Huntington's
Disease
Association

Annual report and financial statements

For the year ended 31 March 2024

Inspired by our community

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Charity number
296453

Company number
02021975

Registered office
Suite 24
Liverpool Science Park
Innovation Centre 1
131 Mount Pleasant
Liverpool
L3 5TF

Auditor
DSG
Castle Chambers
43 Castle Street
Liverpool
L2 9TL

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

Welcome from our Chair and Chief Executive

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

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

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

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

Prof. Hugh Rickards
Chair

Cath Stanley
Chief Executive

Trustees' report

(including Directors' report) for the year ended 31 March 2024

The trustees present their annual report and financial statements for the year ended 31 March 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of Association, the Companies Act 2006 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

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

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

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

Our vision, 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

Our strategy

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

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 currently incurable disease, we help people to make progress against four key outcomes. This year, our evaluation data shows that, because of our support:

93%.
of respondents had a better knowledge and understanding of the disease

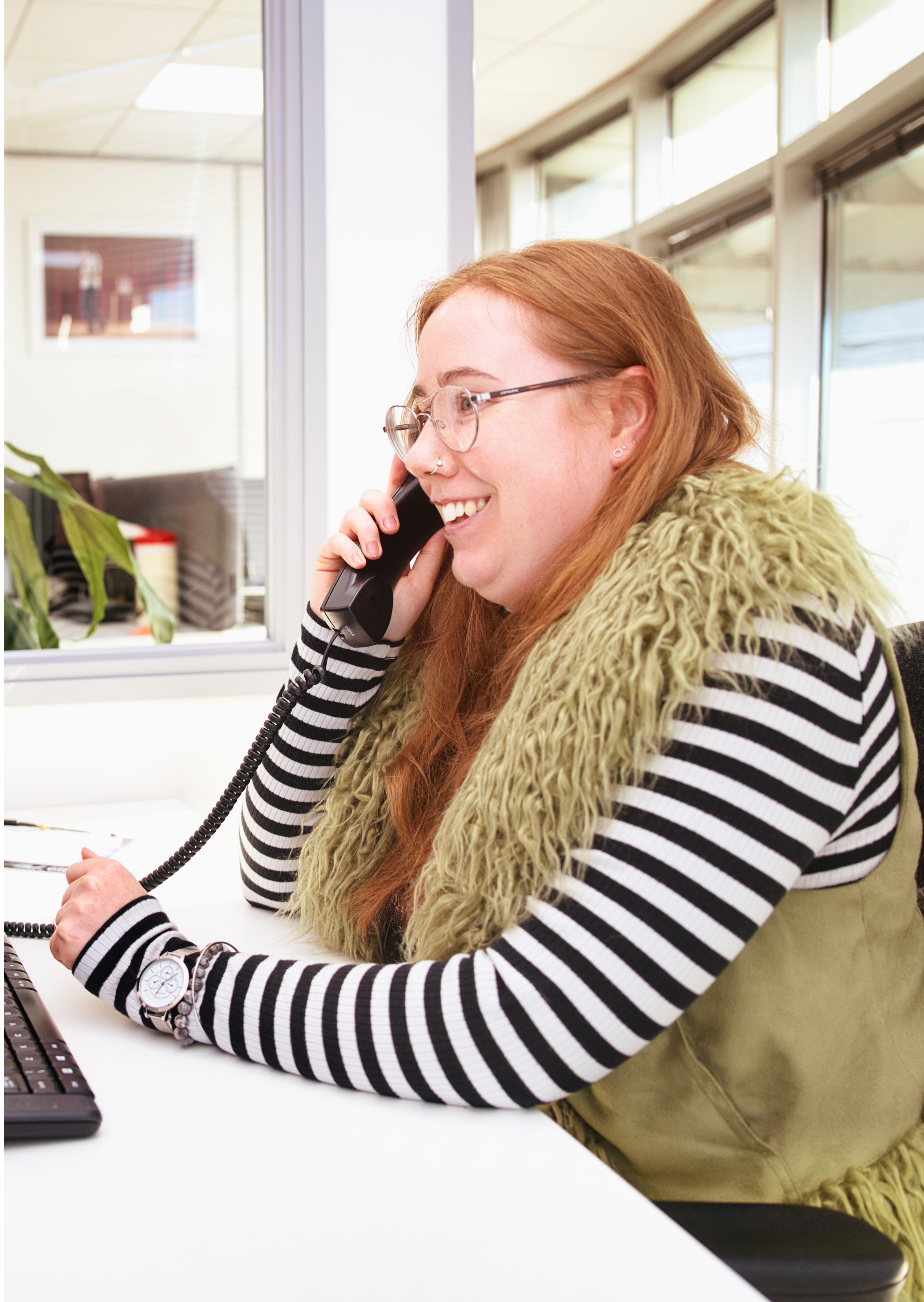
87%.
of respondents felt less isolated

80%.
of respondents felt more resilient and better able to cope with challenge

83%.
of respondents felt more prepared for the future

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

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



Goal 1

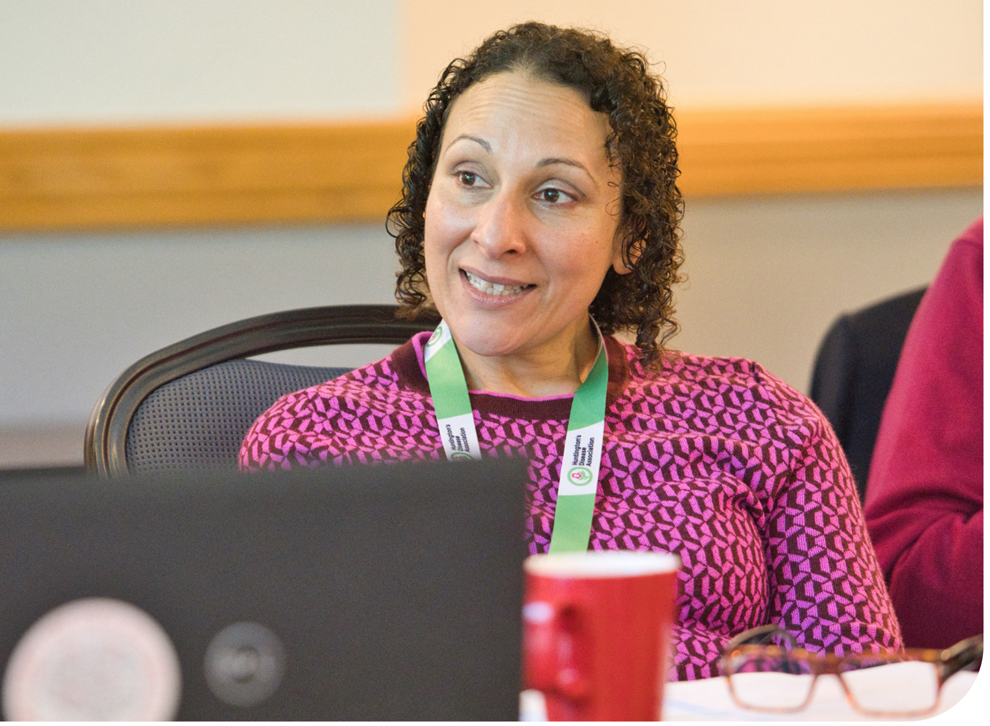
We will ensure that everyone affected by Huntington's disease gets the care and support they need.

Our ambitions under this goal are:

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

This year, we:

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



This year, we have supported 5,111 people through our Advisory service and Youth Engagement service, including...

- 2,416 people with the disease
- 556 people at risk of having the disease
- 1,169 carers
- We welcomed 1,232 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 Advisory service is our core service and remains in high demand. Our team of 21 Specialist Advisers support people across all regions of England and Wales by:

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

Chris

Working with our Adviser to navigate change

Chris turned to his Specialist Adviser when the symptoms of Huntington's disease affected his job.

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

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

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

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

> *"The whole process was very open and my Adviser's support went beyond what I thought."*

We helped children and young people to thrive through HDYES

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

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

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

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

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

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

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

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

We raised awareness through our Mindful of Huntington's campaign

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

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

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

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

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

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

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

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

We championed high quality care through Quality Assured

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

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

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

We provided trusted information and advice

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

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

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

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

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

Goal 2

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

Our ambitions under this goal are:

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

This year, we:

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

We brought families together at our JHD Weekend

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

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

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

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

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

Paramjit & Sheenam

Making treasured memories at our JHD Weekend

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

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

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

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

> "It's like a big family reunion. It's something that keeps Sheenam going and something to look forward to."

We helped people with the cost of living

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

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

62% were receiving welfare benefits

91% were using higher levels of energy in their home because of symptoms

90% had higher living costs because of symptoms - 38% had higher costs because of specialist food and a high calorie diet, 18% because of specialist equipment and adaptations, and 11% because of forgetfulness and compulsive behaviour

65% were very worried about the current price of household energy bills and 27% were fairly worried

67% were worried about the general cost of living and 25% were fairly worried

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

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

Our welfare grants programme continued to provide small grants of up to £350 to people affected by Huntington's disease or Juvenile Huntington's disease. These grants help people to reduce risk and improve quality of life, for example by purchasing a new washing machine or voice banking. This year, we received 53 welfare grant applications and awarded 47 grants with a total value of £14,860.

We saw an 18% increase in applications, up from 45 last year. We gave 18% more grants, up from 40 last year.

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

Dr Sarah Gunn
Lecturer in Clinical Psychology,
University of Leicester

We provided psychological support through online courses

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

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

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

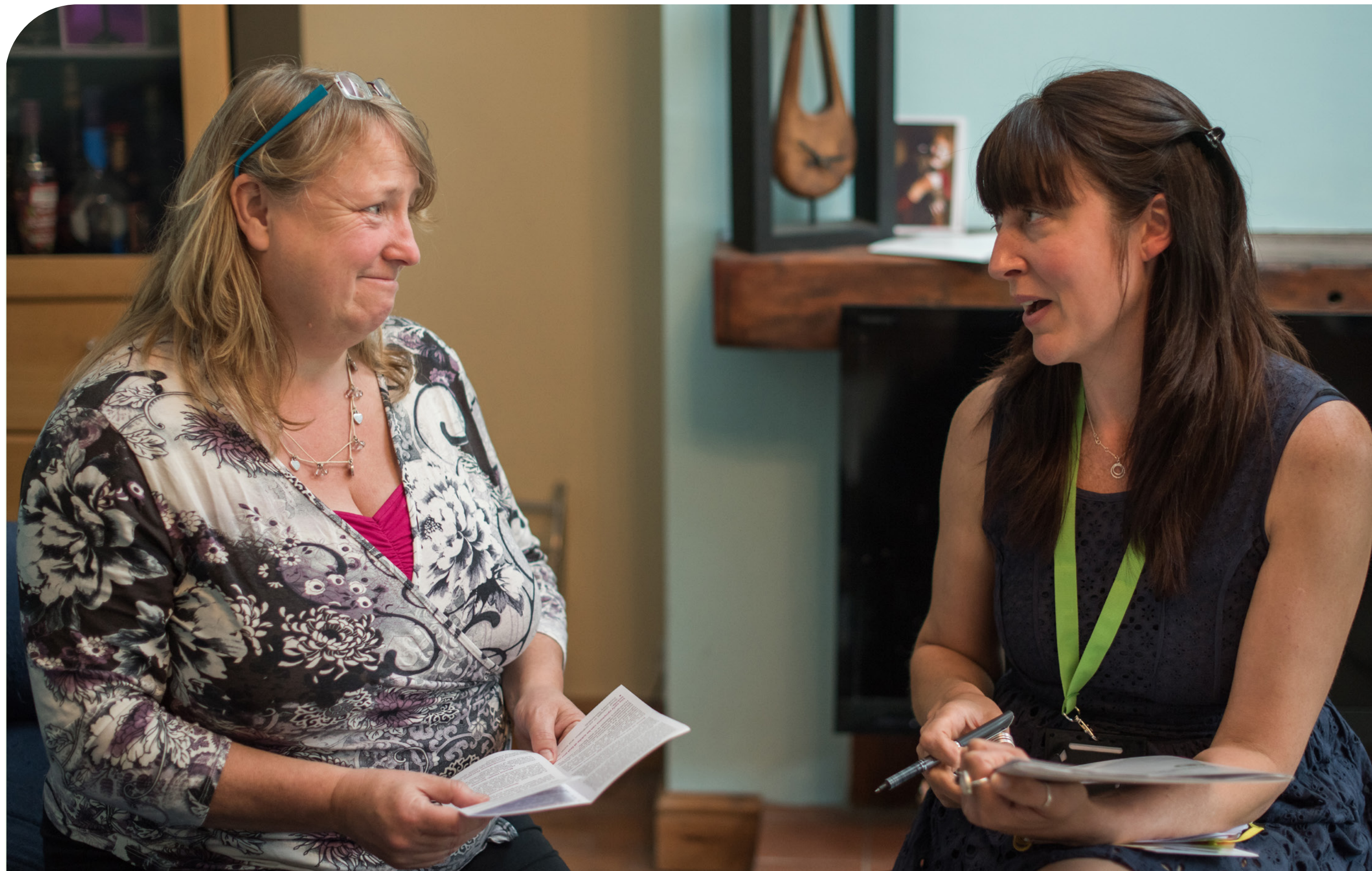
We delivered two Narrative Therapy sessions, one for family carers and one for parents of adult children at risk of Huntington's disease. In Narrative Therapy, participants explore their identity through values, beliefs and support systems. Led by clinical psychologist Mariangels Ferrer Duch, and supported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

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

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

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

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



Goal 3

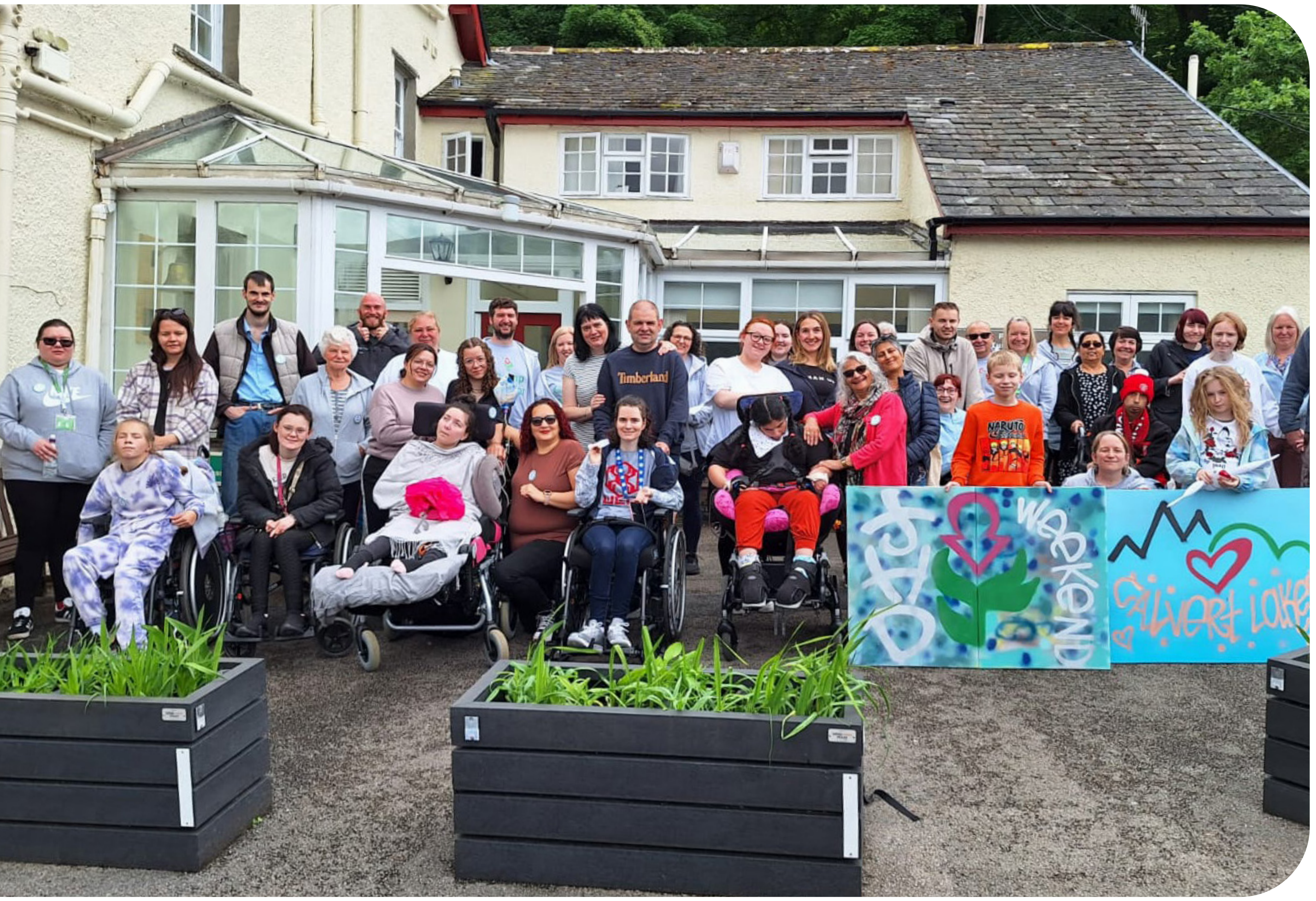
We will make sure the voices of people affected by Huntington's disease are heard and at the heart of everything we do.

Our ambitions under this goal are:

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

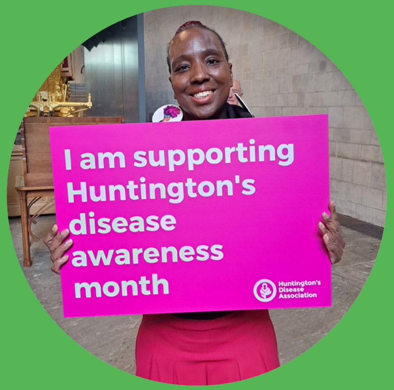
This year, we:

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



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

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



Kemi

Raising awareness and campaigning for change through HD Voice

Kemi is a valued member of HD Voice.

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

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

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

> "I'd like to play a part in raising the profile of the work that HD Voice does as well as raise awareness in other countries."

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

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

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

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

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

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

We launched HD Ambassadors – sharing stories to inspire others

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

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

We trained and educated health and social care professionals

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

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

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

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

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

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

Goal 4

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

Our ambitions under this goal are:

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

This year, we:

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

We shared research updates and opportunities

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

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

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

We worked with Pharmaceutical companies

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

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

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

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

We developed new resources with researchers

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

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

Goal 5

We will be a resilient charity.

Our ambitions under this goal are:

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

This year, we:

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

We launched our Strategy 2023-2027

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

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

We invested in new roles and infrastructure

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

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

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

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

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

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

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

We worked in partnership to support our community

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

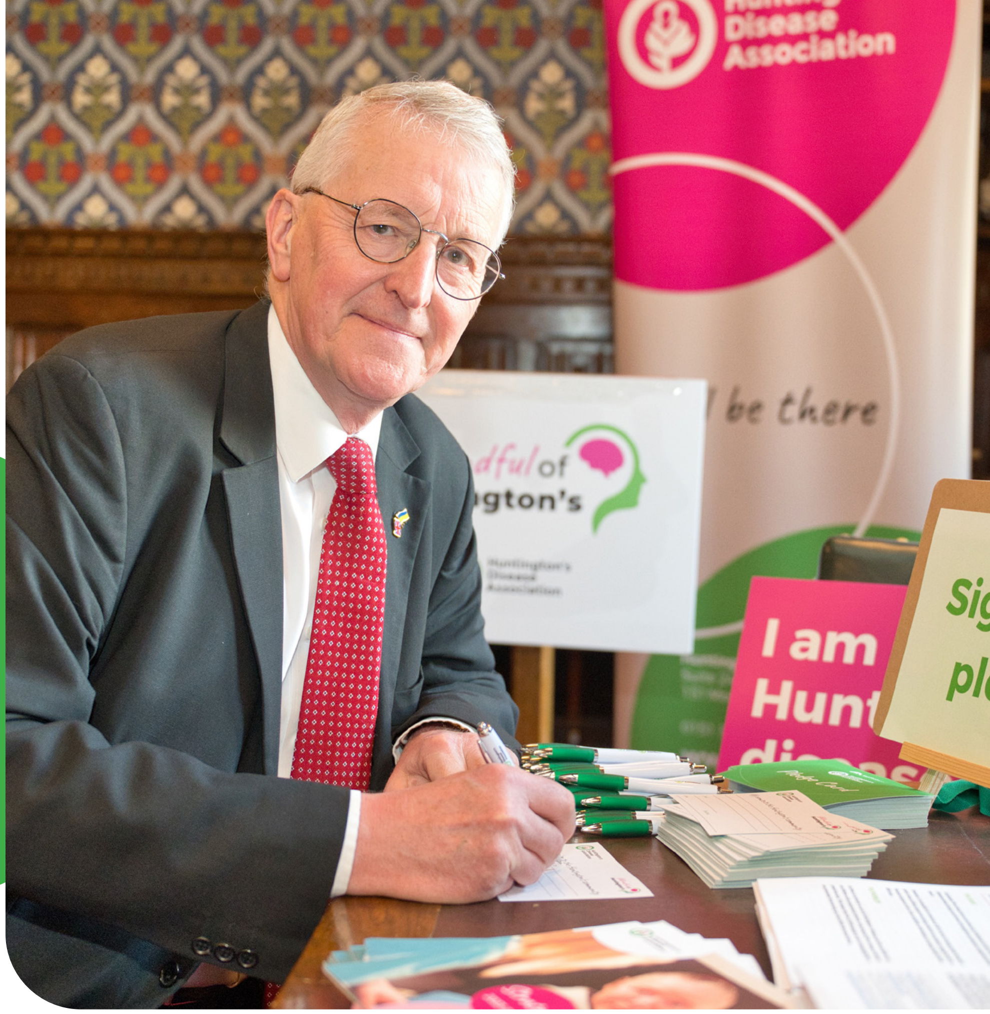
This year we supported the Neurological Alliance's #BackThe1in6 campaign. Giving a voice to people living with a neurological condition, the campaign called on the government to create a Neuro Taskforce to improve services for people with neurological conditions, including access to mental health and wellbeing support.

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

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

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

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



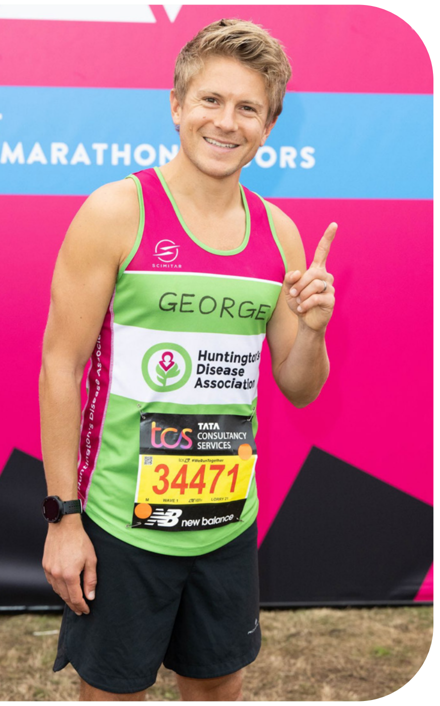
Hilary Benn MP

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

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

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

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



George Rainsford, Patron

We worked with our community and partners to fundraise

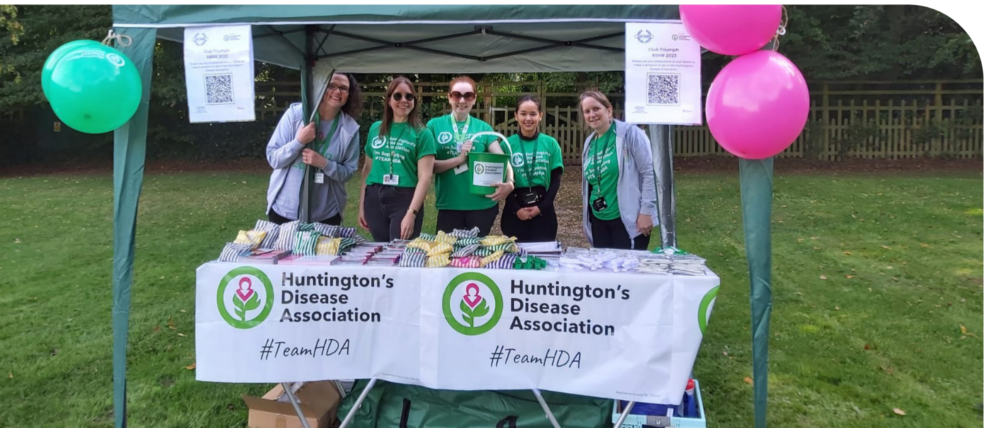
Once again, our amazing community played a huge and highly valued role in raising funds to sustain our lifeline services. We raised an outstanding £517,417 through community fundraising and events. Our #TeamHDA runners, including our patron George Rainsford, raised £68,682.44 through the TCS London Marathon. Our runners also took to the streets from Newcastle to South Shields, raising £20,241.38 through the Great North Run.

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

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

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

We were delighted to be chosen as Charity Partner for the Club Triumph Round Britain Reliability Run, which took place in October. Over 48 hours, over 100 teams drove almost 2,000 miles from Knebworth House to John O'Groats and Lands End, before arriving back at Knebworth House. This fantastic event raised a wonderful £79,846.48.



We experienced a 26% increase in individual giving this year, raising £442,691 from our generous supporters. We raised £12,000 through the Big Give Kind2Mind campaign and £17,012 through the Big Give Christmas Challenge. These funds helped us to provide specialist psychological support to people in our community and deliver the JHD Weekend. We value the support of our Big Give match funders, including a major donor and the Hospital Saturday Fund.

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

Our regular donors donated an amazing £90,753.31 over the year. Our charity lottery goes from strength to strength. We attracted 141 new lottery players this year and raised £22,203.

Legacy giving continues to grow and we received £618,521 from legacy donations this year. 81 people accessed the National Free Wills Network; 6 people went on to write their will for free with 5 people pledging a gift to the charity.

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

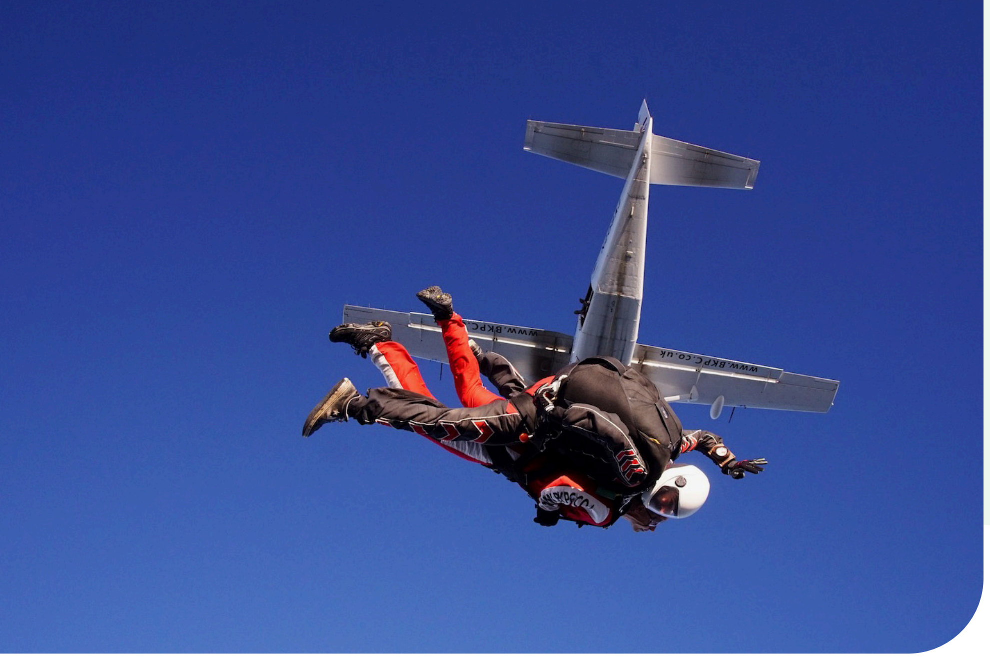
Fundraiser of the Year
Jess Webb

Young Fundraiser of the Year
Kara-Mai Oliver

Fundraising Group of the Year
HD Support Squad

Excellence in Health or Social Care Winners
Fiona Chaabane

Founders Award
The Branches and Support Groups of the Association



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

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

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

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

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

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

George & Scott

Pushing themselves to the limit

Brothers George and Scott are pushing themselves to the limit by taking on a range of fundraising challenges.

Their dad was initially misdiagnosed with Alzheimer's disease before they found out he had Huntington's disease.

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

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

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

> "So far, we have completed a skydive, a Total Warrior 12.5km event, a half marathon, a marathon and a 35-mile walk along the Gritstone Trail."

Future plans

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

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

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

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

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

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

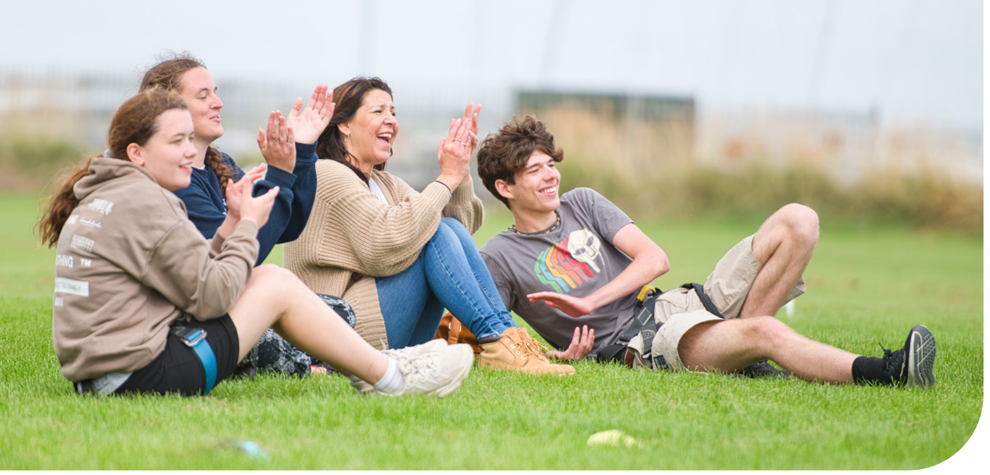
We will attend the EHDN 2024 conference in September to continue to learn and share knowledge about Huntington's disease. Our staff will meet with and contribute to the working groups, which are:

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

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

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

We will extend our HD Ambassadors with new members and seek more opportunities to speak. We will continue to work with HD Voice and encourage more members of the community to have an active voice. We will work with HD Youth Voice as we develop website content for young people.



People's stories will continue to be at the heart of all our communications, including our Awareness Month campaign. Covering all aspects of the disease, each month we will focus on a dedicated topic such as genetic testing, starting a family, and mental health. We will work with the community to capture and share their experiences through our website and social media.

We will continue to work with Enroll-HD to accelerate progress toward effective treatments. We will continue to support HD Buzz, who help us understand the progress being made in research for Huntington's disease.

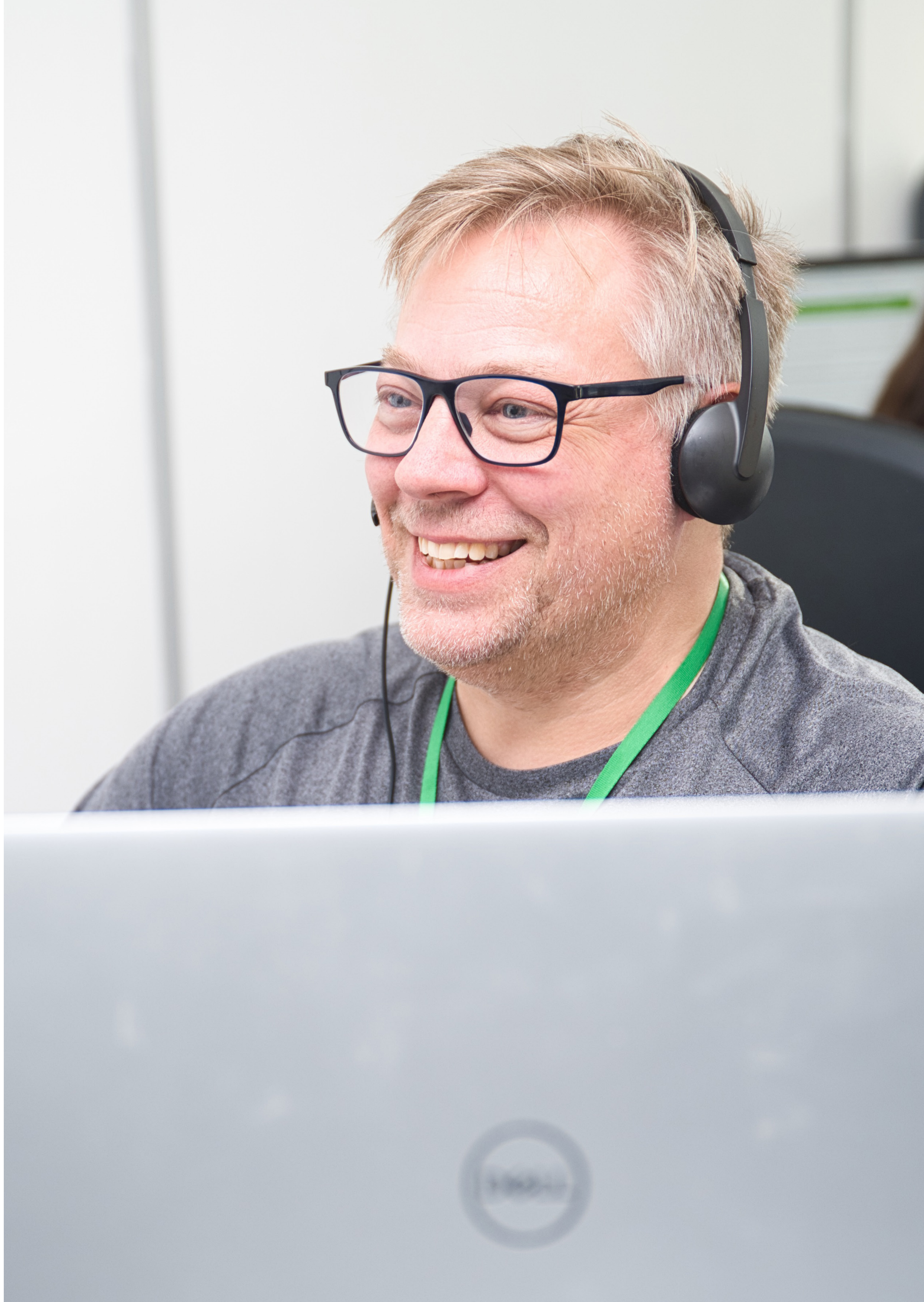
We will continue our work alongside pharmaceutical companies as they develop drugs that could delay symptoms, improve symptoms, and hopefully find a cure. Our attendance at EHDN 2024 will keep us current with the latest research news. The conference also gives us an opportunity to hear from Huntington's disease associations from across the world on best practice in managing the symptoms of Huntington's disease.

Building on our effective engagement with policy makers, we will establish a new role of Head of Policy and Public Affairs. This appointment will ensure we have a stronger voice in parliament and support our campaign for Care Coordinators across England and Wales to ensure that everyone affected by Huntington's disease gets the care and support they need.

A new Volunteer Manager will support our current volunteers, branches and support groups and develop new opportunities for people to get involved. Supporting our financial resilience, we will recruit a new role of Community Fundraiser Co-ordinator.

As the charity continues to develop and grow, we want to ensure the health and wellbeing of our team and provide support, training and development opportunities. We will create a new HR Manager role to support this.

In April 2024, actor Alison Steadman will present our BBC Lifeline appeal to raise awareness of Huntington's disease and appeal for donations. The appeal will be broadcast on BBC One and BBC Two and subsequently be available on our website.



Our year in numbers

5,111

People supported through our Advisory service and Youth service.

Including:

2,416
people with the disease

556
people at risk of having the disease

1,169
carers

1,232
new people were welcomed to our support this year

8
online courses for our community with...

73
attendances

15
webinars with...

456
attendances

Webinar recordings viewed

7,893
times on YouTube

48
HD Voice members

13
HD Youth Voice members

55
Ambassadors

4
new members of our Quality Assured scheme for care homes

A total of 9
homes now accredited through the scheme

17
branches

17
support groups

2	Certificated courses for Professionals with **101** delegates
2	HD Champions courses with **17** delegates
1	Mental Health online study day with **58** delegates
200	training and information sessions for professionals with **1,960** attendances
9	drop-in sessions for professionals with **595** attendances

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

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

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

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

87% of 217
respondents feel less isolated

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

83% of 299
respondents feel more prepared for the future

Structure, governance and management

Governing document

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

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

Dr G El-Nimr

Mr N M Heath (Hon Treasurer)

Professor H Rickards (Chair)

Ms C Lyon

Ms S Barker

Mr S Duckett

Dr N Swales

Ms B E Waters
(resigned 4 November 2023)

Ms H Hubberstey

Ms C K Holmes

Mr D R Thomas

Recruitment and appointment of trustees

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

Organisational structure

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

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

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

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

Trustee induction and training

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

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

Remuneration policy

The trustees have responsibility for setting the pay and remuneration of the charity's key personnel and this is done on an annual basis, including a formal cost of living review. Salaries are benchmarked with other similar organisations across the sector.

Auditor

In accordance with the company's articles, a resolution proposing that DSG be reappointed as auditor of the company will be put at a General Meeting.

Disclosure of information to auditor

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

Small company provisions

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

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

N. M. Heath

Mr N M Heath (Hon Treasurer)

Dated: 28/08/2024

Statement of trustees' responsibilities

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

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

In preparing these accounts, the trustees are required to:

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

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Independent auditor's report

Opinion

We have audited the financial statements of Huntington's Disease Association (the 'charity') for the year ended 31 March 2024 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2024 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

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

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

Chartered Accountants
Statutory Auditor

28 August 2024

Castle Chambers
43 Castle Street
Liverpool
L2 9TL

Statement of financial activities

Including income and expenditure account.
For the year ended 31 march 2024.

	Note	Unrestricted Funds 2024 £	Restricted Funds 2024 £	Total 2024 £	Unrestricted Funds 2023 £	Restricted Funds 2023 £	Total 2023 £
Income from							
Donations and legacies	3	1,673,330	95,106	**1,768,436**	1,298,518	74,311	**1,372,829**
Charitable activities	4	40,404	296,735	**337,139**	28,354	542,026	**570,380**
Other trading activities	5	83,709	-	**83,709**	18,367	-	**18,367**
Investments	6	77,533	-	**77,533**	36,267	-	**36,267**
Other income	7	-	-	**-**	5,735	-	**5,735**
Total income		1,874,976	391,841	**2,266,817**	1,387,241	616,337	**2,003,578**
Expenditure on							
Raising funds	8	293,933	-	**293,933**	292,650	-	**292,650**
Charitable activities	9	1,610,508	468,284	**2,078,792**	1,268,506	473,410	**1,741,916**
Total expenditure		1,904,441	468,284	**2,372,725**	1,561,156	473,410	**2,034,566**
Net gains/(losses) on investments							
Donations and legacies	14	64,416	-	**64,416**	(73,663)	-	**(73,663)**
Net movement in funds		34,951	(76,443)	**(41,492)**	(247,578)	142,927	**(104,651)**
Reconciliation of funds							
Fund balances at 1 Apr 2023		2,158,146	225,977	**2,384,123**	2,405,724	83,050	**2,488,774**
Fund balances at 31 Mar 2024		2,193,097	149,534	**2,342,631**	2,158,146	225,977	**2,384,123**

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 2024.

	Note	2024 £	2024 £	2023 £	2023 £
Fixed assets					
Tangible assets	16		21,714		20,359
Investments	17		1,039,563		875,147
			1,061,277		**895,506**
Current assets					
Stocks	19	8,175		9,007	
Debtors	20	440,245		390,793	
Cash at bank and in hand		987,706		1,243,672	
		1,436,126		**1,643,472**	
Creditors: amounts falling due within one year	**21**	**(154,772)**		**(154,855)**	
Net current assets					
Total assets less current liabilities			**2,342,631**		**2,384,123**
Income funds			**1,281,354**		**1,488,617**
Restricted funds	23		149,534		225,977
Unrestricted funds					
Designated funds	24	301,835		391,424	
General unrestricted funds		1,891,262		1,766,722	
			2,193,097		**2,158,146**
			2,342,631		**2,384,123**

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

The financial statements were approved by the Trustees on 28 August 2024.

N. M. Heath

Mr N M Heath (Hon Treasurer)
Trustee

Company Registration Number 02021975

Statement of cash flows

For the year ended 31 March 2024.

	Note	2024 £	2024 £	2023 £	2023 £
Cash flows from operating activities					
Cash (absorbed by)/generated from operations	29		(218,868)		254,329
Investing activities					
Purchase of tangible fixed assets		(14,631)		(9,840)	
Purchase of investments		(100,000)		-	
Investment income received		77,533		36,267	
Net cash (used in)/generated from investing activities			(37,098)		26,427
Net cash used in financing activities			**-**		**-**
Net (decrease)/increase in cash and cash equivalents			(255,966)		280,756
Cash and cash equivalents at beginning of year			1,243,672		962,916
Cash and cash equivalents at end of year			**987,706**		**1,243,672**

Notes to the financial statements

1 Accounting policies

Charity information
Huntington's Disease Association is a private company limited by guarantee incorporated in England and Wales. The registered office is Suite 24 Liverpool Science Park, Innovation Centre, 131 Mount Pleasant, Liverpool, L3 5TF.

1.1 Accounting convention

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

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

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

1.2 Going concern

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

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

1.3 Charitable funds

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

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

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

1.4 Income

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

Investment income consists of interest and dividends received and receivable.

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

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

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

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

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

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

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

1.5 Expenditure

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

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

1.6 Tangible fixed assets

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

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

Fixtures and fittings 25% straight line

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

1.7 Fixed asset investments

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

1.8 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.9 Stocks

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

1.10 Cash and cash equivalents

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

1.11 Financial instruments

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

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

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

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

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

If an asset is impaired, the impairment loss is the difference between the carrying amount and the present value of the estimated cash flows discounted at the asset’s original effective interest rate. The impairment loss is recognised in net income/(expenditure) for the year.

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

Derecognition of financial assets
Financial assets are derecognised only when the contractual rights to the cash flows from the asset expire or are settled, or when the charity transfers the financial asset and substantially all the risks and rewards of ownership to another entity, or if some significant risks and rewards of ownership

are retained but control of the asset has transferred to another party that is able to sell the asset in its entirety to an unrelated third party.

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

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

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

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

1.12 Employee benefits

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

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

1.13 Retirement benefits

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

1.14 Branch funds

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

2 Critical accounting estimates and judgements

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

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

3 Donations and legacies

	Unrestricted Funds 2024 £	**Restricted Funds 2024 £**	**Total 2024 £**	Unrestricted Funds 2023 £	Restricted Funds 2023 £	Total 2023 £
Donations and gifts	996,636	87,273	1,083,909	968,144	70,121	1,038,265
Legacies receivable	626,258	7,833	634,091	297,406	-	297,406
Branch income	50,436	-	50,436	32,968	4,190	37,158
	1,673,330	**95,106**	**1,768,436**	**1,298,518**	**74,311**	**1,372,829**

4 Income from charitable activities

	Unrestricted Funds 2024 £	**Restricted Funds 2024 £**	**Total 2024 £**	Unrestricted Funds 2023 £	Restricted Funds 2023 £	Total 2023 £
Grants received	3,500	296,735	300,235	6,000	542,026	548,026
Merchandise	14,808	-	14,808	15,708	-	15,708
Other income	22,096	-	22,096	6,646	-	6,646
	40,404	**296,735**	**337,139**	**28,354**	**542,026**	**570,380**

5 Income from other trading activities

	Unrestricted Funds 2024 £	Unrestricted Funds 2023 £
Company sponsorships	51,876	600
Consultancy	31,833	17,767
Other trading activities	**83,709**	**18,367**

6 Income from investments

	Unrestricted Funds 2024 £	Unrestricted Funds 2023 £
Income from listed investments	29,469	25,241
Interest receivable	48,064	11,026
	77,533	**36,267**

7 Other income

	Unrestricted Funds 2024 £	Unrestricted Funds 2023 £
Miscellaneous income	-	5,735

8 Raising funds

	Unrestricted Funds 2024 £	Unrestricted Funds 2023 £
Fundraising and publicity		
Fundraising events	26,675	24,19
Other fundraising costs	57,435	94,196
Staff costs	209,823	174,259
	293,933	**292,650**

9 Charitable activities

	Specialist HD Advisory Service £	**Welfare and Respite Care £**	**Comm. and Policy and Public Affairs £**	**Youth Workers & Juvenile £**	**Branch £**	**Total 2024 £**	**Total 2023 £**
Staff costs	916,084	929	163,624	181,620	19,720	1,281,977	1,006,266
Welfare grants	-	15,112	-	-	16,940	32,052	20,792
Research	-	-	-	-	-	-	20,180
Recruitment	3,471	-	1,549	2,595	320	7,935	3,407
Travel and training	48,842	-	4,173	15,335	1,081	69,431	48,860
Telephone and internet	42,052	-	1,340	1,946	350	45,688	20,566
Other costs	46,733	76	20,419	38,534	29,582	135,344	150,587
Website	-	-	17,727	-	-	17,727	23,945
Marketing	-	-	74,467	-	-	74,467	24,669
Event costs	1,429	-	2,497	33,515	-	37,441	32,077
	1,058,611	**16,117**	**285,796**	**273,545**	**67,993**	**1,702,062**	**1,351,349**
Share of support costs (see note 10)	197,571	18,202	72,808	39,054	36,404	364,039	378,514
Share of governance costs (see note 10)	12,691	-	-	-	-	12,691	12,053
	1,268,873	**34,319**	**358,604**	**312,599**	**104,397**	**2,078,792**	**1,741,916**
Analysis by fund							
Unrestricted funds	1,011,062	26,851	155,599	312,599	104,397	1,610,508	1,268,506
Restricted funds	257,811	7,468	203,005	-	-	468,284	473,410
	1,268,873	**34,319**	**358,604**	**312,599**	**104,397**	**2,078,792**	**1,741,916**

For the year ended 31 March 2023	**Specialist HD Advisory Service £**	**Welfare and Respite Care £**	**Research £**	**Comm. and Policy and Public Affairs £**	**Youth Workers & Juvenile £**	**Branch £**	**Total 2023 £**
Staff costs	793,743	882	882	120,739	72,432	17,588	1,006,266
Welfare grants	-	12,734	-	-	-	8,058	20,792
Research	-	-	20,180	-	-	-	20,180
Recruitment	2,386	-	-	257	764	-	3,407
Travel and training	37,722	-	-	2,490	7,961	687	48,860
Telephone and internet	18,965	-	-	690	675	236	20,566
Other costs	49,406	63	63	54,925	25,143	20,987	150,587
Website	-	-	-	23,945	-	-	23,945
Marketing	-	-	-	24,669	-	-	24,669
Event costs	7,712	-	-	706	23,659	-	32,077
	909,934	**13,679**	**21,125**	**228,421**	**130,634**	**47,556**	**1,351,349**
Share of support costs (see note 10)	204,472	19,338	-	77,352	38,676	38,676	378,514
Share of governance costs (see note 10)	12,053	-	-	-	-	-	12,053
	1,126,459	**33,017**	**21,125**	**305,773**	**169,310**	**86,232**	**1,741,916**
Analysis by fund							
Unrestricted funds	779,438	24,100	1,125	297,715	79,896	86,232	1,268,506
Restricted funds	347,021	8,917	20,000	8,058	89,414	-	473,410
	1,126,459	**33,017**	**21,125**	**305,773**	**169,310**	**86,232**	**1,741,916**

10 Support costs allocated to activities

	2024 £	2023 £
Staff costs	208,524	215,284
Depreciation	13,276	9,618
Head office costs	142,239	153,612
Governance costs	12,691	12,053
	376,730	**390,567**
Analysed between:		
Specialist HD Advisory Service	210,262	216,525
Welfare and Respite Care	18,202	19,338
Communication, policy and public affairs	72,808	77,352
Youth workers and juvenile	39,054	38,676
Communication, policy and public affairs	36,404	38,676
Youth workers and juvenile	**376,730**	**390,567**
Governance costs comprise:		
Audit fees	8,874	8,250
EC meeting costs	3,817	3,803
	12,691	**12,053**

Support costs are allocated of the basis of time spent.

11 Net movement in funds

	2024 £	2023 £
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	8,874	8,250
Depreciation of owned tangible fixed assets	13,276	9,618

12 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year (2023: £nil) and no trustees were reimbursed expenses (2023: two trustees were reimbursed £179).

13 Employees

	2024 Number	2023 Number
The average monthly number of employees during the year was:		
Specialist HD Advisors	25	22
Management	1	1
Fundraising	5	5
Youth Worker	5	2
Administration	6	8
Communications	3	3
Total	**45**	**41**

	2024 £	2023 £
Employment costs		
Wages and salaries	1,501,293	1,240,304
Social security costs	156,408	121,121
Other pension costs	42,623	34,384
Youth workers and juvenile	**1,700,324**	**1,395,809**

	2024 Number	2023 Number
The number of employees whose annual remuneration was more than £60,000 is as follows:		
£70,001 - £80,000	-	1
£80,001 - £90,000	1	-

	2024 £	2023 £
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	315,348	298,495

14 Gains and losses on investments

	Unrestricted Funds 2024 £	Unrestricted Funds 2023 £
Gains/(losses) arising on:		
Revaluation of investments	64,416	(73,663)

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 2023	46,149
Additions	14,631
At 31 March 2024	**60,780**
Depreciation	
At 1 April 2023	25,790
Additions	13,276
At 31 March 2024	**39,066**
Carrying amount	
At 31 March 2024	**21,714**
At 31 March 2023	20,359

17 Fixed asset investments

	Listed investments £
Valuation	
At 1 April 2023	875,147
Additions	100,000
Valuation changes	64,416
At 31 March 2024	**1,039,563**
Carrying amount	
At 31 March 2024	**1,039,563**
At 31 March 2023	875,147

18 Financial instruments

	2024 £	2023 £
Carrying amount of financial assets		
Instruments measured at fair value through profit or loss	1,039,556	875,143

19 Stocks

	2024 £	2023 £
Merchandise	8,175	9,007

20 Debtors

	2024 £	2023 £
Amounts falling due within one year:		
Trade debtors	15,338	3,309
Other debtors	355,844	297,298
Prepayments	69,063	90,186
	440,245	**390,793**

Other debtors include £307,978 (2023: £252,932) of legacies receivable.

21 Creditors: amounts falling due within one year

	2024 £	2023 £
Other taxation and social security	37,190	27,005
Trade creditors	38,709	54,744
Other creditors	20,945	-
Accruals and deferred income	57,928	73,106
	154,772	**154,855**

Included in accruals and deferred income is deferred income of £41,250 (2023: £58,423) relating to income received for future periods.

22 Retirement benefit schemes

	2024 £	2023 £
Defined contribution schemes		
Charge to profit or loss in respect of defined contribution schemes	42,623	34,384

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

The charge to the statement of financial activities in respect of defined contribution schemes was £42,623 (2023 - £34,384).

23 Restricted funds

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

	Balance at 1 Apr 2022 £	Incoming resources £	Resources expended £	Balance at 1 Apr 2023 £	Incoming resources £	Resources expended £	Balance at 31 Mar 2024 £
Research	26,404	7,980	(20,000)	14,384	47,595	-	61,979
The National Lottery Community Fund	-	-	-	-	136,452	(90,168)	46,284
Specialist HD Advisory Service (SHDA)	-	347,021	(347,021)	-	171,944	(164,944)	7,000
Children in Need	4,757	-	(4,757)	-	-	-	-
Lancashire Training Events	4,849	-	-	4,849	-	-	4,849
The Big Give - JHD weekend	-	-	-	-	16,926	-	16,926
The Big Give - Kind2mind	-	1,500	(1,500)	-	13,160	(3,664)	9,496
JHD Weekend	25,472	-	(25,472)	-	3,000	-	3,000
Youth Services	18,241	1,524	(19,765)	-	-	-	-
B&Q Foundation	467	5,000	(2,768)	2,699	-	(2,699)	-
Welfare Fund	2,860	4,329	(6,149)	1,040	2,764	(3,804)	-
Website	-	8,058	(8,058)	-	-	-	-
Jingle Jam	-	240,925	(37,920)	203,005	-	(203,005)	-
	83,050	**616,337**	**(473,410)**	**225,977**	**391,841**	**(468,284)**	**149,534**

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.

Children in Need

This grant is to fund a youth worker.

Lancashire Training Events

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

The Big Give - JHD Weekend

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

The Big Give - Kind2Mind

Restricted funding to support our psychological support programmes.

JHD Weekend

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

Youth Services

This relates to Trusts funding received to fund the work of our Youth Worker.

B&Q Foundation

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

Welfare Fund

Funding received towards welfare grants.

Website

A development grant was received from Uniqure to develop our website.

Jingle Jam

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

24 Unrestricted funds

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

	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**

Previous year	At 1 April 2022 £	Incoming resources £	Resources expended £	Transfers £	Gains and losses £	At 31 March 2023 £
Designated funds						
Special projects fund	184,000	-	(41,110)	-	-	142,890
Branch funds	65,722	26,276	(26,996)	-	-	65,002
Huntington’s Disease Youth Engagement Service	207,000	-	(23,468)	-	-	183,532
General funds	1,949,002	1,360,965	(1,469,582)	-	(73,663)	1,766,722
	2,405,724	**1,387,241**	**(1,561,156)**	**-**	**(73,663)**	**2,158,146**

A designated special projects fund of £400,000 was established as a result of generous legacies received during 2013. It is intended that the fund be used for special projects, which, once instituted, may be developed in accordance with the long-term objectives of the charity. During 2015 and 2016 £130,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support. A further £40,000 of the fund was used to support the new communication initiative in 2017/18 and £16,000 was used in 2018/19 to complete the Care Home Accreditation project. In 2021/22, £30,000 was released to cover costs associated with changes necessitated by the pandemic including reducing the office size, software improvement and project development. The balance of the fund amounting to £184,000 at 1 April 2023 has been allocated in 2023 and 2024 to cover the establishment of new posts covering National Support, Policy and Public Affairs, Data Management and Volunteer Support.

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

25 Analysis of net assets between funds

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
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**

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
At 31 March 2023:			
Tangible assets	20,359	-	20,359
Investments	875,147	-	875,147
Current assets/(liabilities)	1,262,640	225,977	1,488,617
	2,158,146	**225,977**	**2,384,123**

26 Operating lease commitments

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

	2024 £	2023 £
Within one year	31,104	34,627
Between two and five years	39,058	70,926
	70,162	**105,553**

27 Related party transactions

Remuneration of key management personnel

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

	2024 £	2023 £
Aggregate remuneration	315,348	298,495

Transactions with related parties

During the year, one trustee donated £120 (2023: £116).

Mr Nick Heath, a trustee, is chair of Victoria Convalescent Trust which made grants totalling £2,544 (2023: £2,129) to the charity in the year.

Ms Catherine Lyon, a trustee, received a grant from the charity of £2,000 (2023: £Nil) towards funding for her PhD on end of life care and Huntington's Disease.

There were no other related party transactions in the year.

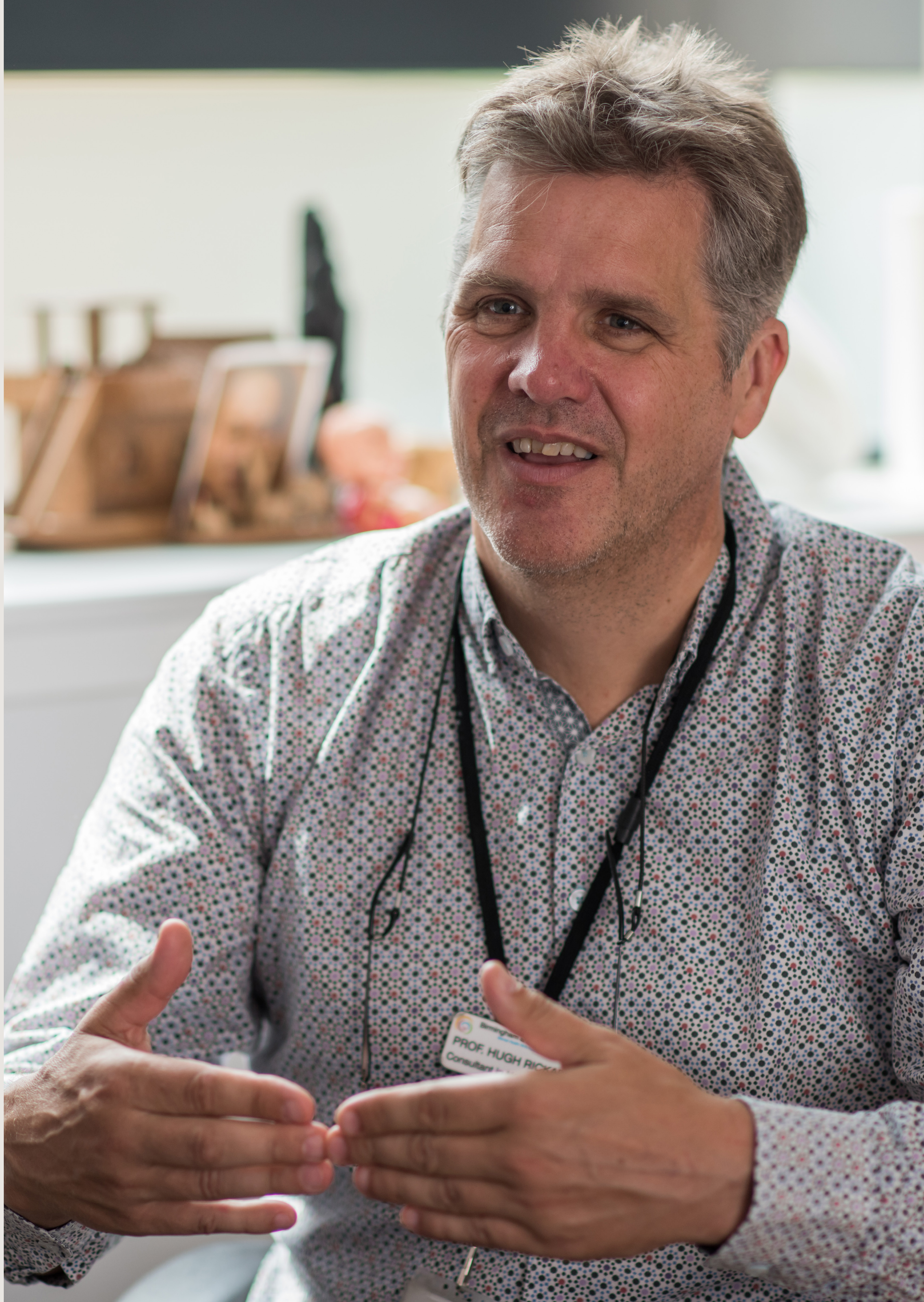
28 Branch funds

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

	2024 £	2023 £
Cash balances		
At 1 April 2023	65,002	65,722
Receipts in year	50,483	37,158
Less:		
Local welfare grants	(16,640)	(8,058)
Sent to head office	(12,639)	(10,882)
Branch activities, local newsletters, equipment, research etc.	(28,648)	(18,938)
At 31 March 2024	**57,558**	**65,002**

29 Cash generated from operations

	2024 £	2023 £
Deficit for the year	(41,492)	(104,651)
Adjustments for:		
Investment income recognised in statement of financial activities	(77,533)	(36,267)
Fair value gains and losses on investments	(64,416)	73,663
Depreciation and impairment of tangible fixed assets	13,276	9,618
Movements in working capital:		
Decrease in stocks	832	1,167
(Increase)/decrease in debtors	(49,452)	286,710
(Decrease)/increase in creditors	(83)	24,089
Cash (absorbed by)/generated from operations	**(218,868)**	**254,329**



Acknowledgements

We would like to thank the following grant makers for their support:

- The 29th May 1961 Charity
- Belron Ronnie Lubner Charitable Foundation
- The Adint Charitable Trust
- The Alice Ellen Cooper Dean Charitable Foundation
- The Ardwick Trust
- The Barbour Foundation
- Chapman Charitable Trust
- The Christopher Laing Foundation
- Chrysalis Trust
- The Drapers' Company
- The Dyers' Company Charitable Trust
- Ethel and Gwynne Morgan Trust
- The Florence Turner Trust
- Fowler Smith & Jones Trust
- The Goldcrest Charitable Trust
- Hadrian Trust
- The Hospital Saturday Fund
- The Ian Askew Charitable Trust
- The Inter-Church Caring Trust
- The J Reginald Corah Foundation Fund
- The John Avins Trust
- The Joseph and Lena Randall Charitable Trust
- The Lord Cozens-Hardy Trust
- May Hearnshaw Charitable Trust
- The Michael and Anna/ Wix Charitable Trust
- The Miss Pannett Charitable Trust
- The National Lottery Community Fund
- The Oakdale Trust
- P F Charitable Trust
- The Paul Bassham Charitable Trust
- Pilkington Charities Fund
- The Proven Family Trust
- The Roger and Jean Jefcoate Trust
- The Roger De Haan Charitable Trust
- Sandra Charitable Trust
- The Sir James Knott Trust
- The Sir James Reckitt Charity
- The Sir James Roll Charitable Trust
- The Sylvia and Colin Shepherd Charitable Trust
- Tesco Charity Trust
- The Sunrise (Sidmouth) Charitable Trust
- The Thomas Sivewright Catto Charitable Settlement

Statutory

- Birmingham City Council
- Cambridgeshire and Peterborough Integrated Care System
- Dorset HealthCare University NHS Foundation Trust
- NHS Cornwall and Isles of Scilly Integrated Care Board
- NHS Devon Integrated Care Board
- NHS Lancashire and South Cumbria Integrated Care Board
- NHS North East and North Cumbria Integrated Care Board

Get in touch

For advice and support or to
speak to a Specialist HD 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

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

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