Huntington's Disease Association

Annual report and financial statements

For the year ended 31 March 2025

Inspired by our community

Charity number
296453

Company number
02021975

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Contents

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

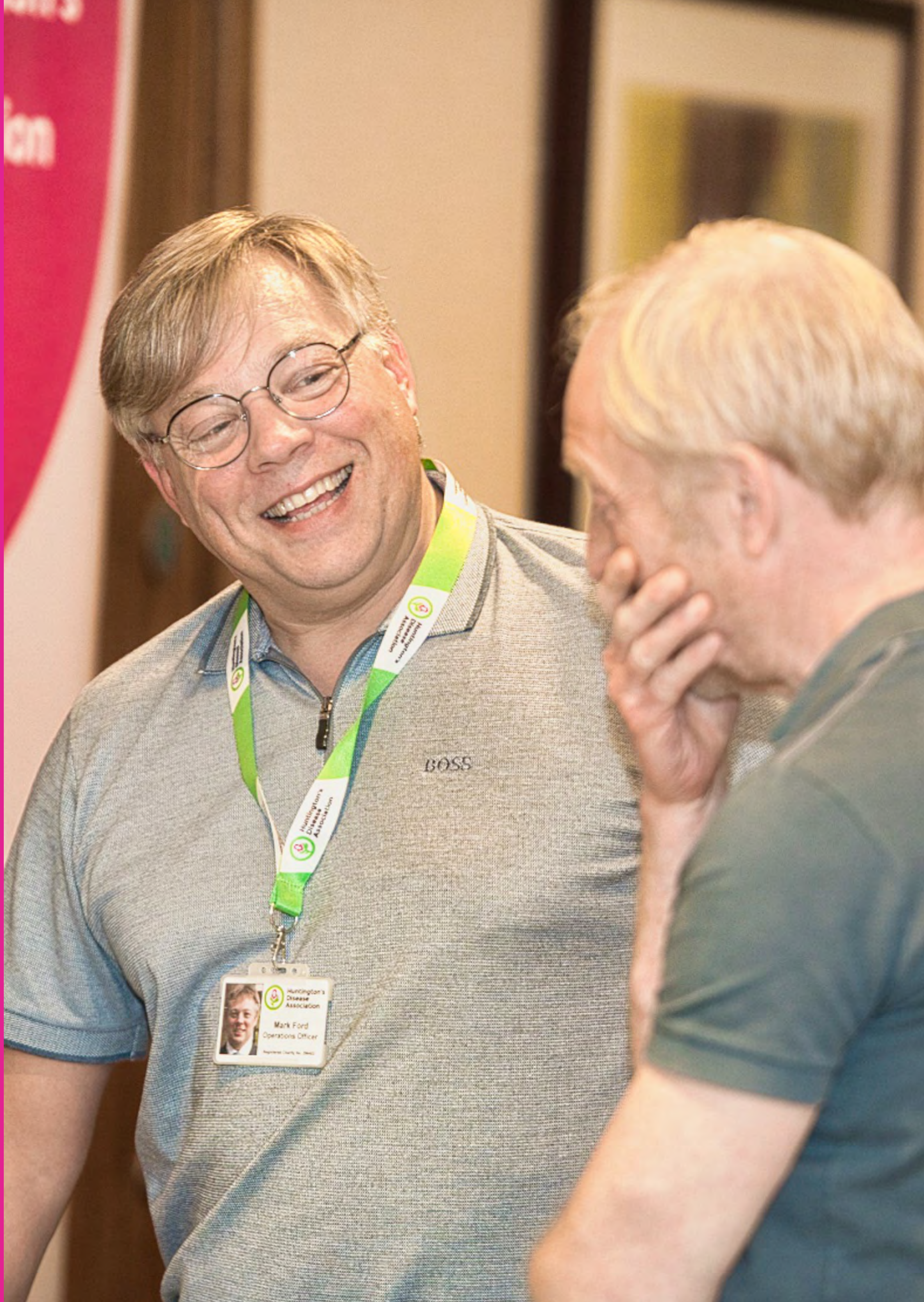
Our values

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

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

10
care homes now accredited through our Quality Assured scheme

3
care homes retained their accreditation

1
care home newly accredited

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
- 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 Advisors 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."*

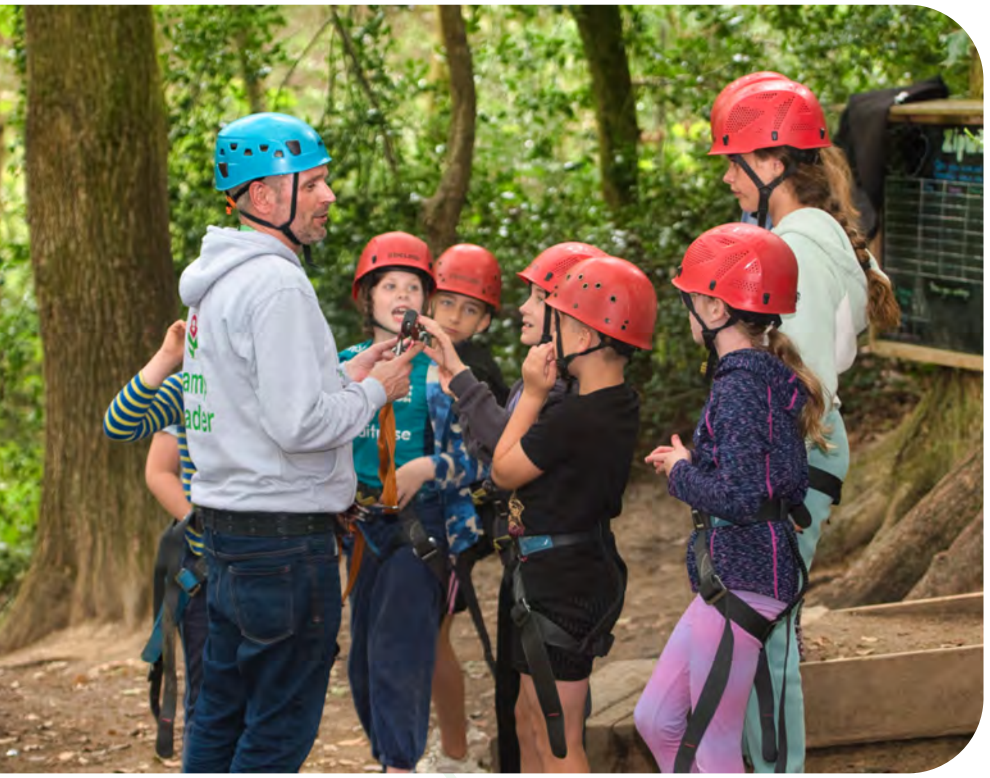
Camilla contacted the Huntington's Disease Association and was put in touch with Charles, one of our Specialist Advisers. *"He was my saviour,"* says Camilla. Charles helped her find an appropriate care home for Lonnie and even delivered training on Huntington's to the care home staff.

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[1]. 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.

Thank you

Thank you for taking 5 minutes to learn about Huntington's disease. Please download your badge which you can use on your social media or email footer. Please share this page with your friends, colleagues and networks so that we can get more people to learn the facts about Huntington's disease.

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.

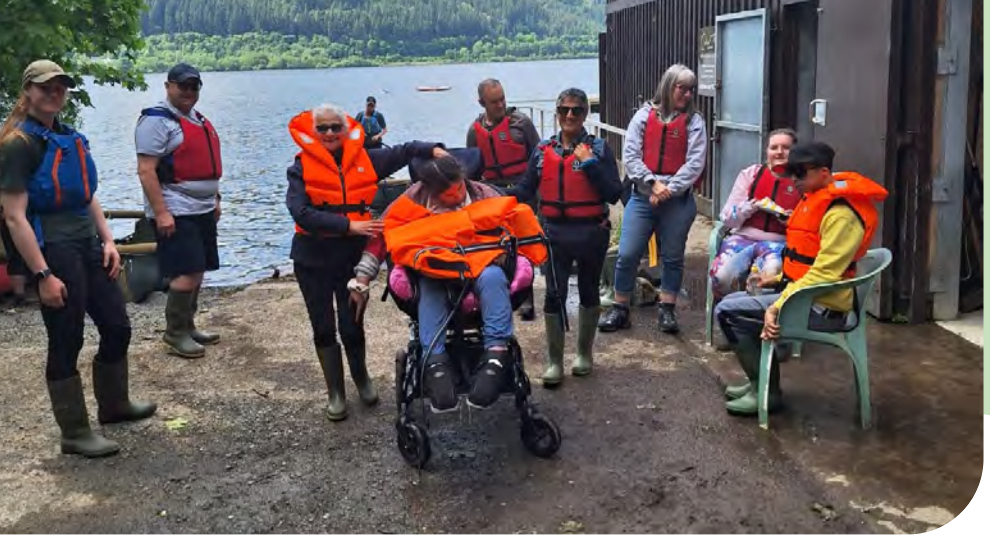
Thank you to our main event sponsors Sage Therapeutics and Wave Life Sciences. We are grateful for their dedication to Huntington's disease research and for helping make this event possible. Thanks also to our other sponsors, UniQure, and Prilenia. Thank you to Roche for their educational grant.

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

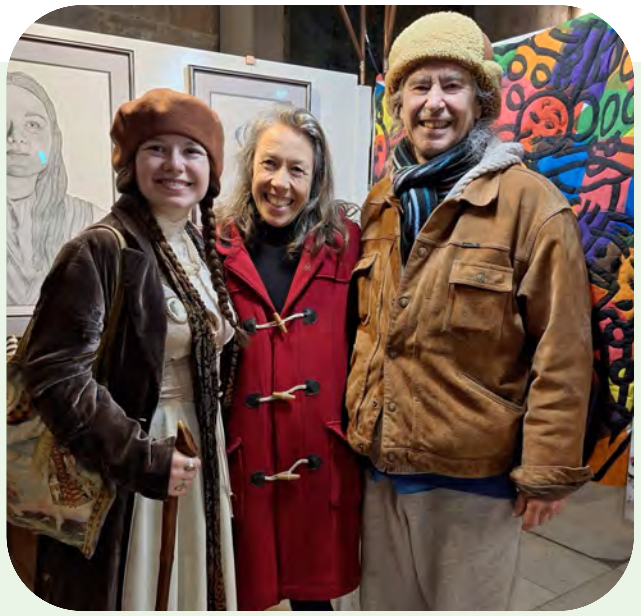
We regularly share information through webinars, which enable us to reach more members of our community and cover subjects of interest. This year, webinar topics included looking after oral hygiene, updates on current research, how to get involved with research through Enroll-HD, understanding genetics, 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.

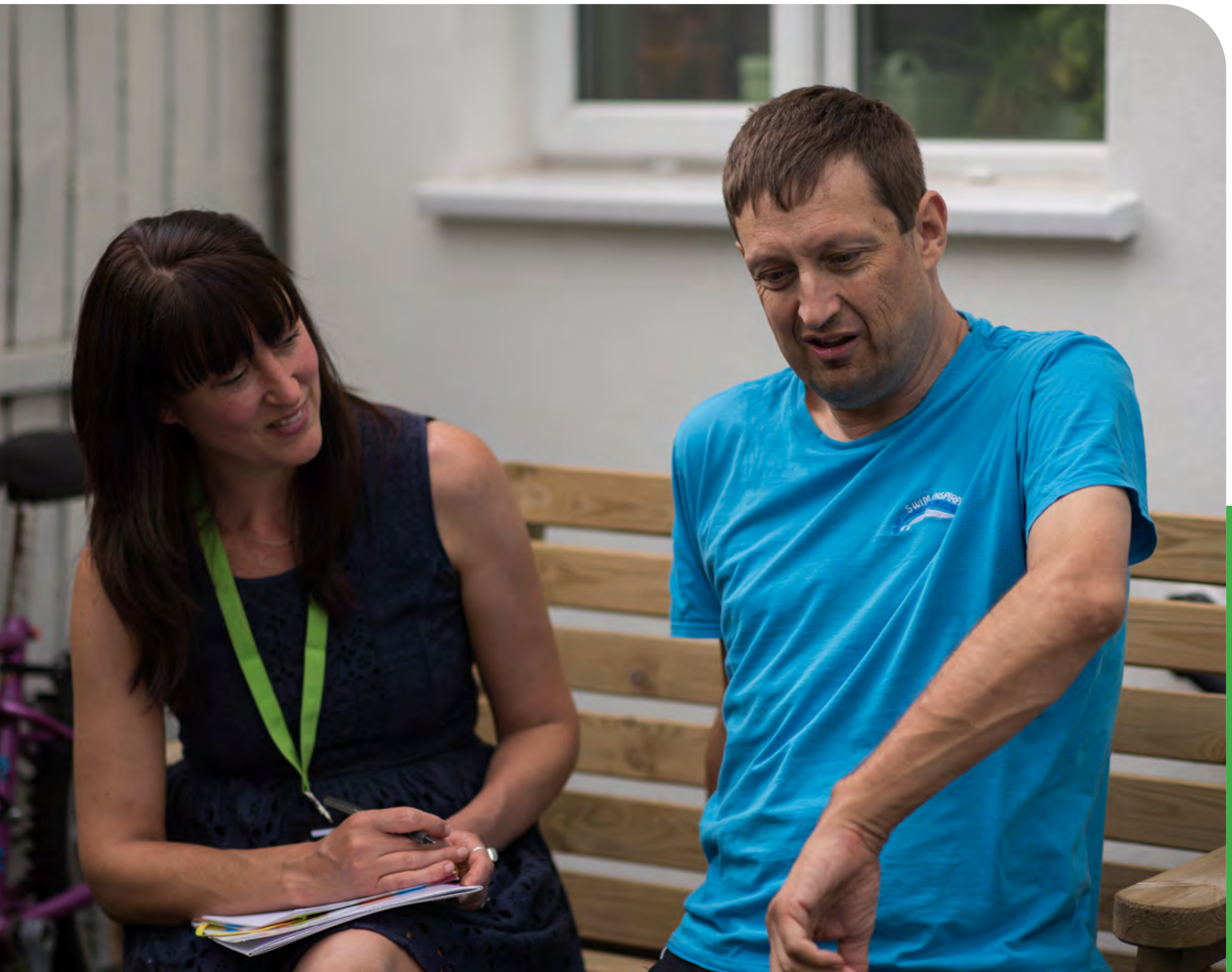


We helped people with the cost of living

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.

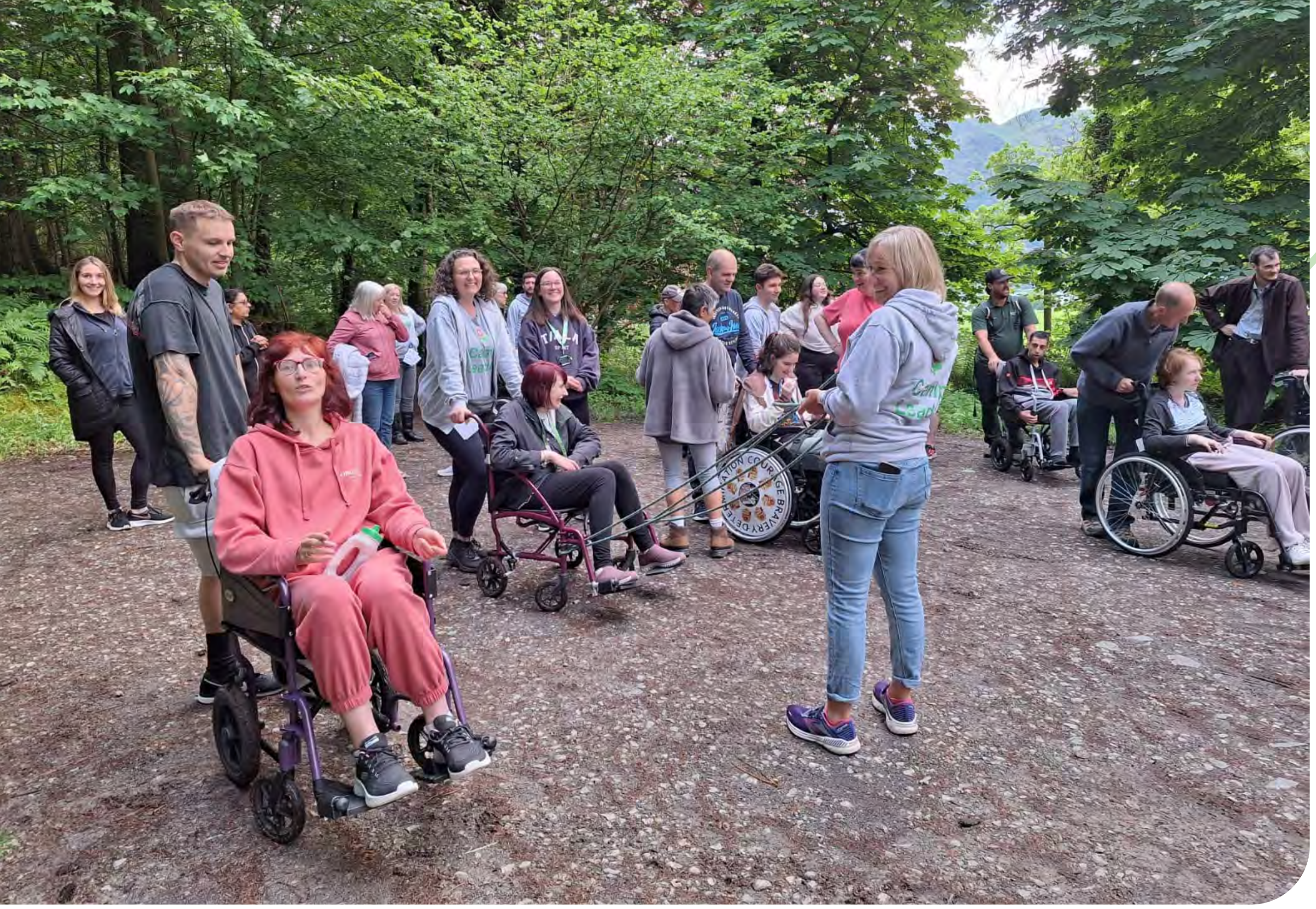
In feedback, 100% of attendees on the Keeping Yourself in Mind course agreed they felt better equipped to deal with the challenges of life with Huntington's disease.

> *"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 partcipant



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

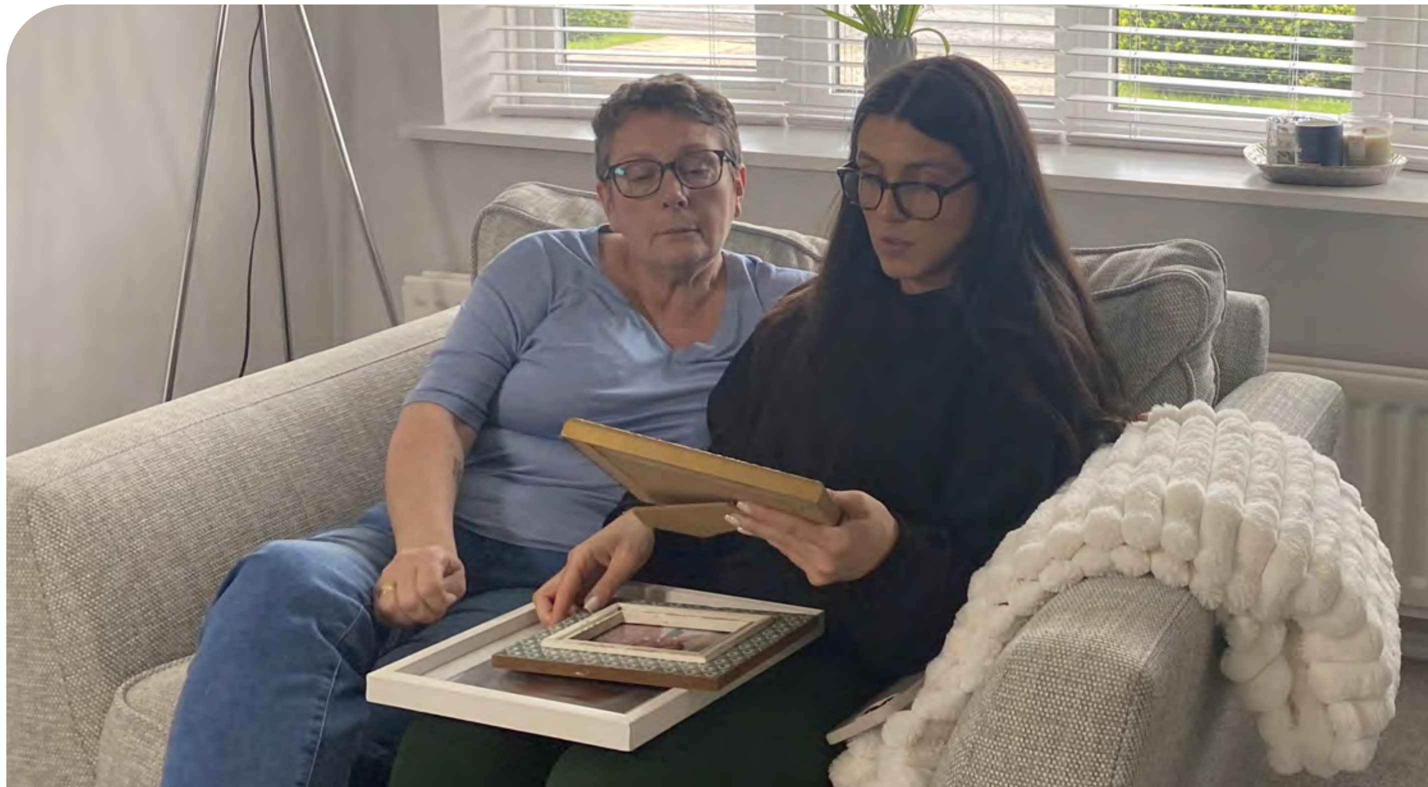
HD Voice is our patient and public involvement group, which gives people affected by Huntington's disease a voice in research and the work we do. There are currently 53 people in the group and many have been involved in activities, ranging from guidance on our surveys and input into new leaflets to advice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

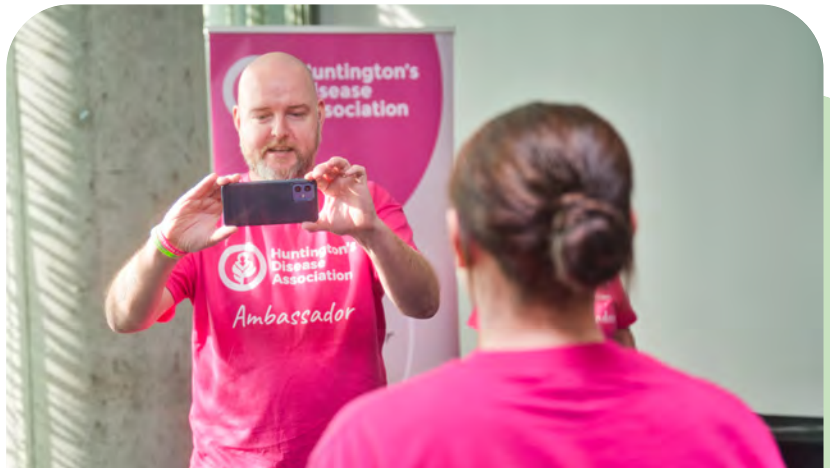
We now have a group of 44 Ambassadors who are willing to share their experience of Huntington's disease with the press and on our platforms. By sharing their stories, they raise awareness of the condition and are able to help others.

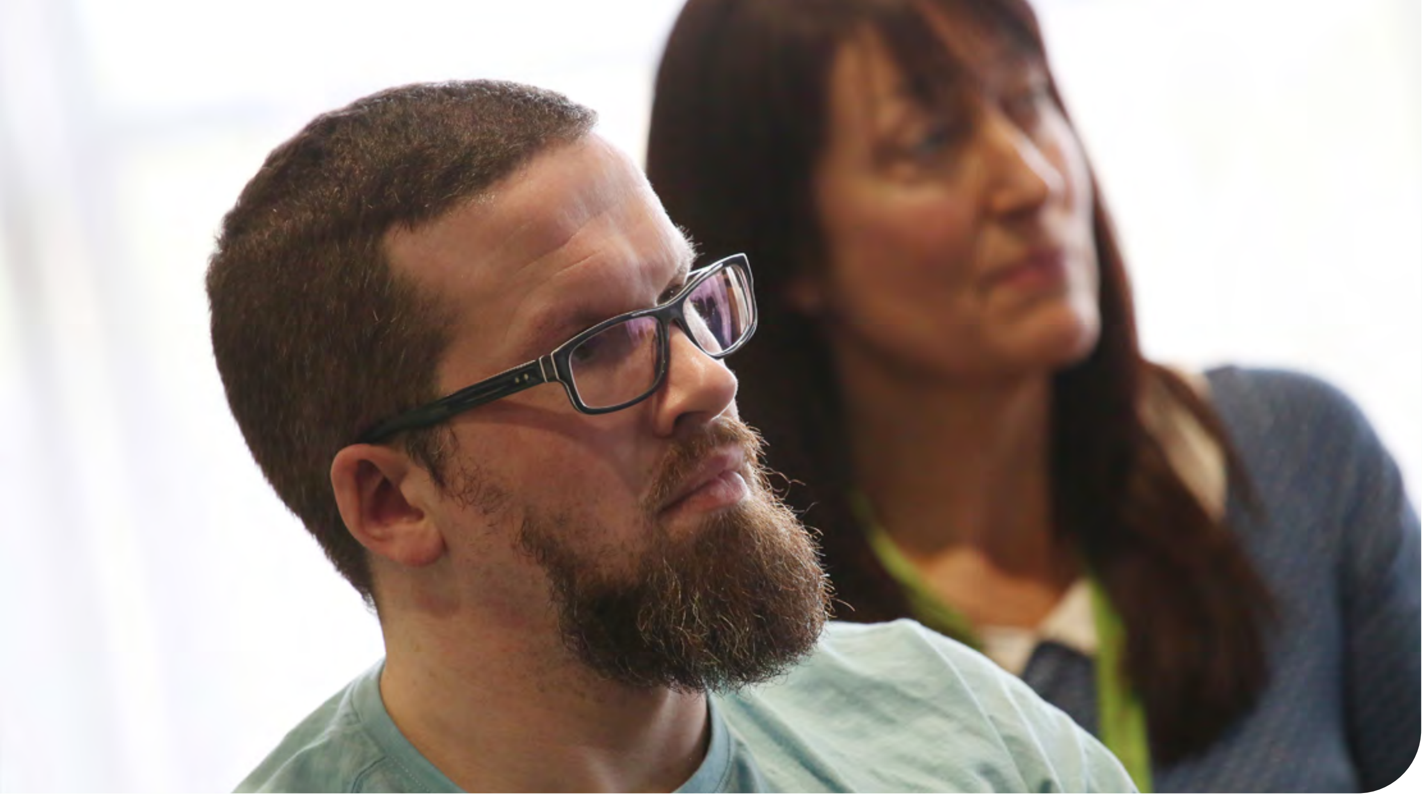
This year, our Ambassadors participated in 41 opportunities to talk about their experiences. This included creating content for blogs, social media stories, and press stories, and being guest speakers at our Community Conference and AGM.

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

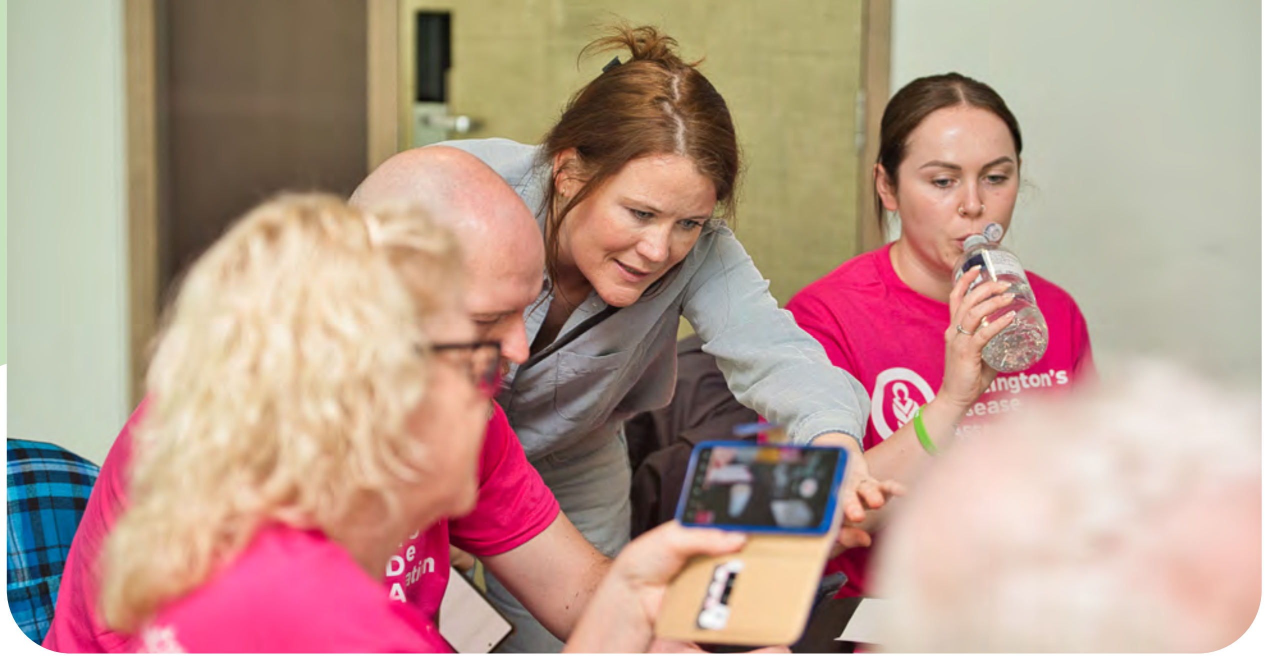
72 professionals attended our Mental Health Study Day, which built on the findings of our mental health report, Unseen and Unheard: The Need to Improve Mental Healthcare for People Living with Huntington's Disease.

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



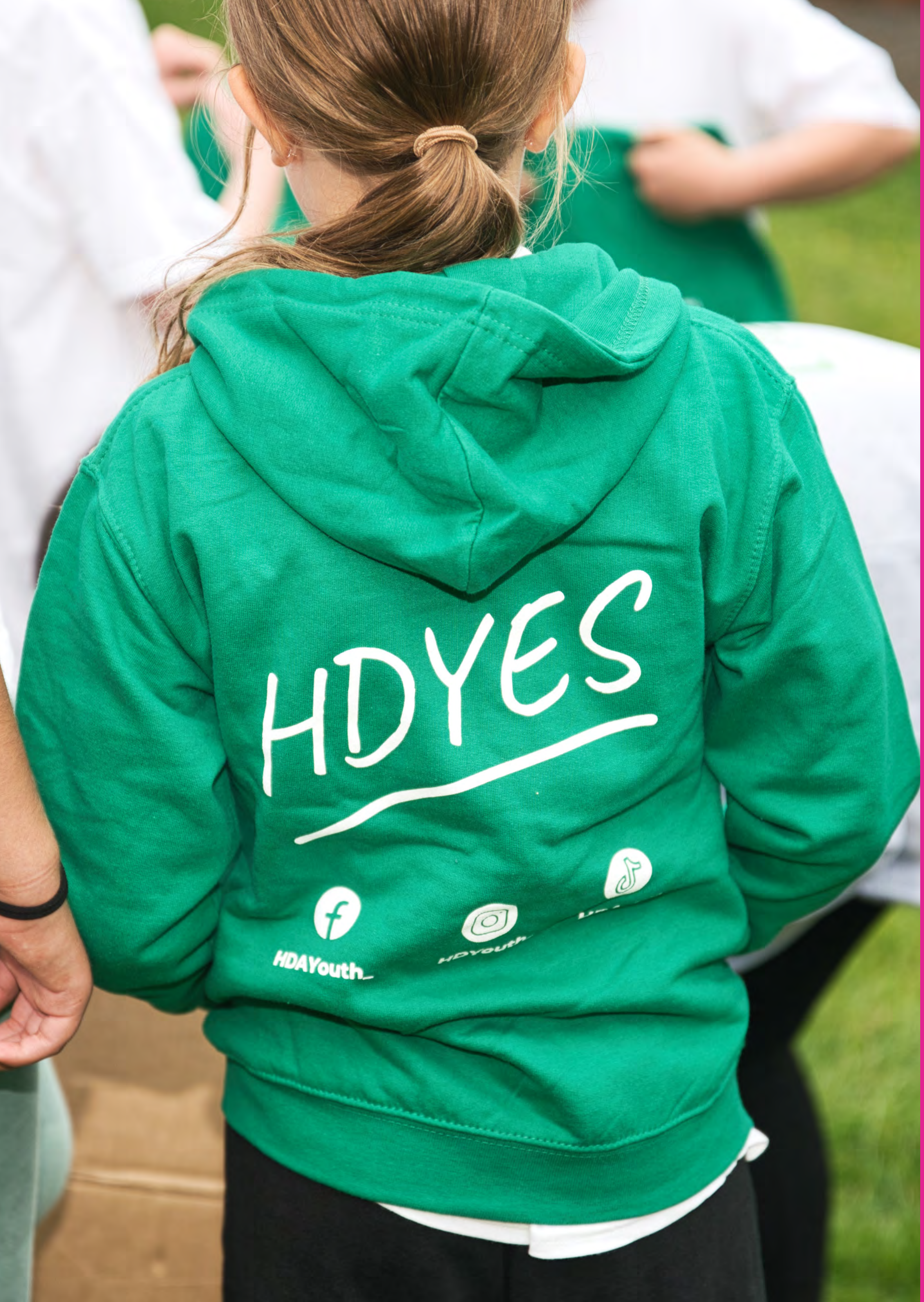
We delivered 19 webinars this year, covering topics such as research, medication, and oral hygiene. We held our first webinar specifically for GPs to help them gain more knowledge about Huntington's disease. The goal was to equip them with the skills and confidence to offer better care to their patients. 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

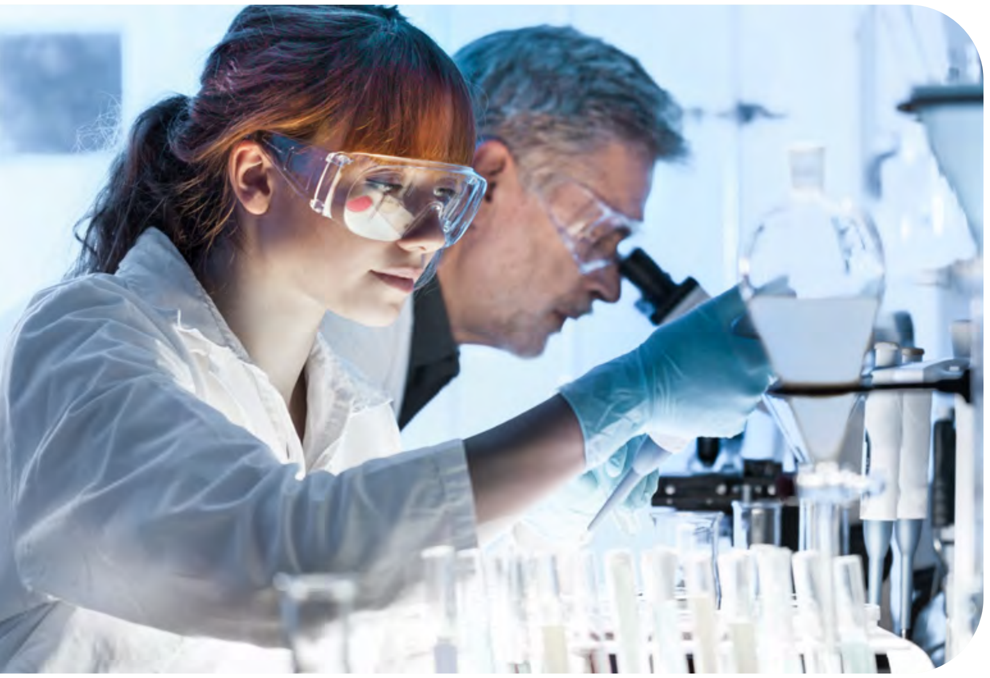
We will not rest until everyone with Huntington's disease has access to treatments.

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

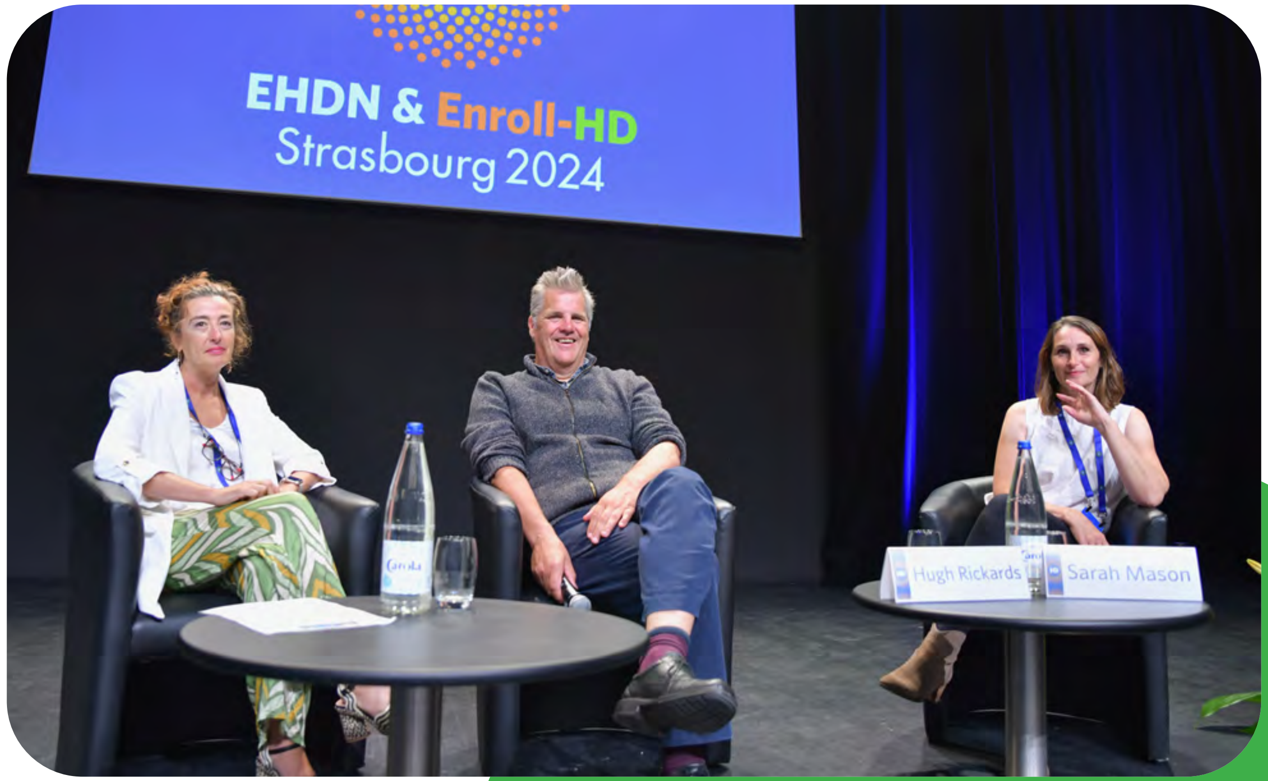


Photo credit: © Gabriele Stautner / artifox.com for EHDN & Enroll-HD

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.

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

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

> "Our early data suggests that people's mental health seems to improve substantially immediately after the course."

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.

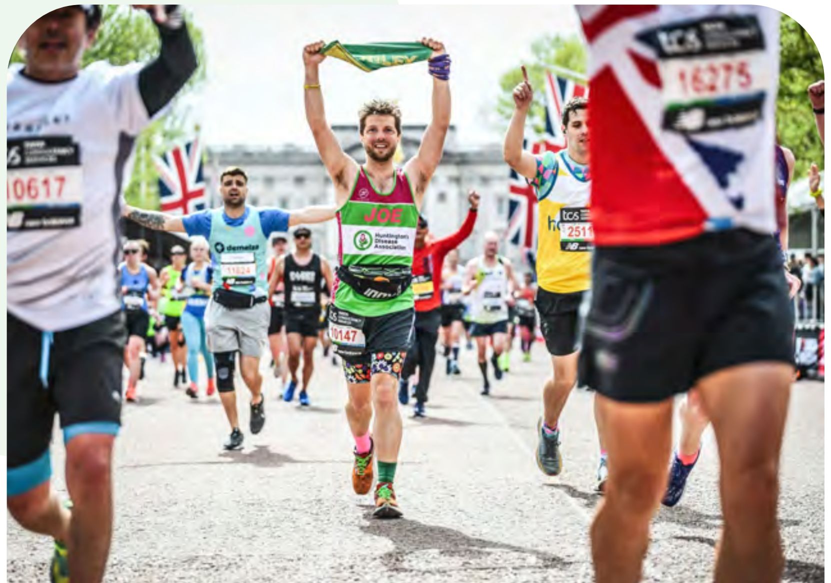
We successfully managed and reported on the first year of our £418,360 three-year grant from The National Lottery Community Fund in support of HDYES, our Youth Engagement Service. This significant funding is making a huge difference to how we support children and young people affected by Huntington's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

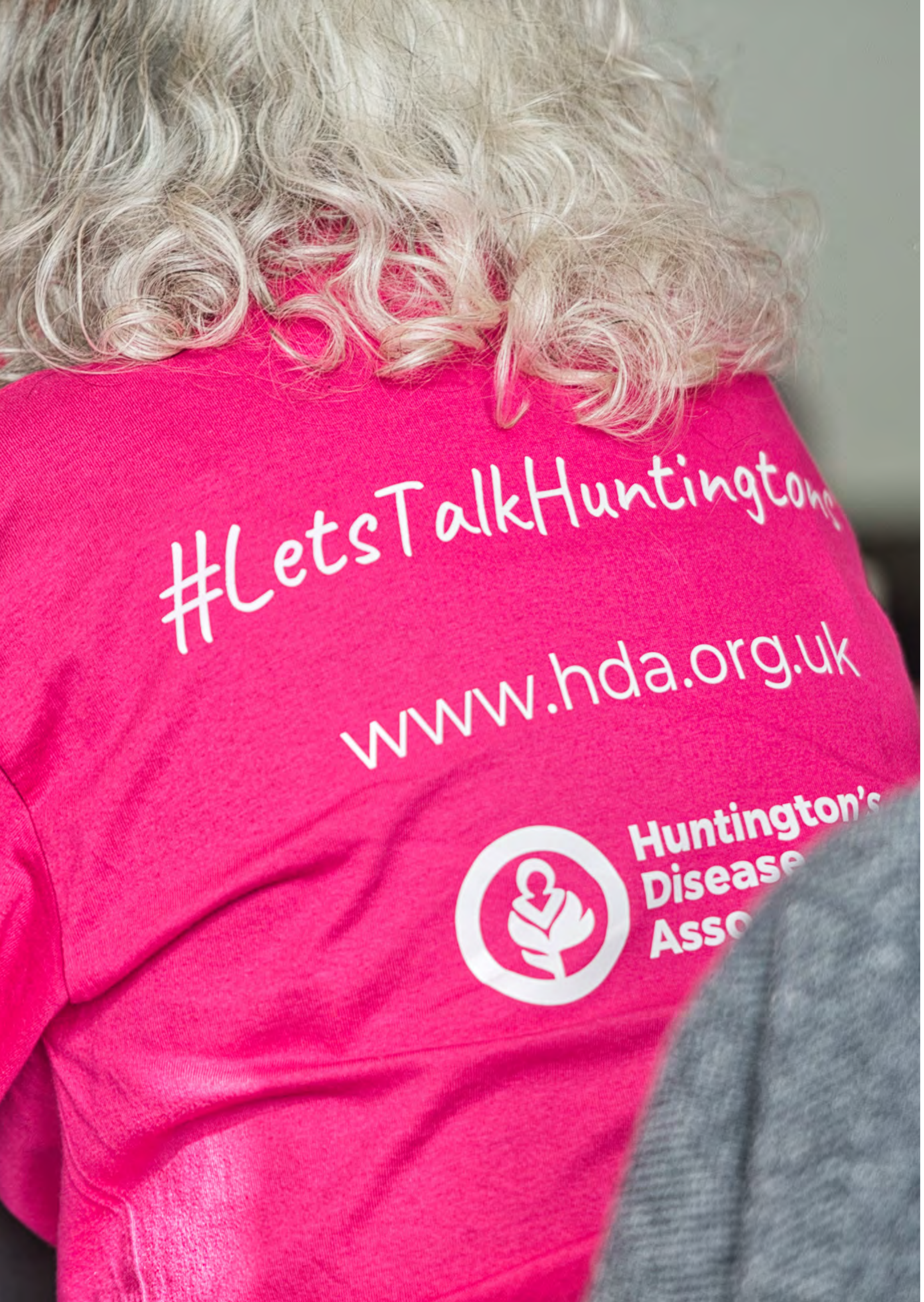
"We were very sad and concerned when we first heard about Dom's diagnosis," says Graham, *"not just for him, but for his family too, as Huntington's is hereditary. Huntington's is one of the forgotten diseases that you don't tend to hear about unless you know somebody who's got it."*

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.

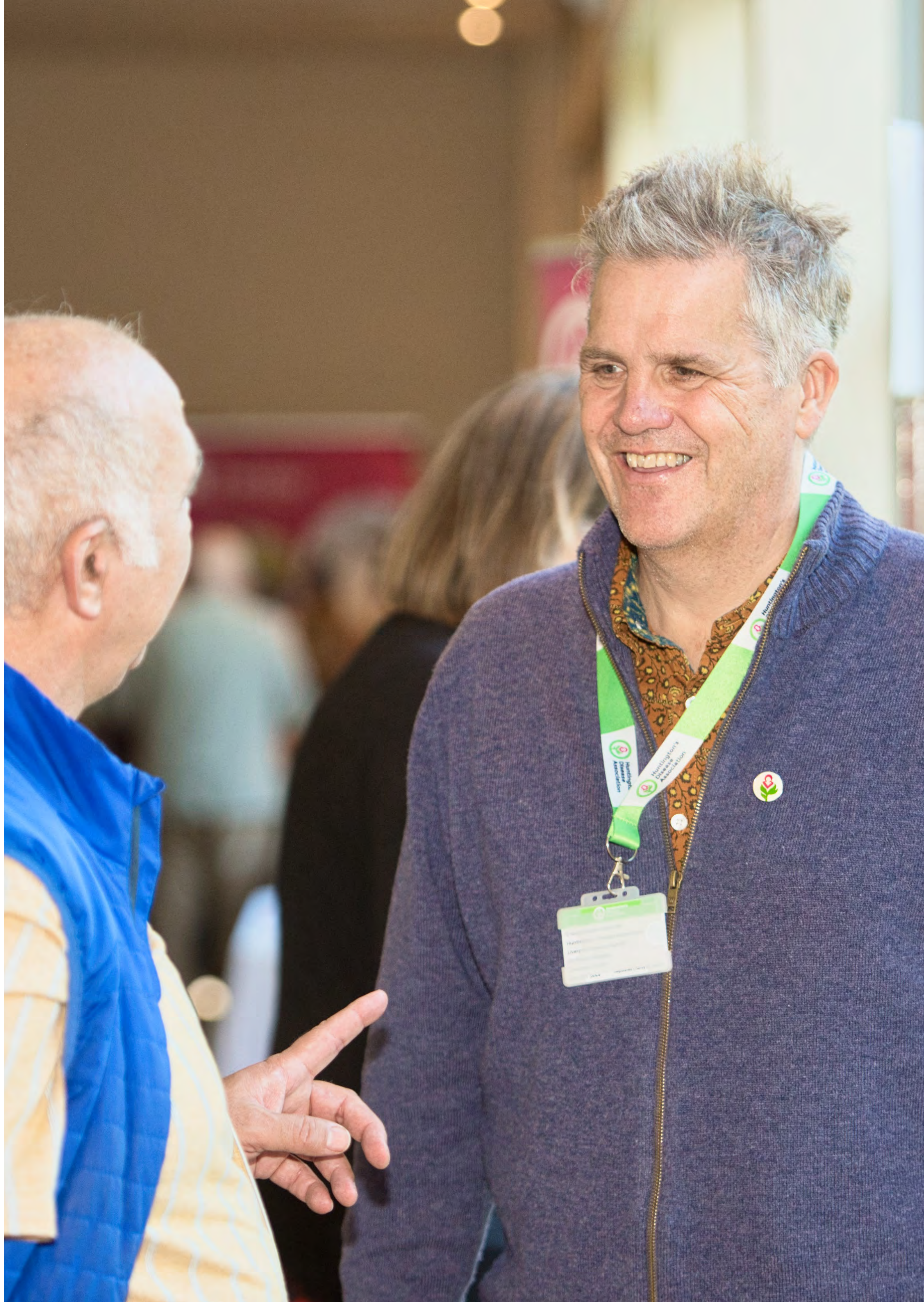
At the year end the restricted funds balance amounted to £158,039 (2024: £149,534). Details are given in note 24 of the specific conditions applicable to these funds. The designated funds which have been set aside for specific purposes were £443,974 (2024: £301,835) and are detailed in note 25 and show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

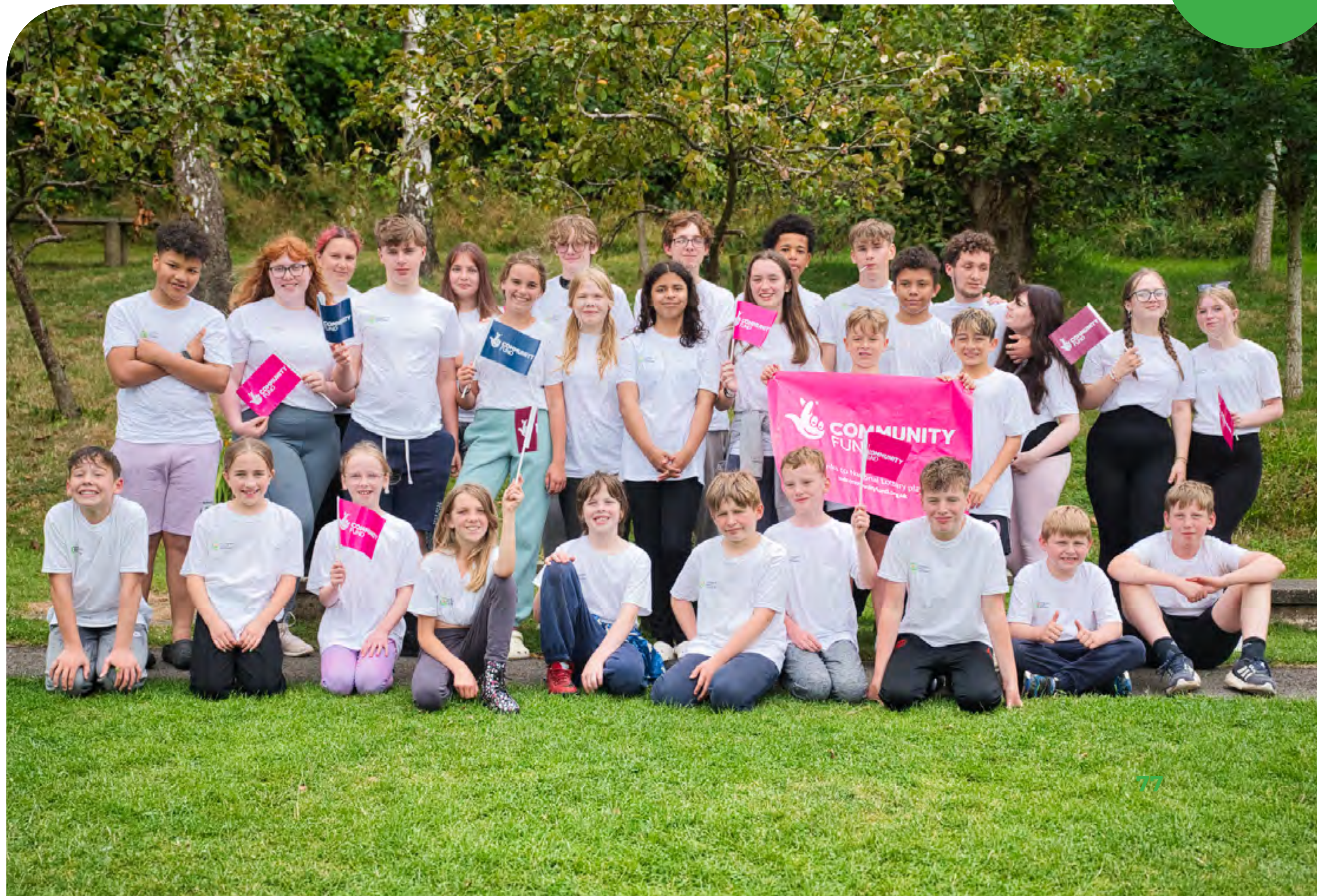
Our 2025 Awareness Month campaign, Behind the Gene will lead with stories from our community. The campaign will highlight the real lives behind Huntington's disease, sharing the invisible challenges and untold stories of people affected by the condition. The campaign includes a factsheet for healthcare 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:

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

DSG resigned as auditor on 11 September 2024. DSG 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.

N.M. Heath

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

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

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

N.M. Heath

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

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
	1,890,663	**92,387**	**1,983,050**	**1,673,330**	**95,106**	**1,768,436**

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
	110,142	**329,279**	**439,421**	**40,404**	**296,735**	**337,139**

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

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

7 Expenditure on raising funds

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

8 Expenditure on charitable activities

	Charitable Expenditure 2025 £	Charitable Expenditure 2024 £
Direct costs		
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
	1,859,614	**1,702,062**
Share of support and governance costs (see note 9)		
Support	523,518	364,039
Governance	11,642	12,691
	2,394,774	**2,078,792**
Analysis by fund		
Unrestricted funds	1,981,613	1,610,508
Restricted funds	413,161	468,284
	2,394,774	**2,078,792**

9 Support costs allocated to activities

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

Support costs are allocated of 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
The average monthly number of employees during the year was:		
Specialist HD Advisors	26	25
Management	1	1
Fundraising	6	5
Youth Worker	5	5
Administration	10	6
Communications	3	3
Total	**51**	**45**

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

	2025 Number	2024 Number
The number of employees whose annual remuneration was more than £60,000 is as follows:		
£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 £
Gains/(losses) arising on:		
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 £
Cost	
At 1 April 2024	60,780
Additions	11,100
Disposals	(19,925)
At 31 March 2025	**51,955**
Depreciation and impairment	
At 1 April 2024	39,066
Depreciation charged in the year	12,294
Eliminated in respect of disposals	(16,472)
At 31 March 2025	**34,888**
Carrying amount	
At 31 March 2025	**17,067**
At 31 March 2024	21,714

17 Fixed asset investments

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

18 Financial instruments

	2025 £	2024 £
Carrying amount of financial assets		
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 £
Amounts falling due within one year:		
Trade debtors	5,249	15,338
Other debtors	639,947	355,844
Prepayments and accrued income	82,983	69,063
	728,179	**440,245**

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
	172,369	**154,772**

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 £
Defined contribution schemes		
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)	-	-	-	-
	225,977	**391,841**	**(468,284)**	**149,534**	**421,666**	**(413,161)**	**158,039**

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 £
Designated funds						
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
General funds	1,891,262	2,110,177	(2,179,982)	(265,813)	(6,870)	1,548,774
	2,193,097	**2,110,177**	**(2,303,656)**	**-**	**(6,870)**	**1,992,748**

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 £
Designated funds						
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
General funds	1,766,722	1,837,132	(1,859,153)	82,145	64,416	1,891,262
	2,158,146	**1,874,976**	**(1,904,441)**	**-**	**64,416**	**2,193,097**

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

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

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	-
	61,265	**70,162**

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 £
Cash balances		
At 1 April 2024	57,558	65,002
Receipts in year	47,840	50,483
Less:		
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	**50,474**	**57,558**

30 Cash generated from operations

	2025 £	2024 £
Deficit for the year	(191,844)	(41,492)
Adjustments for:		
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	
Movements in working capital:		
(Increase)/decrease in stocks	(3,555)	832
(Increase)/decrease in debtors	(287,934)	(49,452)
Increase/(decrease) in creditors	17,597	(83)
Cash absorbed by operations	**(504,272)**	**(218,868)**

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 speak to a Specialist Huntington's Disease Adviser

email **info@hda.org.uk**
phone **0151 331 5444**

www.hda.org.uk

Get involved

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

email **fundraising@hda.org.uk**
phone **0151 331 5445**

Join the conversation

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