our charity, activities, and finances.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

---

## Structure, governance and management

### Governing document

The company is a registered charity founded in 1971 and incorporated on 21 May 1986. The charity is governed by the Memorandum and Articles of Association.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Dr G El-Nimr  
Mr M Ellison (Resigned 21 July 2021)  
Mr N M Heath (Hon Treasurer)  
Dr E M Howard (Vice-Chairperson)  
Professor H Rickards (Chair)  
Ms A C Clarke (Resigned 16 October 2021)  
Dr A Fryer  
Ms C Lyon  
Ms S Barker  
Mr S Duckett  
Dr N Swales  
Ms B E Waters

### Recruitment and appointment of trustees

The Trustees are elected to serve a term of three years at the Annual General Meeting by the voting members of the Association who are the Guarantors.

### Organisational structure

The charity is managed by an Executive Council made up of the trustees which met on five occasions during the year.

The trustees have considered the Charity Commission's general guidance on public benefit in relation to the objectives of the charity. This report sets out those objectives and describes how they have been met in the current year.

The Executive Council members focus on the strategic decisions required for the overall governance of the Huntingtons Disease Association and devolve operational running to the management team.

The Chief Executive and senior managers oversee the operational management of the Huntingtons Disease Association within the policies and guidelines approved by the Executive Council. Prior to board meetings, the Chief Executive provides a written update report to the Executive Council on the operational management of the charity which all senior managers have an input into. The reports provide the Executive Council with a detailed overview of the operational progress of the Association. The Chief Executive attends board meetings to discuss the management reports further and answer any questions trustees may have.

### Trustee induction and training

Most trustees are already familiar with the work of the charity and their training involves briefings on their duties and liabilities. Additionally, new trustees receive an induction pack covering:

- The duties of charity trustees;
- An induction pack outlining duties and responsibilities;
- The Association's Memorandum and Articles of Association, strategic plan, latest published annual report and accounts, financial projections and budgets, and project and programme plans and publications;
- Trustee details and staff structure;
- 'The Essential Trustee: what you need to know' (Charity Commission);
- Minutes and reports submitted to the previous three meetings of the board of trustees.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

---

**Remuneration policy**

The Trustees have responsibility for setting the pay and remuneration of the charity's key personnel and this is done on an annual basis, including a formal cost of living review. Salaries are benchmarked with other similar organisations across the sector.

**Auditor**

In accordance with the company's articles, a resolution proposing that DSG be reappointed as auditor of the company will be put at a General Meeting.

**Disclosure of information to auditor**

Each of the trustees has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

**Small company provisions**

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

The trustees' report was approved by the Board of Trustees.

**Mr N M Heath (Hon Treasurer)**

Dated: 9 September 2022

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF TRUSTEES' RESPONSIBILITIES  
FOR THE YEAR ENDED 31 MARCH 2022**

---

The trustees, who are also the directors of Huntington's Disease Association for the purpose of company law, are responsible for preparing the Trustees' Report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law requires the trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these accounts, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT

## TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

---

### Opinion

We have audited the financial statements of Huntington's Disease Association (the 'charity') for the year ended 31 March 2022 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2022 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the financial statements* section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

### Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the trustees' report has been prepared in accordance with applicable legal requirements.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
INDEPENDENT AUDITOR'S REPORT (CONTINUED)  
TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION**

---

**Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

**Responsibilities of trustees**

As explained more fully in the statement of trustees' responsibilities, the trustees, who are also the directors of the charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

**Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

# **HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT (CONTINUED) TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION**

---

## **Capability of the audit in detecting irregularities, including fraud**

Based on our discussions with the charity's management and the Trustees, we identified that the following laws and regulations are significant to the entity:

- Those laws and regulations considered to have a direct effect on the financial statements include UK financial reporting standards and Charity Law.
- Those laws and regulations for which non-compliance may be fundamental to the operating aspects of the charity and therefore may have a material effect on the financial statements include compliance with the charitable objectives, public benefit, fundraising regulations, safeguarding and health and safety legislation.

These matters were discussed amongst the engagement team at the planning stage and the team remained alert to non-compliance throughout the audit.

Audit procedures undertaken in response to the potential risks relating to irregularities (which include fraud and non-compliance with laws and regulations) comprised of: inquiries of management and the Trustees as to whether the entity complies with such laws and regulations; enquiries with the same concerning any actual or potential litigation or claims; inspection of relevant legal correspondence; review of Trustee meeting minutes; testing the appropriateness of journal entries; and the performance of analytical review to identify unexpected movements in account balances which may be indicative of fraud.

No instances of material non-compliance were identified. However, the likelihood of detecting irregularities, including fraud, is limited by the inherent difficulty in detecting irregularities, the effectiveness of the entity's controls, and the nature, timing and extent of the audit procedures performed. Irregularities that result from fraud might be inherently more difficult to detect than irregularities that result from error. As explained above, there is an unavoidable risk that material misstatements may not be detected, even though the audit has been planned and performed in accordance with ISAs (UK).

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

## **Use of our report**

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

**Andrew Moss (Senior Statutory Auditor)**  
for and on behalf of DSG

9 September 2022

**Chartered Accountants**  
**Statutory Auditor**

Castle Chambers  
43 Castle Street  
Liverpool  
L2 9TL

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF FINANCIAL ACTIVITIES  
INCLUDING INCOME AND EXPENDITURE ACCOUNT**

**FOR THE YEAR ENDED 31 MARCH 2022**

		Unrestricted funds 2022 £	Restricted funds 2022 £	Total Unrestricted funds 2022 £	Restricted funds 2021 £	Total 2021 £
	<b>Notes</b>					
<b>Income from</b>						
Donations and legacies	<b>2</b>	1,723,498	27,981	1,751,479	1,290,255	1,303,691
Charitable activities	<b>3</b>	55,853	319,533	375,386	140,633	539,767
Other trading activities	<b>4</b>	24,975	-	24,975	17,510	17,510
Investments	<b>5</b>	12,941	-	12,941	12,266	12,266
Other income	<b>6</b>	1,544	-	1,544	6,935	6,935
<b>Total income</b>		<u>1,818,811</u>	<u>347,514</u>	<u>2,166,325</u>	<u>1,467,599</u>	<u>1,880,169</u>
<b>Expenditure on:</b>						
Raising funds	<b>7</b>	219,774	-	219,774	-	182,804
Charitable activities	<b>8</b>	879,401	320,346	1,199,747	385,825	1,118,510
<b>Total expenditure</b>		<u>1,099,175</u>	<u>320,346</u>	<u>1,419,521</u>	<u>385,825</u>	<u>1,301,314</u>
Net gains/(losses) on investments	<b>12</b>	<u>(3,937)</u>	<u>-</u>	<u>(3,937)</u>	<u>77,920</u>	<u>77,920</u>
<b>Net movement in funds</b>		<u>715,699</u>	<u>27,168</u>	<u>742,867</u>	<u>630,030</u>	<u>656,775</u>
<b>Reconciliation of funds</b>						
Fund balances at 1 April 2021		<u>1,690,025</u>	<u>55,882</u>	<u>1,745,907</u>	<u>1,059,995</u>	<u>1,089,132</u>
<b>Fund balances at 31 March 2022</b>		<u><u>2,405,724</u></u>	<u><u>83,050</u></u>	<u><u>2,488,774</u></u>	<u><u>55,882</u></u>	<u><u>1,745,907</u></u>

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
BALANCE SHEET**

**AS AT 31 MARCH 2022**

	Notes	2022		2021	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	13		20,137		4,619
Investments	14		948,810		452,747
			968,947		457,366
<b>Current assets</b>					
Stocks	16	10,174		9,559	
Debtors	17	677,503		383,726	
Cash at bank and in hand		962,916		1,000,111	
		1,650,593		1,393,396	
<b>Creditors: amounts falling due within one year</b>	18	(130,766)		(104,855)	
Net current assets			1,519,827		1,288,541
<b>Total assets less current liabilities</b>			2,488,774		1,745,907
<b>Income funds</b>					
Restricted funds	21		83,050		55,882
<u>Unrestricted funds</u>					
Designated funds	22	456,722		286,265	
General unrestricted funds		1,949,002		1,403,760	
		2,405,724		1,690,025	
			2,488,774		1,745,907

The financial statements were approved by the Trustees on 9 September 2022

Mr N M Heath (Hon Treasurer)  
**Trustee**

**Company registration number 02021975**

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
STATEMENT OF CASH FLOWS**

**FOR THE YEAR ENDED 31 MARCH 2022**

	Notes	2022 £	£	2021 £	£
<b>Cash flows from operating activities</b>					
Cash generated from operations	26		473,153		408,504
<b>Investing activities</b>					
Purchase of tangible fixed assets		(23,289)		-	
Purchase of investments		(501,462)		-	
Proceeds from disposal of investments		1,462		-	
Investment income received		12,941		12,266	
<b>Net cash (used in)/generated from investing activities</b>			(510,348)		12,266
<b>Net cash used in financing activities</b>			-		-
<b>Net (decrease)/increase in cash and cash equivalents</b>			(37,195)		420,770
Cash and cash equivalents at beginning of year			1,000,111		579,341
<b>Cash and cash equivalents at end of year</b>			962,916		1,000,111

# HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

---

## 1 Accounting policies

### Charity information

Huntington's Disease Association is a private company limited by guarantee incorporated in England and Wales. The registered office is Suite 24 Liverpool Science Park, Innovation Centre, 131 Mount Pleasant, Liverpool, L3 5TF.

### 1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)". The charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention except for the revaluation of fixed asset investments in accordance with the Charities SORP.

### 1.2 Going concern

The Trustees have reviewed the effect of the Coronavirus pandemic which has had an impact on fundraising streams and the costs of delivering services and have also considered the potential effects of current inflationary pressures and general economic uncertainty on the charity.

At the time of approving the accounts the Trustees consider that the charity has adequate reserves and diverse revenue streams to continue in operational existence for the foreseeable future taking account of economic uncertainties caused by the pandemic. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the accounts.

### 1.3 Charitable funds

*Unrestricted funds* are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

*Designated funds* comprise funds which have been set aside at the discretion of the trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the accounts.

*Restricted funds* are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the accounts.

### 1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Investment income consists of interest and dividends received and receivable.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is disclosed as a contingent asset.

No amounts are included in the financial statements for services donated by volunteers.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

---

**1 Accounting policies**

**(Continued)**

Grants, including grants for the purchase of fixed assets, are recognised in full in the statement of financial activities in the year in which they are receivable.

Deferred income represents grants received in advance of the expenditure to which it is allocated to support.

No amounts are included in these financial statements for goods donated to charity shops or services donated by volunteers.

Income from merchandise sales and fundraising income is recognised as earned (that is, as the related goods or services are provided).

**1.5 Expenditure**

All expenditure has been accounted for on an accruals basis and includes irrecoverable VAT where applicable. Expenditure is allocated to relevant activity categories on a basis that is consistent with the use of that resource. Support costs have been attributable to charitable activity in accordance with best estimates.

Research grants are made each year after approval and recommendation by the Medical Advisory Panel. The amount charged to the profit and loss account represents the cost of projects approved during the year.

**1.6 Tangible fixed assets**

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% straight line
-----------------------	-------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year..

**1.7 Fixed asset investments**

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

**1.8 Impairment of fixed assets**

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

**1.9 Stocks**

Stocks are valued at the lower of cost or selling price less selling costs, after making due allowance for obsolete and slow-moving items. Cost is calculated using the first-in first-out basis of valuation.

**1.10 Cash and cash equivalents**

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

---

**1 Accounting policies**

**(Continued)**

**1.11 Financial instruments**

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

***Basic financial assets***

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

***Impairment of financial assets***

Financial assets, other than those held at fair value through income and expenditure, are assessed for indicators of impairment at each reporting date. Financial assets are impaired where there is objective evidence that, as a result of one or more events that occurred after the initial recognition of the financial asset, the estimated future cash flows have been affected.

If an asset is impaired, the impairment loss is the difference between the carrying amount and the present value of the estimated cash flows discounted at the asset's original effective interest rate. The impairment loss is recognised in net income/(expenditure) for the year.

If there is a decrease in the impairment loss arising from an event occurring after the impairment was recognised, the impairment is reversed. The reversal is such that the current carrying amount does not exceed what the carrying amount would have been, had the impairment not previously been recognised. The impairment reversal is recognised in net income/(expenditure) for the year.

***Derecognition of financial assets***

Financial assets are derecognised only when the contractual rights to the cash flows from the asset expire or are settled, or when the charity transfers the financial asset and substantially all the risks and rewards of ownership to another entity, or if some significant risks and rewards of ownership are retained but control of the asset has transferred to another party that is able to sell the asset in its entirety to an unrelated third party.

***Basic financial liabilities***

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

***Derecognition of financial liabilities***

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

**1 Accounting policies**

**(Continued)**

**1.12 Employee benefits**

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

**1.13 Retirement benefits**

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

**1.14 Branch funds**

The funds of the Association's branches have been consolidated in the accounts.

**2 Donations and legacies**

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2022	2022	2022	2021	2021	2021
	£	£	£	£	£	£
Donations and gifts	888,814	23,381	912,195	727,805	13,436	741,241
Legacies receivable	805,537	3,000	808,537	364,922	-	364,922
Grants	-	-	-	171,450	-	171,450
Branch income	29,147	1,600	30,747	26,078	-	26,078
	<u>1,723,498</u>	<u>27,981</u>	<u>1,751,479</u>	<u>1,290,255</u>	<u>13,436</u>	<u>1,303,691</u>
<b>Grants</b>						
Coronavirus Job Retention Scheme	-	-	-	161,450	-	161,450
Coronavirus Discretionary Grant	-	-	-	10,000	-	10,000
	<u>-</u>	<u>-</u>	<u>-</u>	<u>171,450</u>	<u>-</u>	<u>171,450</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
*FOR THE YEAR ENDED 31 MARCH 2022*

**3 Charitable activities**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Grants received	345,633	525,292
Merchandise	19,812	13,877
Other income	9,941	598
	<u>375,386</u>	<u>539,767</u>
Analysis by fund		
Unrestricted funds	55,853	140,633
Restricted funds	319,533	399,134
	<u>375,386</u>	<u>539,767</u>

**4 Other trading activities**

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	<b>£</b>	<b>£</b>
Consultancy	24,975	17,510
	<u>24,975</u>	<u>17,510</u>

**5 Investments**

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	<b>£</b>	<b>£</b>
Income from listed investments	12,615	11,819
Interest receivable	326	447
	<u>12,941</u>	<u>12,266</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2022**

---

**6 Other income**

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	<b>£</b>	£
Miscellaneous income	1,544	6,935
	<u>          </u>	<u>          </u>

**7 Raising funds**

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	<b>£</b>	£
<u>Fundraising and publicity</u>		
Fundraising events	4,683	9,349
Other fundraising costs	43,830	25,608
Staff costs	171,261	147,847
	<u>          </u>	<u>          </u>
Fundraising and publicity	219,774	182,804
	<u>          </u>	<u>          </u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

8 Charitable activities	Specialist Welfare and HD Advisory Service		Welfare and Respite Care		Research Communication		Youth Worker & Juvenile		Branch		Total 2022		Total 2021	
	£	£	£	£	£	£	£	£	£	£	£	£	£	£
Staff costs	604,237	2,608	795	79,203	86,831	10,000	783,674	793,747						
Welfare grants	-	11,536	-	-	-	8,015	19,551	18,521						
Research	-	-	91	-	-	-	91	144						
Recruitment	593	-	-	435	-	-	1,028	-						
Branch activities	-	-	-	-	-	-	-	-						3,953
Travel and training	14,332	-	-	160	131	-	14,623	1,910						
Telephone and internet	19,949	-	1	504	408	-	20,862	25,039						
Other costs	23,954	38	38	16,366	4,635	20,067	65,098	33,831						
Newsletter	-	-	-	5,334	-	-	5,334	6,391						
Website	-	-	-	15,379	-	-	15,379	-						
Event costs	4,504	-	-	-	351	-	4,855	7,832						
	667,569	14,182	925	117,381	92,356	38,082	930,495	891,368						
Share of support costs (see note 9)	141,678	12,880	-	30,912	20,608	51,520	257,598	219,326						
Share of governance costs (see note 9)	11,654	-	-	-	-	-	11,654	7,816						
	820,901	27,062	925	148,293	112,964	89,602	1,199,747	1,118,510						
<b>Analysis by fund</b>														
Unrestricted funds	547,694	17,608	834	148,293	75,370	89,602	879,401	732,685						
Restricted funds	273,207	9,454	91	-	37,594	-	320,346	385,825						
	820,901	27,062	925	148,293	112,964	89,602	1,199,747	1,118,510						

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

8 Charitable activities	(Continued)									
For the year ended 31 March 2021	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication	Youth Worker & Juvenile	Branch	Total 2021	£	£	£
Staff costs	691,877	691	691	46,753	43,735	10,000	793,747			
Welfare grants	-	18,521	-	-	-	-	18,521			
Research	-	-	144	-	-	-	144			
Branch activities	-	-	-	-	-	3,953	3,953			
Travel and training	1,278	-	-	27	605	-	1,910			
Telephone and internet	24,074	-	-	440	525	-	25,039			
Other costs	12,866	24	24	15,828	5,089	-	33,831			
Newsletter	-	-	-	6,391	-	-	6,391			
Event costs	4,211	-	-	-	3,621	-	7,832			
	734,306	19,236	859	69,439	53,575	13,953	891,368			
Share of support costs (see note 9)	120,627	10,967	-	26,320	17,547	43,865	219,326			
Share of governance costs (see note 9)	7,816	-	-	-	-	-	7,816			
	862,749	30,203	859	95,759	71,122	57,818	1,118,510			

Expenditure on charitable activities was £1,118,510 (2020: £1,403,159) of which £732,685 (2020: £993,538) was unrestricted and £385,825 (2020: £409,621) was restricted.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

**9 Support costs**

	Support costs	Governance costs	2022	Support costs	Governance costs	2021
	£	£	£	£	£	£
Staff costs	124,021	-	124,021	89,189	-	89,189
Depreciation	7,771	-	7,771	4,698	-	4,698
Head office costs	125,806	-	125,806	125,439	-	125,439
Audit fees	-	8,000	8,000	-	7,750	7,750
EC meeting costs	-	3,654	3,654	-	66	66
	<u>257,598</u>	<u>11,654</u>	<u>269,252</u>	<u>219,326</u>	<u>7,816</u>	<u>227,142</u>
Analysed between Charitable activities	<u>257,598</u>	<u>11,654</u>	<u>269,252</u>	<u>219,326</u>	<u>7,816</u>	<u>227,142</u>

Support costs are allocated on the basis of time spent.

**10 Employees**

The average monthly number of employees during the year was:

	2022 Number	2021 Number
Specialist HD Advisors	19	21
Management	1	1
Fundraising	5	5
Youth Worker	1	1
Administration	5	4
Communications	2	1
Total	<u>33</u>	<u>33</u>

**Employment costs**

	2022 £	2021 £
Wages and salaries	963,553	925,269
Social security costs	89,010	82,878
Other pension costs	26,393	22,636
	<u>1,078,956</u>	<u>1,030,783</u>

The number of employees whose annual remuneration was more than £60,000 is as follows:

	2022 Number	2021 Number
£60,001 - £70,000	<u>1</u>	<u>1</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2022**

---

**11 Trustees**

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year (2021: £nil). Two trustees were reimbursed expenses totalling £112 for a subscription and part payment of a training course (2021: no trustees).

**12 Net gains/(losses) on investments**

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2022</b>	2021
	£	£
Revaluation of investments	(3,937)	77,920
	<u>          </u>	<u>          </u>

**13 Tangible fixed assets**

	<b>Fixtures and fittings</b>
	£
<b>Cost</b>	
At 1 April 2021	73,458
Additions	23,289
	<u>          </u>
At 31 March 2022	96,747
	<u>          </u>
<b>Depreciation</b>	
At 1 April 2021	68,839
Depreciation charged in the year	7,771
	<u>          </u>
At 31 March 2022	76,610
	<u>          </u>
<b>Carrying amount</b>	
At 31 March 2022	20,137
	<u>          </u>
At 31 March 2021	4,619
	<u>          </u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2022**

**14 Fixed asset investments**

	<b>Listed investments £</b>
<b>Valuation</b>	
At 1 April 2021	452,747
Additions	501,462
Valuation changes	(3,937)
Disposals	(1,462)
	<hr/>
At 31 March 2022	948,810
	<hr/>
<b>Carrying amount</b>	
At 31 March 2022	948,810
	<hr/> <hr/>
At 31 March 2021	452,747
	<hr/> <hr/>

<b>15 Financial instruments</b>	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
<b>Carrying amount of financial assets</b>		
Debt instruments measured at cost	1,567,032	1,312,051
Instruments measured at fair value through the statement of financial activities	947,551	452,747
	<hr/> <hr/>	<hr/> <hr/>
<b>Carrying amount of financial liabilities</b>		
Measured at cost	90,253	85,739
	<hr/> <hr/>	<hr/> <hr/>
<b>16 Stocks</b>	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Merchandise	10,174	9,559
	<hr/> <hr/>	<hr/> <hr/>
<b>17 Debtors</b>	<b>2022</b>	<b>2021</b>
<b>Amounts falling due within one year:</b>	<b>£</b>	<b>£</b>
Trade debtors	15,455	270
Other debtors	608,214	361,545
Prepayments	53,834	21,911
	<hr/> <hr/>	<hr/> <hr/>
	677,503	383,726
	<hr/> <hr/>	<hr/> <hr/>

Other debtors include £575,845 (2021: £304,539) of legacies receivable.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

**18 Creditors: amounts falling due within one year**

	<b>2022</b>	<b>2021</b>
	£	£
Other taxation and social security	25,512	19,116
Trade creditors	48,286	40,524
Accruals and deferred income	56,968	45,215
	<u>130,766</u>	<u>104,855</u>

Included in accruals and deferred income is deferred income of £37,600 (2021: £5,600) relating to income received for future periods.

**19 Retirement benefit schemes**

**Defined contribution schemes**

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

The charge to the statement of financial activities in respect of defined contribution schemes was £26,393 (2021 - £22,636).

**20 Operating lease commitments**

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	<b>2022</b>	<b>2021</b>
	£	£
Within one year	28,580	17,752
Between two and five years	96,233	10,620
	<u>124,813</u>	<u>28,372</u>

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

**21 Restricted funds**

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds		Movement in funds		Movement in funds		Movement in funds	
	Balance at 1 April 2020 £	Incoming resources £	Resources expended £	Balance at 1 April 2021 £	Incoming resources £	Resources expended £	Balance at 31 March 2022 £	
Research	-	16,844	(144)	16,700	9,795	(91)	26,404	
Specialist HD Advisory Service (SHDA)	-	334,744	(334,744)	-	268,674	(268,674)	-	
Children in Need	845	42,133	(38,221)	4,757	-	-	4,757	
Lancashire Training Events	-	4,849	-	4,849	-	-	4,849	
Juvenile Huntingtons Disease	-	-	-	-	135	(135)	-	
JHD Weekend	20,624	4,000	-	24,624	1,000	(152)	25,472	
Publications (Mazars)	1,500	-	(1,500)	-	-	-	-	
Youth Services	-	10,000	(6,952)	3,048	52,500	(37,307)	18,241	
BUPA Old Carers	6,168	-	(4,264)	1,904	-	(1,904)	-	
B & Q Foundation	-	-	-	-	5,000	(4,533)	467	
Welfare Fund	-	-	-	-	10,410	(7,550)	2,860	
	29,137	412,570	(385,825)	55,882	347,514	(320,346)	83,050	

**Research**

Research funds are raised to promote medical and social/ therapeutic research of direct significance to Huntington's Disease sufferers and their families. Our Medical Advisory Board reviews all applications on an annual basis before a decision is taken by our Executive Council. Funds were received from individuals, organisations and Branches requesting their donation be spent on this activity.

**Specialist HD Advisory Service (SHDA)**

The network of Specialist HD Advisers was maintained during the year. Restricted funding relating purely to this service and for each geographical area was received from numerous sources in the period.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

---

<b>21 Restricted funds</b>	<b>(Continued)</b>
<b>Children in Need</b> This grant is to fund a youth worker.	
<b>Lancashire Training Events</b> Money raised towards an awareness/training event in the Fylde Coast area.	
<b>Juvenile HD</b> This fund relates to income raised by a supporter who requested the funds be used to raise awareness of Juvenile Huntingtons Disease.	
<b>JHD Weekend</b> These relate to individual donations and grants that have been or are to be spent on the JHD weekend.	
<b>Publications (Mazars)</b> This was an award of £12,000 to update five of our publications	
<b>Youth Services</b> This relates to Trusts funding received to fund the work of our Youth Worker	
<b>Bupa Old Carers</b> We were awarded funding by BUPA UK Foundation to create an online area to support older carers aged 65+.	
<b>B&amp;Q Foundation</b> Funding received from B&Q Foundation for enhancing quality of life and helping to reduce risks by providing financial assistance to maintain, repair or improve housing	
<b>Welfare Fund</b> Funding received from B&Q Foundation for enhancing quality of life and helping to reduce risks by providing financial assistance to maintain, repair or improve housing.	

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE  
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)  
FOR THE YEAR ENDED 31 MARCH 2022**

**22 Designated funds**

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

	Movement in funds		Movement in funds		Movement in funds		Movement in funds	
	Balance at 1 April 2020 £	Incoming resources £	Resources expended £	Balance at 1 April 2021 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 March 2022 £
Special projects fund	214,000	-	-	214,000	-	-	(30,000)	184,000
Branch funds	94,081	26,078	(47,894)	72,265	20,992	(27,535)	-	65,722
Huntington's Disease Youth Engagement Service	-	-	-	-	-	-	207,000	207,000
	308,081	26,078	(47,894)	286,265	20,992	(27,535)	177,000	456,722

A designated special projects fund of £400,000 was established as a result of generous legacies received during 2013. It is intended that the fund be used for special projects, which, once instituted, may be developed in accordance with the long-term objectives of the charity. During 2015 and 2016 £130,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support. A further £40,000 of the fund was used to support the new communication initiative in 2017/18 and £16,000 was used in 2018/19 to complete the Care Home Accreditation project. In 2021/22, £30,000 was released to cover costs associated with changes necessitated by the pandemic including reducing the office size, software improvement and project development. The balance of the fund amounting to £184,000 has been allocated to cover a substantial portion of the 2022/23 budget deficit arising from new posts covering National Support, Policy and Public Affairs, Data Management and Volunteer Support.

The Trustees have now committed £207,000 for the expansion of the highly successful Huntington's Disease Youth Engagement Service (Youth Project). Funding will be sought from external sources and it is anticipated that the commitment of our own resources shall enhance the viability of the Project.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2022**

**23 Analysis of net assets between funds**

	<b>Unrestricted funds</b>	<b>Restricted funds</b>	<b>Total</b>	Unrestricted funds	Restricted funds	Total
	<b>2022</b>	<b>2022</b>	<b>2022</b>	2021	2021	2021
	£	£	£	£	£	£
Fund balances at 31 March 2022 are represented by:						
Tangible assets	20,137	-	20,137	4,619	-	4,619
Investments	948,810	-	948,810	452,747	-	452,747
Current assets/(liabilities)	1,436,777	83,050	1,519,827	1,232,659	55,882	1,288,541
	<u>2,405,724</u>	<u>83,050</u>	<u>2,488,774</u>	<u>1,690,025</u>	<u>55,882</u>	<u>1,745,907</u>

**24 Related party transactions**

**Remuneration of key management personnel**

The remuneration of key management personnel, which consists of the Chief Executive and the heads of departments, is as shown below.

	<b>2022</b>	<b>2021</b>
	£	£
Aggregate remuneration	<u>217,690</u>	<u>241,187</u>

**Transactions with related parties**

During the year, one trustee donated £120 (2021: £4,625).

There were no other related party transactions in the year.

**HUNTINGTON'S DISEASE ASSOCIATION  
COMPANY LIMITED BY GUARANTEE**  
**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)**  
**FOR THE YEAR ENDED 31 MARCH 2022**

**25 Branch funds**

Reports received from branches are set out below and incorporated into the accounts.

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
<b>Cash balances</b>		
At 1 April 2021	72,265	94,081
Receipts in year	30,747	26,078
Less :		
Local welfare grants	(7,468)	(12,108)
Sent to head office	(9,755)	(31,833)
Branch activities, local newsletters, equipment, research etc	(20,067)	(3,953)
	<u>65,722</u>	<u>72,265</u>
At 31 March 2022	<u><u>65,722</u></u>	<u><u>72,265</u></u>

**26 Cash generated from operations**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Surplus for the year	742,867	656,775
Adjustments for:		
Investment income recognised in statement of financial activities	(12,941)	(12,266)
Fair value gains and losses on investments	3,937	(77,920)
Depreciation and impairment of tangible fixed assets	7,771	4,698
Movements in working capital:		
(Increase) in stocks	(615)	(3,668)
(Increase) in debtors	(293,777)	(112,392)
Increase/(decrease) in creditors	25,911	(46,723)
	<u>473,153</u>	<u>408,504</u>
<b>Cash generated from operations</b>	<u><u>473,153</u></u>	<u><u>408,504</u></u>

**HUNTINGTONS DISEASE ASSOCIATION**

England & Wales - Charity number 296453

---

# Accounts

---

**Charity Registration No. 296453**

**Company Registration No. 02021975 (England and Wales)**

**HUNTINGTON'S DISEASE ASSOCIATION  
ANNUAL REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2021**

# HUNTINGTON'S DISEASE ASSOCIATION

## LEGAL AND ADMINISTRATIVE INFORMATION

---

<b>Patrons</b>	Tony Hadley Shane Richie
<b>Trustees</b>	Dr G El-Nimr Mr N M Heath (Hon Treasurer) Dr E M Howard (Vice-Chairperson) Professor H Rickards (Chair) Ms A C Clarke Dr A Fryer Ms C Lyon Ms S Barker Mr S Duckett Dr N Swales Ms B E Waters
<b>Chief executive</b>	Mrs C Stanley RGN,BSc (Hons)
<b>Charity number</b>	296453
<b>Company number</b>	02021975
<b>Registered office</b>	Suite 24 Liverpool Science Park Innovation Centre 131 Mount Pleasant Liverpool L3 5TF
<b>Auditor</b>	DSG Castle Chambers 43 Castle Street Liverpool L2 9TL
<b>Bankers</b>	National Westminster Bank Plc 66/68 St John's Road Battersea London SW11 1PB

---

# HUNTINGTON'S DISEASE ASSOCIATION

## CONTENTS

---

	<b>Page</b>
Trustees report	1 - 15
Statement of Trustees responsibilities	16
Independent auditor's report	17 - 19
Statement of financial activities	20
Balance sheet	21
Statement of cash flows	22
Notes to the financial statements	23 - 41

---

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT)

**FOR THE YEAR ENDED 31 MARCH 2021**

---

The Trustees present their report and financial statements for the year ended 31 March 2021.

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 Charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)".

### Objectives and activities

#### Charity objects

The Association's objects are the relief and treatment of those suffering from or believed to be suffering from Huntington's disease and to provide financial support for such persons and their families in need and for research and the dissemination of the results of such research for the public benefit into the cause and possible cures whether partial or complete and possible prevention of the said disease.

#### Huntington's disease, a brief overview

Huntington's disease is a rare neurological disorder that is caused by a faulty gene passed down through families. Each child of a parent with Huntington's has a 50% chance of inheriting the faulty gene. The disease affects the central nervous system, the network of nerve tissues in the brain and spinal cord that co-ordinate the body's activities. It is a progressive condition that causes changes in movement, thinking, emotions, eating and speech that worsen over time. Symptoms usually begin between the ages of 30 and 50, though they can also develop much earlier or later. If someone begins to show symptoms before the age of 20, this is known as Juvenile Huntington's disease. It is estimated that around 8,000 people are living with Huntington's and 32,000 are at risk of developing it in the United Kingdom.

#### Vision

A better life for anyone affected by Huntington's disease.

#### Mission

To enable everyone affected by Huntington's disease to live life to their full potential by:

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community and influencing policymakers

#### Values

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive

#### Who we are

The charity was founded in 1971 after a family who had been given a diagnosis of Huntington's sent a letter to a local paper asking if anyone knew of any other families in a similar situation. It began as a support group with 76 members and was known initially as the 'Association to Combat Huntington's Chorea', later becoming the Huntington's Disease Association.

Feedback from families that they would benefit from professionals with knowledge and understanding of the illness led to a 1993 project known as CASE – Care, Advice, Support and Education. This project saw the birth of our Specialist Huntington's Disease Advisory service that continues to be a valued resource and focus for development to this day.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

The Huntington's Disease Association provides support to anyone affected by Huntington's or anyone involved in their care and support across England and Wales. We also work closely with other Huntington's disease charities across the UK and Ireland. We now have 31 staff members from a wide range of backgrounds. From nursing and social care to fundraising and administration, all united in our dedication to supporting people living with and affected by Huntington's.

#### What we do

##### Specialist Advisory Service

The Specialist Huntington's disease Advisory service provides practical information, advice and emotional support to people with Huntington's and their families across England and Wales. Our advisers promote local services, assist with the organisation of care packages and answer crisis calls to ensure people affected by Huntington's receive the best possible care and support available. They also offer training, advice and support to professionals involved in the care of people with Huntington's to improve quality of care.

##### Juvenile Huntington's disease support

We are the only Huntington's disease charity with a dedicated Specialist Juvenile Huntington's Adviser in the world, supporting people affected by the juvenile form of the disease and their families across England and Wales.

##### Youth Services

We have a Huntington's Disease Youth Engagement service (HDYES) providing support to young people aged 8-25 living in families affected by Huntington's. HDYES is co-ordinated by a Youth Engagement Co-ordinator currently covering the whole of England and Wales.

##### Membership

We have a membership of over 5000 people, made up of both families living with Huntington's disease and health and social care professionals caring for people with Huntington's.

##### Branches and Support Groups

We are linked to a number of local Huntington's Disease Association branches and support groups, all led by dedicated volunteers. These groups provide invaluable peer support on a local level. They support many aspects of the Huntington's Disease Association's work.

##### Partnership working

We are a charity with limited resources and so we work closely with other organisations for maximum impact and influence. Organisations we regularly work with include the Neurological Alliance and Genetic Alliance UK. We also work with other Huntington's disease charities including the European and International Huntington's Associations.

##### Research projects

We work with scientific, clinical and social researchers and experts in the field of Huntington's in their search for ways to improve care and treatment. One day, we hope for a cure for the disease.

##### Supporters

We have an army of committed supporters who dedicate their time and energy to raising awareness, supporting those affected by the disease and fundraising to help ensure we can continue supporting those who need our help.

#### **Aims and objectives in 2020/21**

The following goals underpin the Huntington's Disease Association's five-year strategy and were the focus of the charity's work throughout 2020/21:

- Improved quality care and support
  - Better knowledge and understanding of Huntington's
  - Greater opportunity for peer support and community involvement
  - Improved understanding of Huntington's and the Huntington's Disease Association's role with the general public
  - A strong charity to better champion the needs of our community
  - Supporting Huntington's research
-

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

---

### Achievements and performance

#### Our impact in 2020/21

##### *Improved quality care and support*

As the COVID-19 pandemic continued in 2020/21, the whole of the UK faced unprecedented social and economic challenges - isolation, financial uncertainty, difficulty accessing health services and losing loved ones to mention just a few. These difficulties were felt profoundly by millions of people during the year but for the Huntington's community, they are regrettably commonplace. As a rare, progressive and degenerative condition, Huntington's is often misunderstood and frequently misdiagnosed with many people, healthcare professionals and the general public alike, never having encountered the condition and its complexities. With such a reliance on the UK's health services as a result of the pandemic, our mission to champion the needs of those affected by Huntington's disease and improve quality care and support was imperative. We worked hard throughout the year trying to ensure the needs of those affected by Huntington's were understood and adequately met at a time when nationally, healthcare resources were limited and facing acute disruption.

Our Specialist Huntington's Disease Advisers provided information and advice to 4,148 people affected by Huntington's disease throughout 2020/21, which included 759 new referrals to our advisory service. 51% were adults with Huntington's who were either experiencing symptoms or were not yet symptomatic, 8% were adults at risk of developing the condition, 1% were adults who had tested negative for the condition, 2% were young people with Juvenile Huntington's, 26% were carers, 5% were young people living in families affected by the disease and 7% were people who didn't tell us their connection to Huntington's. We also supported a small number of people with rare conditions akin to Huntington's for which there is no dedicated charity support, such as Dentatorubral-pallidoluysian atrophy (DPRLA) and Neuroacanthocytosis.

With the country in national lockdown for large parts of the year and many members of the Huntington's community shielding for their own safety, we had to move swiftly to adapt our support services, processes and resources to make sure we could continue to provide information and advice to those that needed it. In-person contact, unfortunately, had to stop, but this meant less extensive travel across the country and more advisers manning our telephone and email helpline ready to help. During the year, our Huntington's helpline responded to 9,849 calls and 26,812 emails to both people affected by Huntington's and health and social care professionals involved in their care. Other communication methods, such as eNewsletters, direct messages via our website or social media and texts, continued to be utilised as a means of accessing and providing advice and support. Various remote communication methods were introduced during the year to facilitate face-to-face contact for more complex cases, including video support calls and virtual Multi-Disciplinary Team meetings. Virtual Specialist Huntington's Disease Adviser surgeries were also successfully trialled to allow our advisers to use their time most effectively to help more people.

People made contact with us for many reasons throughout the year, whether to obtain emotional support, seek advice or learn more about Huntington's. 95% of those who completed our post-contact survey informed that we were able to help them, 86% informed that we were able to provide them with information and advice and 74% felt their knowledge and understanding of Huntington's had improved as a result of the contact. With increased isolation and people facing a variety of challenging situations throughout the year, our advisers proactively reached out to people in the Huntington's community to help ensure they didn't feel they were facing the pandemic and the progression of the condition alone. 53% of those who had contact with an adviser said that they felt more able to cope, 49% reported feeling less isolated and 33% told us we helped them with a crisis situation.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

2020/21 was a difficult year for many, not least for children and young people who also had to contend with home-schooling, isolation from loved ones and missing milestone moments, such as starting a new school or completing an important examination, completely virtually in many cases. For young people in the Huntington's community, these challenges were in addition to those they were already facing through living with a loved one affected by Huntington's and seeing them gradually deteriorate. Our Specialist Huntington's Disease Youth Engagement service (HDYES) supported 212 young people between the ages of 8-25 throughout the year, including 56 new referrals. They also provided information and advice to many of their parents, guardians and schools. With in-person visits unable to take place during the year, our Youth Engagement Co-ordinator provided online drop-in sessions for young people and those involved in their care, covering topics such as COVID-19 queries and coping with being home from school. A HDYES Facebook page was also created during the year to help widen virtual communication and support for young people during this difficult period.

Our website continued to be used extensively throughout the year as an accurate source of information about Huntington's disease, particularly as a result of the pandemic which encouraged more people than ever towards the use of digital resources. With 150,272 visits to our site between April 2020 to March 2021, 18,682 of which entered via our social media channels, it became clear that our digital resources were integral to many people's Huntington's journey. Throughout the year, we took steps to develop our website and social channels further, increasing our use of informative blogs, creating more downloadable resources and improving the site's functionality thus creating useful information that is more easily accessible to a wider audience. We also received our blue verification tick on Facebook highlighting that we are a recognised and reputable organisation that people can trust.

We were able to continue to provide financial support to the Huntington's community via our welfare grants programme. A total of £4,527 grant funding was spent in 2020/21, in providing 13 grants for items such as, a wheelchair battery pack, a bicycle and a laptop. Such items were provided on the basis that they would greatly help to improve people's quality of life.

Specialist healthcare services for people affected by Huntington's disease vary greatly across the country culminating in a complex post-code lottery for quality care. This can range from no services at all to inconsistent services with different team names, varying referral criteria and support offered. As an organisation, we are committed to addressing this inequality and throughout the year we worked to begin mapping services across England and Wales to build a clear picture of what support is available to the Huntington's community. This information is invaluable in helping us to evidence service gaps, highlight best practice and ultimately work towards achieving equal and consistent access to quality care and support for people affected by Huntington's.

As part of our commitment to challenging disparity and gaps in services, we worked with a group of like-minded health and social care professionals on a project to review and take steps to improve support for people affected by Huntington's and other neurological conditions in prisons. Mental health support was another unmet need identified during the year that we worked hard to improve. Mental illness is a common feature of Huntington's disease but the symptoms are often viewed as part and parcel of Huntington's and not as a mental health need that could be individually treated. As a result, many people affected by Huntington's do not receive the most appropriate support when it comes to their mental health. To help combat this, we were involved in consultation for the Mental Health Act and a scoping exercise looking at unmet mental health needs for the Mental Health Implementation Programme to assist in NHS England's planning. We also worked closely with members of the British Psychological Society who created guidelines relating to psychological services that include Huntington's to look at ways of better informing people what psychological services can offer and how this support can be accessed.

As a small charity representing a rare condition, it is important that we join with like-minded organisations to provide the Huntington's community with a stronger voice to ensure they are well represented in discussions with key policy and decision-makers. We continued to work closely with the Neurological Alliance, joining more than 80 other organisations representing varying neurological conditions, to collectively influence policy and ensure joined-up care for people at each stage of their condition. Throughout 2020/21, we represented Huntington's in a number of subgroups relating to mental health, rare diseases and COVID-19's impact on neurological conditions. Our Chief Executive joined the Neurological Alliance's board as a trustee; all of which helped us to propel the needs of the Huntington's community to the forefront of discussions and push for change.

---

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

**FOR THE YEAR ENDED 31 MARCH 2021**

---

We represented Huntington's at National Neurosciences Advisory Group meetings in 2020/21, focussing on future development of more clearly defined care pathways for neurology and capturing patient experience. We also attended a meeting with NHS England Chief, Sir Simon Stevens, during the year to bring his attention to COVID-19's effect on neurological services. Our links with Rare Disease UK continued during the year and we attended a Rare Disease Patient Round table. Here we looked at the future of the Rare Disease Strategy and have been invited to become a patient representative for the Department of Health and Social Care for the stakeholder engagement they plan to undertake in creating the UK Rare Diseases Framework. We continued to align ourselves with the NCVO to ensure the Huntington's Disease Association was represented in key discussions affecting the charity sector, particularly in relation to the impact of the COVID-19 pandemic.

Our collaborative work with the Department of Work and Pensions and Personal Independence Payments (PIP) assessors at both Capita and the Independent Assessment Service (IAS), continued to be invaluable during the year in helping us to assist people affected by Huntington's disease in obtaining the financial support they are entitled to but sometimes struggle to access.

### ***Better knowledge and understanding of Huntington's***

Educating people about Huntington's remained a key priority for the Huntington's Disease Association throughout the year. With a number of COVID-related hospital admissions for people with Huntington's and many facing difficulties in adhering to the safety measures of the pandemic, such as social distancing and wearing a mask, knowledge and understanding of the condition by medical professionals and the general public was of paramount importance in 2020/21. The COVID-19 resource hub created on our website to provide information, advice and resources continued to be updated and developed as each change in national policies for England and Wales occurred throughout the year to ensure accurate information and resources relevant to the Huntington's community were available. Resources included mask exemption cards and leaflets explaining Huntington's to help educate people in public settings such as supermarkets and emergency departments. These pages were visited 9,692 times throughout the year.

We added to our information guides during the year with the creation of a genetic testing guide aimed at those going through or considering a genetic Huntington's test, and a wellbeing guide for older carers as part of the BUPA UK funded Older carers project. Our suite of guides focussing on various aspects of Huntington's were viewed and downloaded 8,843 times throughout the year.

We made improvements to our website in 2020/21 during the year, creating an information resource landing page in which all of our guides, magazines, webinars and useful downloadable resources can be found and accessed quickly to make learning about Huntington's easier.

With in-person training events suspended and an increased reliance on digital technology, we worked hard throughout 2020/21 to develop a series of webinars to educate more people about the complexities of Huntington's disease. The webinars were aimed at Huntington's families and health and social care professionals alike and covered a range of topics, such as coping with loss, speech and language therapy, research, physical activity at home and various Q & A's; all delivered by experts in their respective fields. A total of 28 webinars were delivered during this period which were well received and attended by over 500 people.

In addition to the webinar series, our advisers continued to deliver training and advice to health and social care professionals. The social distancing restrictions associated with the pandemic meant that this training had to be moved online and delivered virtually for the first time. 47 training sessions and 22 informal information sessions about Huntington's were delivered to 391 health and social care professionals throughout 2020/21. Survey evaluations of these sessions revealed that 100% of those who attended training with us felt that their knowledge and understanding had improved and that they were in a better position to provide quality care and support moving forward.

We produced our twice-yearly magazine/newsletter throughout the year containing informative articles about Huntington's, personal stories, upcoming events and fundraising activities to enable our membership to keep up to date with upcoming opportunities for involvement, learn practical tips for care management and find out about developments in Huntington's research.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

We continued to work with the Association of British Insurers (ABI) during the year on guidance they are creating regarding insurance, making sure that it was clear and applicable to the Huntington's community by reviewing its content and providing information about the condition. Through our work with the ABI, we hope that this will help both improve access to affordable insurance products for people affected by Huntington's and also make guidance much clearer to help create a smoother application process.

#### ***Greater opportunity for peer support and community involvement***

The Huntington's community understand the condition the most and it is important that they are given the opportunity to connect to share their knowledge and support each other. We were committed throughout the year to creating peer support and community involvement opportunities.

Many professionals who support and care for people affected by Huntington's have little or no prior knowledge of the condition. In addition to providing training and information resources to expand their knowledge, we strongly encouraged peer support amongst the professional community to share best practice knowledge and to promote better standards of care. During the year we created a 'professional hub' on our online message board, specifically for Occupational Therapists in the first instance, as a secure forum in which they can ask questions of each other and seek peer support to enhance their knowledge, understanding and practice in caring for people affected by Huntington's.

Our volunteer branch and support group network played an integral part in supporting people affected by Huntington's throughout the year. Despite the challenges that the various COVID-19 lockdowns brought, our branch and support group volunteers showed tremendous resilience with many groups using video-calling to continue running support meetings and social get-togethers safely. They really were a lifeline for many people during the year in times of extreme isolation. We also introduced a regular virtual meeting with branch and support group leaders throughout 2020/21 for training, reviewing and communicating process changes and sharing ideas and upcoming opportunities for involvement.

Our planned in-person support events for 2020/21 were cancelled, like all events across the UK, as a result of the COVID-19 pandemic in order to adhere to social distancing requirements and keep our vulnerable community safe. We were however thrilled to take many of our events online during the year, such as our information and peer support event for young adults aged 18-45 affected by Huntington's and our Annual General Meeting in which the accounts and work of the charity during the year were presented to the membership. Whilst there are undeniable benefits to in-person events, there were also positive aspects to having moved these online, not least because they were accessible to more people and more cost-effective without expensive accommodation and travel costs included.

We also introduced a number of new online events in 2020/21 to bring members of the Huntington's community together. These events included regular Zoom calls for families affected by Juvenile Huntington's disease, quarterly virtual coffee mornings that were open to all, both national and local online peer support meetings for carers, Christmas quizzes for adults and children alike, a virtual pantomime and a circus skills session aimed at the children and young people in our community.

Patient and public involvement group, HD Voice, went from strength to strength during the year, increasing its membership to 39 members. Our volunteers continued to review and comment on a number of internal and external projects to help strengthen and develop work by both the charity and external researchers. HDVoice ensured the needs and experiences of the Huntington's community were well represented. The group introduced monthly virtual meetings for the first time in 2020/21 which proved to be successful for learning, sharing and discussing different projects. We also expanded our volunteer opportunities in 2020/21 with a social media volunteer role which was carried out by a young graduate who brought invaluable ideas and created engaging content which was shared on our social channels throughout the year.

With limited in-person interaction possible due to the pandemic, it was more important than ever that we continued to develop our online peer support platforms as a way of helping people stay in touch. Our online message board continued to provide a forum for people seeking peer support. As we worked to provide varied and engaging content across our social channels, our followers grew steadily to 14,374 on Facebook, 3,506 on Twitter, 1,556 on Instagram, 675 on LinkedIn by year-end March 2021. Our social channels also provided an opportunity for our followers to connect and interact with each other.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

Through the circulation of eNewsletters, including quarterly communications to our branches and support groups and quarterly editions of Incoming!, our dedicated fundraising communication, we kept the community up to date with upcoming opportunities.

Our dedicated supporters spent the year organising imaginative fundraising initiatives from virtual sweepstakes to online quiz nights and solo endurance challenges, joining together to raise vital funds to support the Huntington's Disease Association through the financial uncertainty of the pandemic. We are incredibly grateful for their continued support.

#### ***Improved understanding of Huntington's and the Huntington's Disease Association's role with the general public***

Raising awareness of Huntington's disease and the work and services of our charity continued to be a key focus for us in 2020/21.

Huntington's Disease Awareness Month in May provided us with an opportunity to raise the profile of Huntington's bringing understanding to those that knew very little or nothing at all before. The timing of the first national lockdown meant that our plans had to be quickly amended so that people could take part from home and maintain COVID-19 social distancing. During the month, we encouraged the Huntington's community to Hashtag SpeakOut4HD by sharing our videos, blogs and social media posts far and wide, holding virtual events to raise awareness and adding an awareness banner to their social media profile pictures. We shared information about Huntington's throughout the month, including informative videos, personal stories about life with Huntington's and live Q & A opportunities with key staff at the charity. A number of people in the Huntington's community also took part in virtual and socially distanced picnics to raise vital awareness of the condition during the month.

We continued to advise on scripts and storylines for prime-time tv shows, including BBC's Casualty and ITV's Emmerdale throughout the year to ensure their ongoing Huntington's storylines were true to life and to bring knowledge and understanding of this little known disease to millions throughout the country.

In a year of such uncertainty and restriction, our focus was clear, we needed to ensure our support services remained accessible to all and that the Huntington's community knew we would be there for them if they needed our help. We encouraged people to join our mailing list to ensure we could keep people updated. We increased our electronic communications, sharing updates on how we were adapting our services and new resources to help with the challenges faced by the community.

We joined together with many other charities as part of the Directory of Social Change and National Council for Voluntary Organisations led campaigns- HashtagSaveOurSector, HashtagEveryDayCounts and HashtagNeverMoreNeeded, to highlight to the UK government the financial uncertainty and difficulties facing the third sector as a direct result of COVID-19 restrictions. With key income generators such as events and fundraising activities stopped almost overnight, the sector needed financial support from the government. Such support would have permitted the retention of staff to deliver services that were potential lifelines for isolated and vulnerable communities, as opposed to the furlough scheme that meant a reduction in workforce at a time when they were needed most. We urged the Huntington's community to get behind the campaign and write to their local MPs to raise maximum awareness.

During the year, we worked with folk singer, Sylvie Lewis to launch a social media campaign, Hashtag Sing4HD to raise both awareness of Huntington's and vital funds for our charity during the first COVID-19 lockdown. As part of the campaign, musicians recorded themselves singing then challenged another person to sing whilst asking those watching to donate. Sylvie sang first and was followed by 11 other professional musicians, many of whom had a large following bringing important awareness to many.

Throughout the year we were approached by a number of authors wishing to include Huntington's in fictional storylines to review and ensure an accurate portrayal, including a children's book 'Owlbert explains Huntington's' and 'Coming back to you' by Lilly Hayden who donated sales royalties to us and included information about the charity in the back of her book. We also reviewed and commented on Dr Oliver Quarrell's latest edition of 'HD, the facts' that also included information about the charity to bring greater knowledge of our services to many readers.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### **FOR THE YEAR ENDED 31 MARCH 2021**

---

We created new media guidance for members of the Huntington's community speaking to the media on our behalf to help ensure consistent messaging in relation to the condition and the work of the charity.

Our Chief Executive wrote articles about Huntington's that were published with Orphanet and in the Neuro Rehab Times during 2020/21 to raise further awareness within the professional community.

We introduced new merchandise throughout the year in the form of branded face masks which were well received by the community, allowing them to support our work and continue to raise awareness during the pandemic.

We took part in RAREfest20 during the year, a free, virtual, interactive science, technology, advocacy and arts exhibition with a focus on rare diseases, organised by the Cambridge Rare Disease Network. We had a short video explaining Huntington's disease featured during the event and took part in a question and answer session to provide further information about the condition to those that wanted to learn more.

Summer 2020 saw the Huntington's Disease Alliance UK and Ireland, a collation of Huntington's associations, ourselves included, begin work on a national Huntington's awareness campaign, Hashtag FamilyMatters, to provide greater insight into the condition and what it is like to live with Huntington's disease. In February 2021, on Rare Disease Day, the Huntington's community were informed of the campaign plans, how they could get involved and the expected launch during awareness month in May 2021. An incredible awareness opportunity that will bring greater knowledge and understanding of Huntington's disease to the general public.

#### ***A strong charity to better champion the needs of our community***

COVID-19 brought many challenges to the charity during the year, from financial uncertainty and home-working to almost overnight service delivery changes, however, our mission and commitment to supporting the Huntington's community never wavered and we adapted to meet these challenges head-on.

2020/21 was the third year of our five year strategic plan and as a result of the pandemic, a number of our plans were paused, such as the expansion of our care home accreditation scheme which was unfeasible during lockdown with increased social distancing measures in place in care homes across the country. However, other elements of the strategy, such as widening our digital support, digitising processes and reducing our environmental footprint, were achieved ahead of schedule. Important changes had to be made to our fundraising and communications strategies to adapt to the changing fundraising landscape with the postponement of most fundraising events and the increased reliance on digital communication during the year.

We made the difficult decision in 2020/21 to utilise the government's Coronavirus Job Retention Scheme, furloughing 15 staff members across the Advisory, Fundraising and Operations departments of the charity. This provided much needed financial support at a time of great uncertainty and allowed us to continue delivering support and advice services to the Huntington's community when it was needed most. This action helped ensure the running costs of the charity could be met in the absence of key income streams, such as fundraising events, and ensured we would emerge from COVID-19 restrictions in a strong position to better champion the needs of those affected by Huntington's.

With our staff working almost entirely from home during the pandemic and facing unprecedented pressures both at work and at home, staff welfare and wellbeing was of paramount importance. We ensured regular communication with our teams via meetings, telephone check-ins and eNewsletters, provided access to exercise classes during the working day, shared wellbeing resources and encouraged staff to move away from their desks and spend time outdoors, whilst observing government guidelines around outdoor activities, during their breaks. With a number of employees caring for loved ones who were shielding or home-schooling young children, we encouraged a flexible approach to the working day to allow staff to navigate these new challenges more easily alongside their existing workloads. Furloughed staff were contacted regularly and on return to work were allocated a 'buddy' to help them transition back to work and learn the new processes implemented whilst they were away. We ensured all relevant COVID-19 processes and procedures were set up and we ensured our central office base was COVID-secure.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

With the support of the Huntington's community, our communications became almost entirely digital, with our member magazine moving online only for the first time. The benefits of this were threefold, the magazine content was shared more widely, our carbon footprint was reduced and the money we saved in removing the printing element of such communications were reallocated to help fund vital advice and support services to help ensure no one has to face Huntington's alone.

We made improvements to our website during the year, moving to a new web agency who have worked with our communications team to improve webpage functionality and navigation and ensure our site remains secure.

A number of our workforce made the decision to retire or move on to new ventures during the year. Additionally, our Chair of trustees, Andrew Bickerdike stood down at the 2020 AGM after five years in the role and longer as a trustee. We are incredibly thankful to all for their dedication in supporting families affected by Huntington's during their time with the charity. This provided us with an opportunity to review our services, identify gaps and agree on the roles required to best meet the current needs of the Huntington's community. We were pleased to welcome Professor Hugh Rickards as our new Chair of trustees, an existing trustee on our board, who will be an incredible figurehead and spokesperson for the charity as we move through the changing landscape of Huntington's care, support and research.

Data security and protection remained a priority throughout the year to ensure GDPR compliance. Our databases were regularly reviewed and our outsourced I.T company ensured our I.T and information systems were fully protected. We began the process of reviewing the data we hold as a charity during the year with an external consultant to gain a better understanding of our services and the people we support. We also took steps to improve our monitoring and evaluation processes, setting up quarterly review meetings, further developing our evaluation surveys and improving our impact reporting.

Relevant training was carried out by employees and trustees throughout 2020/21 in line with their individual roles for their continued professional development.

Our board of trustees met frequently throughout the year to monitor the charity's performance both financially and operationally and ensure compliance with the charity governance code and the charity commission's good practice guidelines. In addition to scheduled meetings, the board and finance sub-committee met on a number of occasions throughout the year to safely navigate the charity through the challenges of the pandemic.

#### ***Supporting Huntington's research***

Huntington's research faced a disappointing setback in 2020/21 with the ending of the GENERATION-HD1 and PRECISION-HD trials as the drugs being trialled didn't perform as hoped. We ensured that the Huntington's community were kept up to date and informed as and when we learned more about the reasons for the premature conclusion of the trials and what the next steps would be. Whilst this was a disappointing outcome, it is widely regarded in the research community that these trials helped provide invaluable information that will be integral in driving future research forward to develop an effective treatment.

We continued to financially support and promote HD Buzz, a website that explains current Huntington's research in plain English and encourage people to participate in Enroll-HD, the world's largest observational study for Huntington's disease to enable researchers to gain better insight into the condition.

With the possibility of an effective treatment for Huntington's still very much on the horizon, it was a key focus for our charity to continue supporting the work of Huntington's researchers, make links with pharmaceutical companies and take steps towards gathering further data about the condition. In 2020/21, we continued our work with HCD Economics, Shift Healthcare and Tessella respectively on Huntington's health economics and burden of illness projects. These projects are helping us to learn more about the financial impact of Huntington's and will help build supportive evidence to present to policy and decision-makers so that they can make more informed choices and ensure fair and equal access to future treatments.

During the year, our staff team received training from pharmaceutical company, Roche, on clinical trials including how they work, criteria for entry and the process of licensing and funding any future treatments. This knowledge and insight is invaluable for our team so that they can better support members of the Huntington's community interested in or already taking part in clinical trials.

---

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

HD Voice, our patient and public participation group, continued to provide a voice for the Huntington's community in relation to research and service development. Two HDVoice members took part in a rare disease co-ordination project led by University College London during the year. They also represented the charity on HDCOPE, the European Patient and Public Participation group; on HEALTHE-RND, a European project looking to develop an eHealth Care model for rare and neurodegenerative diseases; and DOMINO-HD, a European study looking at the relationship between genetic and lifestyle factors and Huntington's symptom progression.

Throughout the year, we helped to facilitate regular meetings of the UK Huntington's Disease Network, chaired by Professor Hugh Rickards, which brought key clinicians and researchers together to discuss plans, projects and challenges being faced by the Huntington's research community. These meetings were invaluable in sharing best practice, seeking solutions and gaining understanding of the issues facing research sites and lay organisations across the UK and Europe.

#### **Fundraising**

As COVID-19 took hold across the UK and the first lockdown took place in March 2020, it became clear our fundraising strategy for the year would have to be significantly adjusted to ensure our services could remain open and operational during what was to be a tough year ahead for many people living with Huntington's disease.

Early in the year, we launched a COVID-19 appeal raising £25,950; adding to the annual growth we have seen in donations from individuals which overall totalled £285,074.

In 2020/2021 our income from Community Fundraising and Events was severely disrupted by the effects of COVID-19. However, thanks to our committed supporters we saw this income stream pick up from the third quarter onwards bringing the total raised overall to £221,648. During the lockdowns of 2020/2021, committed supporters came up with new and imaginative ways to support our work including Mr and Mrs Winser who raised £2,110 from sales of homemade chutney and Julie Hayden who organised driveway sales raising £4,100. Our thanks go to these and the hundreds of fundraisers who came out to support our work.

Our HashtagTeamHDA of runners coped amazingly with the postponement of the Virgin Money London Marathon 2020 just one month before it was due to take place. The event moved to October 2020 before it was postponed once again. However, many of our runners carried on with their training and fundraising taking part in the Virtual London Marathon in October 2020. We are so grateful and proud of HashtagTeamHDA. Likewise, many nationally organised events were cancelled including parachute jumps, Great North Run and almost all national and overseas challenges. However, we saw people organising and taking on their own challenges such as the Manchester United RTC Under 11 Squad who took on the fantastic challenge of covering 200 miles through walking, running or cycling and raising a fantastic £7,372, Tom Crowder who took on the Three Peaks Challenge in between lockdowns raising over £5,000 and Harvey Scowcroft who raised over £5,000 with a 24-hour Strava Zwift indoor bike ride on a smart trainer.

Working through the pandemic allowed us to examine some of our practices around fundraising, giving us an opportunity to develop our new fundraising challenge, HashtagHD8000, with the first in the series, HashtagHDMove raising £13,854 in January 2021. We look forward to HashtagHD8000 becoming our flagship annual fundraising activity for the charity.

Our work with corporates and local businesses saw Marks and Spencer, Edge Lane in Liverpool raising £4,192 and continuing to support our work well into 2020. Our thanks go to employees at Brit Insurance for nominating us for their Employee Charity Scheme with a donation of £10,000. We were also delighted to receive a donation of £2,000 from Ixico PLC. We formed a new partnership with Marshalls Garden with the development of the Christmas Amaryllis, which retailed in the period leading up to Christmas 2020 raising just over £1,524. These are just a few of the businesses and their employees who supported our work.

In a year unlike any other, we are thankful to the various Trusts and Foundations who supported our work in 2020/2021. Their support helped us continue our work offering advice, information and support for people affected by Huntington's disease.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

All the funding we received was, and continues to be, important; however, we were particularly grateful for the funding we received from the various COVID-19 emergency funding programmes. This included £92,751 from the Julia and Hans Rausing Trust, £80,976 administered by The National Lottery Community Fund on behalf of the Office for Civil Society, £20,025 from various Community Foundations and additional support from many long-term Trust and Foundation supporters.

In statutory funding, we continued to deliver services through grant agreements across a number of Clinical Commissioning Group areas including Blackburn with Darwen, Cambridgeshire and Peterborough, Devon, Kernow and Sunderland. In addition, we successfully delivered year one of our two-year contract with Birmingham City Council for delivering services for people affected by Huntington's disease across the city.

Our three-year Children in Need grant came to an end in 2020/2021. We are incredibly thankful for their support enabling us to establish HDYES - such an important service for children and young people affected by Huntington's disease.

Putting people with Huntington's disease at the heart of our work is key to letting the world know about Huntington's disease and its effect upon individuals, families and communities. We will continue to work collaboratively with staff and supporters to share their stories and powerful messages.

We also turned our attention to understanding our data management across the department and wider organisation identifying ways to improve our communications with supporters.

We monitor return on investment on all our fundraising activities and meet or exceed all statutory and regulatory obligations.

We are a member of the Fundraising Regulator and we follow the Institute of Fundraising best practice guide and Charity Commission guidance for Charity Trustees (CC20). We comply with the Privacy and Electronic Communications Regulations (PECR). The Huntington's Disease Association recognises that we may work with people in vulnerable circumstances so protection of vulnerable people is something we take seriously. We adhere to the Institute of Fundraising's guidance – 'Treating Donors Fairly - Fundraising with people in vulnerable circumstances'.

For the year 2020/2021 we did not receive any complaints about our fundraising practices/approaches

#### **Financial review**

The results for the year show an overall surplus of £656,775 (2020: £61,383) made up of a surplus on the general fund of £630,030 (2020: £54,943) and a surplus on the restricted funds of £26,745 (2020: £6,440).

The surplus arose during the first 12 months of the pandemic which caused a major disruption to our services and a substantial reduction in costs due to restrictions imposed. This can be seen from the accounts which also show income boosted by the £161,450 Coronavirus Job Retention Scheme, which enabled us to retain staff during the first lockdown, and substantial one-off grants and individual donations. In addition, investment gains of £77,920 reflected the bounce back from the depressed Stock Market levels of March 2020.

The Trustees, through the Finance Committee, have monitored developments closely and considered how the surplus should be utilised taking account of the uncertainties arising from the pandemic and the consequent need to boost reserves. Budgeted expenditure has been increased by boosting the number of Specialist Huntington's Advisors and strengthening the data management, impact assessment and policy and communications operations. It is anticipated that the underlying deficit for 2021/22 and the subsequent two years will be approximately £200,000 per annum.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

#### **Reserves Policy**

The reserve requirement of the charity is to enable the salaries of staff members and running costs to be covered in the event of short-term income fluctuations. As a result of the uncertainties arising from the pandemic, it was agreed that the target for general reserves needed to be increased to nine months recurring costs being approximately £1m.

At the year end, free reserves available excluding the designated project reserve and funds held by branches stood at £1,403,760 (2020: £751,954) and therefore comfortably exceeded target. As noted in the Financial Review, the Trustees have agreed a policy to utilise surplus reserves over the next three years to develop the Association for the benefit of those impacted by Huntington's Disease.

The Trustees have assessed the major risks to which the Charity is exposed and are satisfied that systems are in place to mitigate exposure to major risks. The impact of the Coronavirus pandemic has been closely monitored by the Trustees and the Finance Committee. The success of the Reserves Policy means that the charity is well placed to make considered decisions on measures that may need to be taken as the crisis unfolds.

#### **Future plans 2021/22**

After a year like no other, we are pleased to have emerged from the pandemic in a strong position that will allow us to continue in our mission to enable everyone affected by Huntington's disease to live life to their full potential. In the year ahead we plan to learn from the challenges of the last year and as COVID-19 restrictions begin to ease, use this knowledge to adapt our services to include best practice from both before and during the pandemic.

We will continue to offer and expand the ways in which people can access support from us through the year, with the video support call option offered during the pandemic becoming a permanent feature. As COVID-19 restrictions ease, our advisers will return to in-person support through attendance at clinics and home visits in some circumstances, recognising that not everyone will access remote support and more complex cases may be better-discussed face to face.

We will recommence our ongoing projects that were put on hold during the pandemic. The BUPA UK funded Older Carers project will be brought to a conclusion in 2021/22 with resources developed to enhance support and access to information for older generations who may be less confident utilising digital technology. HD Quality Assured, our care home accreditation scheme, will be re-opened as social distancing restrictions begin to ease, with a number of care homes having already expressed an interest in taking part in the scheme in the year ahead.

We will begin a new project, in conjunction with Roche, to map Huntington's services across England and Wales to gain a better understanding of Huntington's care and support provision, identify service gaps and work towards the implementation of a best-practice care model for the condition. This will expand on the mapping work we carried out in 2020/21 and will help to improve standards of care.

Our youth support materials will also be developed during the year with funding sourced to create guides aimed specifically at teenagers living in families affected by Huntington's, and teaching staff supporting children from families affected by the condition.

Online training has been so successful during the year that we plan to develop this further by trialling our Huntington's certificated course for professionals as a digital event for the first time in June 2021. We will also recruit an education lead in the year to allow us to become more proactive and further develop our training offer to provide greater knowledge and understanding of Huntington's to the health and social care sector. We will also continue to develop our series of webinars to shine a light on all aspects of Huntington's disease for families affected by the condition and health and social care professionals alike.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### *FOR THE YEAR ENDED 31 MARCH 2021*

---

We plan to embrace digital further, making changes to our website's capabilities including improving the search functionality and user experience from mobile devices, streamlining and improving website content, and developing our digital communications further. A role dedicated to managing the charity's social media channels will be recruited during the year to help us reach more people who need our support or want to know more about Huntington's. This role will also provide our existing communications team with more scope to develop our eNewsletters, member magazines, guides and other resources throughout the year.

We will continue to raise awareness and understanding of Huntington's with the Huntington's Disease Alliance UK and Ireland's HashtagFamilyMatters campaign set to raise the profile of Huntington's disease in 2021/22 and highlight our services to more people to help us reach those who need our support.

We will continue to work with our branch and support group network throughout the year and explore ways in which we can improve the support and resources we provide to help them deliver peer support to a greater number of people affected by Huntington's in local communities throughout England and Wales. Opportunities for community involvement and peer support will also continue to be developed throughout the year, from in-person and online events to digital platforms and volunteer roles.

We plan to recruit to the teams who lost staff to retirement and new job opportunities in 2020/21 to relieve pressure and return the workforce to full capacity as the country begins to return to more normal times without COVID-19 restrictions. This will ensure we can continue to meet the needs of the Huntington's community and develop our services further through the year.

We plan to expand our fundraising team in 2021/22 to develop individual giving for the charity and make improvements to our charity membership offer. With many public events postponed until 2022, we will continue to develop new and innovative ways people can get involved in supporting our work.

Continuing with our data review, we plan to develop our use and understanding of the data we hold and recruit a Data Manager to manage our client and supporter databases and oversee the transition to a new database system.

We will also explore equipment and technology to better facilitate our work, such as call handling systems and cloud-based information management systems, and invest as appropriate. We also plan to introduce a hybrid working model for our office-based staff to reduce our office space and overheads and use these funds more effectively to support the community.

We will continue to work in partnership with other organisations that allow us to provide the Huntington's community with a stronger voice to their needs and the challenges they face better known. We will explore further how we as a charity can work more proactively and become more influential with policy and decision-makers to help bring an effective treatment for Huntington's a step closer and improve standards of care and support.

Our board of trustees will join together for a strategy planning weekend in the year ahead to begin looking at the charity's priorities for our next strategic plan set to launch in 2023/24. A skills audit for the board will also be undertaken to identify any recruitment needs to ensure the charity is safely guided through the years ahead. Consultation with our community will also begin in 2021/22 to assess their needs and requirements to help inform our future strategic direction.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

#### Structure, governance and management

##### Governing document

The company is a registered charity founded in 1971 and incorporated on 21 May 1986. The charity is governed by the Memorandum and Articles of Association.

The Trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Mr A Bickerdike (Chairperson) (Resigned 18 November 2020)

Dr G El-Nimr

Mr M Ellison (Resigned 20 July 2021)

Mr N M Heath (Hon Treasurer)

Dr E M Howard (Vice-Chairperson)

Professor H Rickards (Chair)

Ms A C Clarke

Dr A Fryer

Ms C Lyon

Ms S Barker

Mr S Duckett

Dr N Swales

(Appointed 18 November 2020)

Ms B E Waters

(Appointed 18 November 2020)

##### Recruitment and appointment of trustees

The Trustees are elected to serve a term of three years at the Annual General Meeting by the voting members of the Association who are the Guarantors.

##### Organisational structure

The charity is managed by an Executive Council made up of the trustees which met on five occasions during the year.

The trustees have considered the Charity Commission's general guidance on public benefit in relation to the objectives of the charity. This report sets out those objectives and describes how they have been met in the current year.

The Executive Council members focus on the strategic decisions required for the overall governance of the Huntingtons Disease Association and devolve operational running to the management team.

The Chief Executive and senior managers oversee the operational management of the Huntingtons Disease Association within the policies and guidelines approved by the Executive Council. Prior to board meetings, the Chief Executive provides a written update report to the Executive Council on the operational management of the charity which all senior managers have an input into. The reports provide the Executive Council with a detailed overview of the operational progress of the Association. The Chief Executive attends board meetings to discuss the management reports further and answer any questions trustees may have.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

*FOR THE YEAR ENDED 31 MARCH 2021*

---

### **Trustee induction and training**

Most trustees are already familiar with the work of the charity and their training involves briefings on their duties and liabilities. Additionally, new trustees receive an induction pack covering:

- The duties of charity trustees;
- An induction pack outlining duties and responsibilities;
- The Association's Memorandum and Articles of Association, strategic plan, latest published annual report and accounts, financial projections and budgets, and project and programme plans and publications;
- Trustee details and staff structure;
- 'The Essential Trustee: what you need to know' (Charity Commission);
- Minutes and reports submitted to the previous three meetings of the board of trustees.

### **Remuneration policy**

The Trustees have responsibility for setting the pay and remuneration of the charity's key personnel and this is done on an annual basis, including a formal cost of living review. Salaries are benchmarked with other similar organisations across the sector.

### **Auditor**

In accordance with the company's articles, a resolution proposing that DSG be reappointed as auditor of the company will be put at a General Meeting.

### **Disclosure of information to auditor**

Each of the Trustees has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

The Trustees report was approved by the Board of Trustees.

**Mr N M Heath (Hon Treasurer)**

Dated: 27 September 2021

# HUNTINGTON'S DISEASE ASSOCIATION

## STATEMENT OF TRUSTEES RESPONSIBILITIES

*FOR THE YEAR ENDED 31 MARCH 2021*

---

The Trustees, who are also the directors of Huntington's Disease Association for the purpose of company law, are responsible for preparing the Trustees Report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company Law requires the Trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the Charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the accounts comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT

### TO THE TRUSTEES OF HUNTINGTON'S DISEASE ASSOCIATION

---

#### Opinion

We have audited the financial statements of Huntington's Disease Association (the 'Charity') for the year ended 31 March 2021 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and the notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2021 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

#### Other information

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The Trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

#### Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of our audit:

- the information given in the Trustees report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the Trustees report has been prepared in accordance with applicable legal requirements.

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT (CONTINUED)

### TO THE TRUSTEES OF HUNTINGTON'S DISEASE ASSOCIATION

---

#### **Matters on which we are required to report by exception**

In the light of the knowledge and understanding of the Charity and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report included within the Trustees report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the Trustees report and from the requirement to prepare a strategic report.

#### **Responsibilities of Trustees**

As explained more fully in the statement of Trustees responsibilities, the Trustees, who are also the directors of the Charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

#### **Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT (CONTINUED)

### TO THE TRUSTEES OF HUNTINGTON'S DISEASE ASSOCIATION

---

#### **Capability of the audit in detecting irregularities, including fraud**

Based on our discussions with the charity's management and the Trustees, we identified that the following laws and regulations are significant to the entity:

- Those laws and regulations considered to have a direct effect on the financial statements include UK financial reporting standards and Charity Law.
- Those laws and regulations for which non-compliance may be fundamental to the operating aspects of the charity and therefore may have a material effect on the financial statements include compliance with the charitable objectives, public benefit, fundraising regulations, safeguarding and health and safety legislation.

These matters were discussed amongst the engagement team at the planning stage and the team remained alert to non-compliance throughout the audit.

Audit procedures undertaken in response to the potential risks relating to irregularities (which include fraud and non-compliance with laws and regulations) comprised of: inquiries of management and the Trustees as to whether the entity complies with such laws and regulations; enquiries with the same concerning any actual or potential litigation or claims; inspection of relevant legal correspondence; review of Trustee meeting minutes; testing the appropriateness of journal entries; and the performance of analytical review to identify unexpected movements in account balances which may be indicative of fraud.

No instances of material non-compliance were identified. However, the likelihood of detecting irregularities, including fraud, is limited by the inherent difficulty in detecting irregularities, the effectiveness of the entity's controls, and the nature, timing and extent of the audit procedures performed. Irregularities that result from fraud might be inherently more difficult to detect than irregularities that result from error. As explained above, there is an unavoidable risk that material misstatements may not be detected, even though the audit has been planned and performed in accordance with ISAs (UK).

A further description of our responsibilities is available on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

#### **Use of our report**

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

**Andrew Moss BA FCA (Senior Statutory Auditor)**  
for and on behalf of DSG

27 September 2021

**Chartered Accountants**  
**Statutory Auditor**

Castle Chambers  
43 Castle Street  
Liverpool  
L2 9TL

# HUNTINGTON'S DISEASE ASSOCIATION

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2021

		Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 2020 £
	<b>Notes</b>						
<b>Income and endowments from:</b>							
Donations and legacies	2	1,290,255	13,436	1,303,691	1,151,744	38,828	1,190,572
Charitable activities	3	140,633	399,134	539,767	91,930	373,938	465,868
Other trading activities	4	17,510	-	17,510	10,258	-	10,258
Investments	5	12,266	-	12,266	12,385	-	12,385
Other income	6	6,935	-	6,935	2,035	-	2,035
<b>Total income</b>		<b>1,467,599</b>	<b>412,570</b>	<b>1,880,169</b>	<b>1,268,352</b>	<b>412,766</b>	<b>1,681,118</b>
<b>Expenditure on:</b>							
Raising funds	7	182,804	-	182,804	177,950	-	177,950
Charitable activities	8	732,685	385,825	1,118,510	993,538	409,621	1,403,159
<b>Total resources expended</b>		<b>915,489</b>	<b>385,825</b>	<b>1,301,314</b>	<b>1,171,488</b>	<b>409,621</b>	<b>1,581,109</b>
Net gains/(losses) on investments	12	77,920	-	77,920	(38,626)	-	(38,626)
Gross transfers between funds		-	-	-	(3,295)	3,295	-
<b>Net movement in funds</b>		<b>630,030</b>	<b>26,745</b>	<b>656,775</b>	<b>54,943</b>	<b>6,440</b>	<b>61,383</b>
Fund balances at 1 April 2020		1,059,995	29,137	1,089,132	1,005,052	22,697	1,027,749
<b>Fund balances at 31 March 2021</b>		<b>1,690,025</b>	<b>55,882</b>	<b>1,745,907</b>	<b>1,059,995</b>	<b>29,137</b>	<b>1,089,132</b>

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

# HUNTINGTON'S DISEASE ASSOCIATION

## BALANCE SHEET

AS AT 31 MARCH 2021

	Notes	2021		2020	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	13		4,619		9,317
Investments	14		452,747		374,827
			<u>457,366</u>		<u>384,144</u>
<b>Current assets</b>					
Stocks	16	9,559		5,891	
Debtors	15	383,726		271,334	
Cash at bank and in hand		1,000,111		579,341	
		<u>1,393,396</u>		<u>856,566</u>	
<b>Creditors: amounts falling due within one year</b>	17	(104,855)		(136,060)	
Net current assets			<u>1,288,541</u>		<u>720,506</u>
<b>Total assets less current liabilities</b>			<u>1,745,907</u>		<u>1,104,650</u>
<b>Creditors: amounts falling due after more than one year</b>	18		-		(15,518)
<b>Net assets</b>			<u><u>1,745,907</u></u>		<u><u>1,089,132</u></u>
<b>Income funds</b>					
Restricted funds	20		55,882		29,137
<u>Unrestricted funds</u>					
Designated funds	21	286,265		308,081	
General unrestricted funds		1,403,760		751,914	
			<u>1,690,025</u>		<u>1,059,995</u>
			<u><u>1,745,907</u></u>		<u><u>1,089,132</u></u>

The financial statements were approved by the Trustees on 27 September 2021

Mr N M Heath (Hon Treasurer)  
Trustee

Professor H Rickards (Chair)  
Trustee

Company Registration No. 02021975

# HUNTINGTON'S DISEASE ASSOCIATION

## STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2021

---

	Notes	2021 £	£	2020 £	£
<b>Cash flows from operating activities</b>					
Cash generated from operations	27		408,504		160,881
<b>Investing activities</b>					
Purchase of tangible fixed assets		-		(5,340)	
Purchase of investments		-		(75,000)	
Investment income received		12,266		12,385	
<b>Net cash generated from/(used in) investing activities</b>			12,266		(67,955)
<b>Net cash used in financing activities</b>			-		-
<b>Net increase in cash and cash equivalents</b>			420,770		92,926
Cash and cash equivalents at beginning of year			579,341		486,415
<b>Cash and cash equivalents at end of year</b>			1,000,111		579,341

---

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS

**FOR THE YEAR ENDED 31 MARCH 2021**

---

### 1 Accounting policies

#### Charity information

Huntington's Disease Association is a private company limited by guarantee incorporated in England and Wales. The registered office is Suite 24 Liverpool Science Park, Innovation Centre, 131 Mount Pleasant, Liverpool, L3 5TF.

#### 1.1 Accounting convention

The financial statements have been prepared in accordance with the Charity's Memorandum and Articles of Association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)". The Charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention except for the revaluation of fixed asset investments in accordance with the Charities SORP.

#### 1.2 Going concern

The Trustees have reviewed the effect of the Coronavirus pandemic which has had an impact on fundraising streams and the costs of delivering services.

At the time of approving the accounts the Trustees consider that the charity has adequate reserves and diverse revenue streams to continue in operational existence for the foreseeable future taking account of economic uncertainties caused by the pandemic. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the accounts.

#### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Designated funds comprise funds which have been set aside at the discretion of the Trustees for specific purposes. The purposes and uses of the designated funds are set out in the notes to the accounts.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the accounts.

#### 1.4 Income

Income is recognised when the Charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Investment income consists of interest and dividends received and receivable.

Cash donations are recognised on receipt. Other donations are recognised once the Charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the Charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is disclosed as a contingent asset.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

---

### 1 Accounting policies

(Continued)

Deferred income represents grants received in advance of the expenditure to which it is allocated to support.

#### 1.5 Expenditure

All expenditure has been accounted for on an accruals basis and includes irrecoverable VAT where applicable. Expenditure is allocated to relevant activity categories on a basis that is consistent with the use of that resource. Support costs have been attributable to charitable activity in accordance with best estimates.

Research grants are made each year after approval and recommendation by the Medical Advisory Panel. The amount charged to the profit and loss account represents the cost of projects approved during the year.

#### 1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% straight line
-----------------------	-------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year..

#### 1.7 Fixed asset investments

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

#### 1.8 Impairment of fixed assets

At each reporting end date, the Charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

#### 1.9 Stocks

Stocks are valued at the lower of cost or net realisable value after making due allowance for obsolete and slow-moving items. Cost is calculated using the first-in first-out basis of valuation.

Net realisable value is the estimated selling price less all estimated costs of completion and costs to be incurred in marketing, selling and distribution.

#### 1.10 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

#### 1 Accounting policies

(Continued)

##### 1.11 Financial instruments

The Charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the Charity's balance sheet when the Charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

##### **Basic financial assets**

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

##### **Impairment of financial assets**

Financial assets, other than those held at fair value through income and expenditure, are assessed for indicators of impairment at each reporting date. Financial assets are impaired where there is objective evidence that, as a result of one or more events that occurred after the initial recognition of the financial asset, the estimated future cash flows have been affected.

If an asset is impaired, the impairment loss is the difference between the carrying amount and the present value of the estimated cash flows discounted at the asset's original effective interest rate. The impairment loss is recognised in net income/(expenditure) for the year.

If there is a decrease in the impairment loss arising from an event occurring after the impairment was recognised, the impairment is reversed. The reversal is such that the current carrying amount does not exceed what the carrying amount would have been, had the impairment not previously been recognised. The impairment reversal is recognised in net income/(expenditure) for the year.

##### **Derecognition of financial assets**

Financial assets are derecognised only when the contractual rights to the cash flows from the asset expire or are settled, or when the Charity transfers the financial asset and substantially all the risks and rewards of ownership to another entity, or if some significant risks and rewards of ownership are retained but control of the asset has transferred to another party that is able to sell the asset in its entirety to an unrelated third party.

##### **Basic financial liabilities**

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 1 Accounting policies

(Continued)

#### *Derecognition of financial liabilities*

Financial liabilities are derecognised when the Charity's contractual obligations expire or are discharged or cancelled.

#### 1.12 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the Charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

#### 1.13 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

#### 1.14 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

#### 1.15 Branch funds

The funds of the Association's branches have been consolidated in the accounts.

### 2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2021	2021	2021	2020	2020	2020
	£	£	£	£	£	£
Donations and gifts	727,805	13,436	741,241	804,671	26,272	830,943
Legacies receivable	364,922	-	364,922	254,495	3,305	257,800
Grants	171,450	-	171,450	-	-	-
Other	26,078	-	26,078	92,578	9,251	101,829
	<u>1,290,255</u>	<u>13,436</u>	<u>1,303,691</u>	<u>1,151,744</u>	<u>38,828</u>	<u>1,190,572</u>
<b>Donations and gifts</b>						
Community Fundraising	226,038	-	226,038	554,853	6,222	561,075
Other	501,767	13,436	515,203	249,818	20,050	269,868
	<u>727,805</u>	<u>13,436</u>	<u>741,241</u>	<u>804,671</u>	<u>26,272</u>	<u>830,943</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 2 Donations and legacies

(Continued)

#### Grants

Coronavirus Job Retention Scheme	161,450	-	161,450	-	-	-
Coronavirus Discretionary Grant	10,000	-	10,000	-	-	-
	<u>171,450</u>	<u>-</u>	<u>171,450</u>	<u>-</u>	<u>-</u>	<u>-</u>

### 3 Charitable activities

	2021 £	2020 £
Grants received	525,292	423,438
Merchandise	13,877	10,901
Other income	598	31,529
	<u>539,767</u>	<u>465,868</u>
Analysis by fund		
Unrestricted funds	140,633	91,930
Restricted funds	399,134	373,938
	<u>539,767</u>	<u>465,868</u>

### 4 Other trading activities

	Unrestricted funds 2021 £	Unrestricted funds 2020 £
Raffle and sponsorship	-	308
Company sponsorships	-	9,950
Consultancy	17,510	-
	<u>17,510</u>	<u>10,258</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 5 Investments

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	£	£
Income from listed investments	11,819	10,896
Interest receivable	447	1,489
	<u>12,266</u>	<u>12,385</u>

### 6 Other income

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	£	£
Miscellaneous income	6,935	2,035
	<u>6,935</u>	<u>2,035</u>

### 7 Raising funds

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	£	£
<u>Fundraising and publicity</u>		
Fundraising events	9,349	16,775
Other fundraising costs	25,608	20,050
Staff costs	147,847	141,125
	<u>182,804</u>	<u>177,950</u>
Fundraising and publicity	182,804	177,950
	<u>182,804</u>	<u>177,950</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 8 Charitable activities

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication	Youth Worker & Juvenile	Branch	Total 2021	Total 2020
	£	£	£	£	£	£	£	£
Staff costs	691,877	691	691	46,753	43,735	10,000	793,747	872,441
Welfare grants	-	18,521	-	-	-	-	18,521	38,608
Research	-	-	144	-	-	-	144	11,998
Juvenile	-	-	-	-	-	-	-	2,816
Branch activities	-	-	-	-	-	3,953	3,953	48,324
Travel and training	1,278	-	-	27	605	-	1,910	71,919
Camps, conferences and AGM	-	-	-	-	-	-	-	36,894
Telephone and internet	24,074	-	-	440	525	-	25,039	25,625
Other costs	12,866	24	24	15,828	5,089	-	33,831	35,672
Newsletter	-	-	-	6,391	-	-	6,391	9,453
Publications and merchandise	-	-	-	-	-	-	-	9,066
Event costs	4,211	-	-	-	3,621	-	7,832	-
	<u>734,306</u>	<u>19,236</u>	<u>859</u>	<u>69,439</u>	<u>53,575</u>	<u>13,953</u>	<u>891,368</u>	<u>1,162,816</u>
Share of support costs (see note 9)	120,627	10,967	-	26,320	17,547	43,865	219,326	228,860
Share of governance costs (see note 9)	7,816	-	-	-	-	-	7,816	11,483
	<u>862,749</u>	<u>30,203</u>	<u>859</u>	<u>95,759</u>	<u>71,122</u>	<u>57,818</u>	<u>1,118,510</u>	<u>1,403,159</u>

Expenditure on charitable activities was £1,118,510 (2020: £1,403,159) of which £732,685 (2020: £993,538) was unrestricted and £385,825 (2020: £409,621) was restricted.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 8 Charitable activities

(Continued)

For the year ended 31 March 2020

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication	Youth Worker & Juvenile	Branch	Total 2020
	£	£	£	£	£	£	£
Staff costs	758,251	688	688	46,010	56,804	10,000	872,441
Welfare grants	-	38,608	-	-	-	-	38,608
Research	-	-	11,998	-	-	-	11,998
Juvenile	-	-	-	-	2,816	-	2,816
Branch activities	-	-	-	-	-	48,324	48,324
Travel and training	61,530	-	-	374	10,015	-	71,919
Camps, conferences and AGM	16,612	-	-	-	20,282	-	36,894
Telephone and internet	24,215	-	-	329	1,081	-	25,625
Other costs	29,126	60	60	3,948	1,041	1,437	35,672
Newsletter	-	-	-	9,453	-	-	9,453
Publications and merchandise	-	-	-	9,066	-	-	9,066
	<u>889,734</u>	<u>39,356</u>	<u>12,746</u>	<u>69,180</u>	<u>92,039</u>	<u>59,761</u>	<u>1,162,816</u>
Share of support costs (see note 9)	137,316	11,443	-	16,020	16,020	48,061	228,860
Share of governance costs (see note 9)	11,483	-	-	-	-	-	11,483
	<u><u>1,038,533</u></u>	<u><u>50,799</u></u>	<u><u>12,746</u></u>	<u><u>85,200</u></u>	<u><u>108,059</u></u>	<u><u>107,822</u></u>	<u><u>1,403,159</u></u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 9 Support costs

	Support costs £	Governance costs £	2021 £	Support costs £	Governance costs £	2020 £
Staff costs	89,189	-	89,189	89,352	-	89,352
Depreciation	4,698	-	4,698	4,062	-	4,062
Head office costs	125,439	-	125,439	135,446	-	135,446
Audit fees	-	7,750	7,750	-	7,608	7,608
EC meeting costs	-	66	66	-	3,875	3,875
	<u>219,326</u>	<u>7,816</u>	<u>227,142</u>	<u>228,860</u>	<u>11,483</u>	<u>240,343</u>
Analysed between Charitable activities	<u>219,326</u>	<u>7,816</u>	<u>227,142</u>	<u>228,860</u>	<u>11,483</u>	<u>240,343</u>

### 10 Employees

The average monthly number of employees during the year was:

	2021 Number	2020 Number
Specialist HD Advisors	21	21
Management	1	2
Fundraising	5	3
Youth Worker	1	2
Administration	4	5
Communications	1	1
Total	<u>33</u>	<u>34</u>

#### Employment costs

	2021 £	2020 £
Wages and salaries	940,269	1,004,671
Social security costs	67,878	75,173
Other pension costs	22,636	23,074
	<u>1,030,783</u>	<u>1,102,918</u>

The number of employees whose annual remuneration was £60,000 or more were:

	2021 Number	2020 Number
£60,000 - £69,999	<u>1</u>	<u>-</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

---

### 11 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the Charity during the year.

### 12 Net gains/(losses) on investments

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	£	£
Revaluation of investments	77,920	(38,626)
	<u>77,920</u>	<u>(38,626)</u>

### 13 Tangible fixed assets

	<b>Fixtures and fittings</b>
	£
<b>Cost</b>	
At 1 April 2020	73,458
	<u>73,458</u>
At 31 March 2021	73,458
	<u>73,458</u>
<b>Depreciation and impairment</b>	
At 1 April 2020	64,141
Depreciation charged in the year	4,698
	<u>68,839</u>
At 31 March 2021	68,839
	<u>68,839</u>
<b>Carrying amount</b>	
At 31 March 2021	4,619
	<u>4,619</u>
At 31 March 2020	9,317
	<u>9,317</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 14 Fixed asset investments

	Listed investments £
<b>Cost or valuation</b>	
At 1 April 2020	374,827
Valuation changes	77,920
At 31 March 2021	<u>452,747</u>
<b>Carrying amount</b>	
At 31 March 2021	<u>452,747</u>
At 31 March 2020	<u><u>374,827</u></u>

### 15 Debtors

	2021 £	2020 £
<b>Amounts falling due within one year:</b>		
Trade debtors	270	34,572
Other debtors	361,545	205,601
Prepayments and accrued income	21,911	31,161
	<u>383,726</u>	<u>271,334</u>

Other debtors include £304,539 (2020: £154,000) of legacies receivable.

### 16 Stocks

	2021 £	2020 £
Merchandise	9,559	5,891
	<u>9,559</u>	<u>5,891</u>

### 17 Creditors: amounts falling due within one year

	2021 £	2020 £
Other taxation and social security	19,116	24,869
Trade creditors	40,524	26,080
Accruals and deferred income	45,215	85,111
	<u>104,855</u>	<u>136,060</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

---

<b>18 Creditors: amounts falling due after more than one year</b>	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Accruals and deferred income	-	15,518
	<u>          </u>	<u>          </u>

### **19 Retirement benefit schemes**

#### **Defined contribution schemes**

The Charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the Charity in an independently administered fund.

The charge to profit or loss in respect of defined contribution schemes was £22,636 (2020 - £23,074).

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 20 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds				Movement in funds			
	Balance at 1 April 2019 £	Incoming resources £	Resources expended £	Transfers £	Balance at 1 April 2020 £	Incoming resources £	Resources expended £	Balance at 31 March 2021 £
Research	-	8,703	(11,998)	3,295	-	16,844	(144)	16,700
Specialist HD Advisory Service (SHDA)	-	292,955	(292,955)	-	-	334,744	(334,744)	-
Children in Need	-	38,196	(37,351)	-	845	42,133	(38,221)	4,757
Lancashire Training Events	-	-	-	-	-	4,849	-	4,849
JHD Weekend	22,697	19,482	(21,555)	-	20,624	4,000	-	24,624
Publications (Mazars)	-	12,000	(10,500)	-	1,500	-	(1,500)	-
Youth Services	-	20,000	(20,000)	-	-	10,000	(6,952)	3,048
BUPA Old Carers	-	20,930	(14,762)	-	6,168	-	(4,264)	1,904
Events	-	500	(500)	-	-	-	-	-
	<u>22,697</u>	<u>412,766</u>	<u>(409,621)</u>	<u>3,295</u>	<u>29,137</u>	<u>412,570</u>	<u>(385,825)</u>	<u>55,882</u>

#### Research

Research funds are raised to promote medical and social/ therapeutic research of direct significance to Huntington's Disease sufferers and their families. Our Medical Advisory Board reviews all applications on an annual basis before a decision is taken by our Executive Council. Funds were received from individuals, organisations and Branches requesting their donation be spent on this activity.

#### Specialist HD Advisory Service (SHDA)

The network of Specialist HD Advisers was maintained during the year. Restricted funding relating purely to this service and for each geographical area was received from numerous sources in the period.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

*FOR THE YEAR ENDED 31 MARCH 2021*

---

### 20 Restricted funds

(Continued)

#### **Children in Need**

This grant is to fund a youth worker.

#### **Lancashire Training Events**

Money raised towards an awareness/training event in the Fylde Coast area

#### **JHD Weekend**

These relate to individual donations and grants that have been or are to be spent on the JHD weekend.

#### **Publications (Mazars)**

This was an award of £12,000 to update five of our publications

#### **Youth Services**

This relates to Trusts funding received to fund the work of our Youth Worker

#### **Bupa Old Carers**

We were awarded funding by BUPA UK Foundation to create an online area to support older carers aged 65+

#### **Events**

A branch donation with a request that it is to be spent on HDA Events and Activities

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

#### 21 Designated funds

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

	Movement in funds			Movement in funds			Balance at 31 March 2021 £
	Balance at 1 April 2019 £	Incoming resources £	Resources expended £	Balance at 1 April 2020 £	Incoming resources £	Resources expended £	
Special projects fund	214,000	-	-	214,000	-	-	214,000
Branch funds	111,215	101,829	(118,963)	94,081	26,078	(47,894)	72,265
	<u>325,215</u>	<u>101,829</u>	<u>(118,963)</u>	<u>308,081</u>	<u>26,078</u>	<u>(47,894)</u>	<u>286,265</u>

A designated special projects fund of £400,000 was established as a result of generous legacies received during 2013. It is intended that the fund be used for special projects, which, once instituted, may be developed in accordance with the long-term objectives of the charity. During 2015 and 2016 £130,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support. A further £40,000 of the fund was used to support the new communication initiative in 2017/18 and £16,000 was used in 2018/19 to complete the Care Home Accreditation project.

The Trustees have not released any of the designated funds in 2020/21 but anticipate that a re-evaluation in 2021/22 will be required to reflect the impact of the pandemic and research developments on future requirements.

#### 22 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2021 £	2021 £	2021 £	2020 £	2020 £	2020 £
Fund balances at 31 March 2021 are represented by:						
Tangible assets	4,619	-	4,619	9,317	-	9,317
Investments	452,747	-	452,747	374,827	-	374,827
Current assets/ (liabilities)	1,232,659	55,882	1,288,541	691,369	29,137	720,506
Long term liabilities	-	-	-	(15,518)	-	(15,518)
	<u>1,690,025</u>	<u>55,882</u>	<u>1,745,907</u>	<u>1,059,995</u>	<u>29,137</u>	<u>1,089,132</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

---

### 23 Related party transactions

#### Remuneration of key management personnel

The remuneration of key management personnel, which consists of the Chief Executive and the heads of departments, is as shown below.

	2021 £	2020 £
Aggregate compensation	241,187	168,042

#### Transactions with related parties

During the year a donation of £4,625 (2020: £25,000) was received from a Trustee.

### 24 Operating lease commitments

At the reporting end date the Charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2021 £	2020 £
Within one year	17,752	48,129
Between two and five years	10,620	28,655
	<u>28,372</u>	<u>76,784</u>

### 25 Contingent asset

Following the death of the life tenant, the contingent asset has now been recognised.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 26 Branch funds

Reports received from branches are set out below and incorporated into the accounts.

	2021 £	2020 £
Cash balances at 1 April 2020	94,081	111,215
Receipts in year	26,078	101,829
Less :		
Local welfare grants	(12,108)	(27,293)
Sent to head office	(31,833)	(43,346)
Branch activities,local newsletters,equipment,research etc	(3,953)	(48,324)
Cash balances at 31 March 2021	<u>72,265</u>	<u>94,081</u>

### 27 Cash generated from operations

	2021 £	2020 £
Surplus for the year	656,775	61,383
Adjustments for:		
Investment income recognised in statement of financial activities	(12,266)	(12,385)
Fair value gains and losses on investments	(77,920)	38,626
Depreciation and impairment of tangible fixed assets	4,698	4,062
Movements in working capital:		
(Increase) in stocks	(3,668)	(1,087)
(Increase)/decrease in debtors	(112,392)	71,522
(Decrease) in creditors	(46,723)	(1,240)
<b>Cash generated from operations</b>	<u>408,504</u>	<u>160,881</u>

### 28 Analysis of changes in net funds

The Charity had no debt during the year.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

---

#### 29 Acknowledgements

We would like to thank the following grant makers for their support:

BBC Children in Need  
Birmingham City Council  
Bruce Wake Charitable Trust  
Cambridgeshire County Council  
Chapman Charitable Trust  
Charles S French Charitable Trust  
Community Foundation for Merseyside  
Community Foundation Tyne & Wear and Northumberland  
County Durham Community Foundation  
Douglas Arter Foundation  
Funding from Suffolk Community Foundation through the Private Fund - JA  
Liverpool City Council  
Milles Charitable Foundation Limited  
Milton Damerel Trust  
Mr and Mrs J A Pye's Charitable Settlement  
NHS Blackburn with Darwen Clinical Commissioning Group  
NHS Cambridge & Peterborough Clinical Commissioning Group  
NHS Devon Clinical Commissioning Group  
NHS Kernow Clinical Commissioning Group  
NHS Sunderland Clinical Commissioning Group  
P F Charitable Trust  
P H Holt Charitable Trust  
Sir James Knott Trust  
Steve Morgan Foundation  
Tanner Trust  
The Adint Charitable Trust  
The Alan Edward Higgs Charity  
The Ardwick Trust  
The Barbour Foundation  
The Barratt Development PLC Charitable Foundation  
The Benham Charitable Settlement  
The Birmingham District Nursing Charitable Trust  
The Charles Jacob Charitable Trust  
The Chrysalis Trust  
The Clive and Sylvia Richard Charitable Trust  
The Community Foundation for Lancashire  
The Dyers Company Charitable Trust  
The Edgar E Lawley Foundation  
The Edward and Dorothy Cadbury Trust  
The Eleanor Rathbone Charitable Trust  
The Ernest Kleinwort Charitable Trust  
The Eveson Charitable Trust  
The February Foundation  
The Frederick & Phyllis Cann Trust  
The George A. Moore Foundation  
The Goldcrest Charitable Trust  
The Grace Trust  
The Hadrian Trust  
The Hemby Trust  
The Ian Askew Charitable Trust  
The J Reginald Corah Fund

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

**FOR THE YEAR ENDED 31 MARCH 2021**

---

### 29 Acknowledgements

(Continued)

The J.G. Graves Charitable Trust  
The James Tudor Foundation  
The John Avins Trust  
The John James Bristol Foundation  
The Joseph and Annie Cattle Trust  
The Joseph And Lena Randall Charitable Trust  
The Julia and Hans Rausing Trust  
The Lawson Trust  
The Leach Fourteenth Trust  
The London Community Foundation  
The Lord Cozens-Hardy Trust  
The National Lottery Community Fund  
The Neighbourly Community Fund  
The Peter Stebbings Memorial Charity  
The Roger De Haan Charitable Trust  
The Simon And Philip Cohen Charitable Trust  
The Sir James Reckitt Charity  
The Sobell Foundation  
The Sovereign Health Care Charitable Trust  
The Sunrise (Sidmouth) Charitable Trust  
The Sylvia And Colin Shepherd Charitable Trust  
The Thomas Sivewright Catto Charitable Settlement  
The Valentine Charitable Trust  
The Wilfred And Elsie Elkes Charity Fund  
The William Leech Foundation  
The Wixamtree Trust  
Tory Family Foundation

We would also like to thank all supporters who helped the Huntington's Disease Association during the year to bring us closer to our vision - a better life for anyone affected by Huntington's disease.