ANNUAL REPORT AND FINANCIAL STATEMENTS

For the year ending 31 March 2023

Registered Charity No. 296453
Company Registration No. 2021975 (England and Wales)

Huntington's Disease Association

Charity registration number 296453

Company registration number 02021975 (England and Wales)

HUNTINGTON'S DISEASE ASSOCIATION

COMPANY LIMITED BY GUARANTEE

ANNUAL REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

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

Patrons	Tony Hadley	
	Shane Richie	
	George Rainsford	
Trustees	Dr G El-Nimr	
	Mr N M Heath (Hon Treasurer)	
	Professor H Rickards (Chair)	
	Ms C Lyon	
	Ms S Barker	
	Mr S Duckett	
	Dr N Swales	
	Ms B E Waters	
	Ms H Hubberstey	(Appointed 20 October 2022)
	Ms C K Holmes	(Appointed 20 October 2022)
	Mr D R Thomas	(Appointed 20 October 2022)
Chief executive	Mrs C Stanley BSc (Hons)	
Charity number	296453	
Company number	02021975	
Registered office	Suite 24 Liverpool Science Park Innovation Centre 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	

HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
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The trustees present their annual report and financial statements for the year ended 31 March 2023.

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

Objectives and activities

Charity objects

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

Huntington's disease, a brief overview

Huntington's disease is a rare neurological disorder that is caused by a faulty gene passed down through families. Each child of a parent with Huntington's has a 50% chance of inheriting the faulty gene. The disease affects the central nervous system, the network of nerve tissues in the brain and spinal cord that co-ordinate the body's activities. It is a progressive condition that causes changes in movement, thinking, emotions, eating and speech that worsen over time. Symptoms usually begin between the ages of 30 and 50, though they can also develop much earlier or later. If someone begins to show symptoms before the age of 20, this is known as Juvenile Huntington's disease. It is estimated that around 8,000 people are living with Huntington's and 32,000 are at risk of developing it in the United Kingdom.

2022 saw the end of the Huntington Disease Association's five year strategy. Throughout 2021 and 2022 we were reflecting on what we had achieved as we planned for the next strategy for 2023 to 2027.

Our Vision

A better life for anyone affected by Huntington's disease.

Mission

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

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community and influencing policymakers

At the end of the five-year strategy, we undertook an impact report to see what difference we had made.

> " We thought no one understood us until we met you"

Values

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive

Who we are

The charity was founded in 1971 after a family who had been given a diagnosis of Huntington's sent a letter to a local paper asking if anyone knew of any other families in a similar situation. It began as a support group with 76 members and was known initially as the 'Association to Combat Huntington's Chorea', later becoming the Huntington's Disease Association.

Feedback from families that they would benefit from professionals with knowledge and understanding of the illness led to a 1993 project known as CASE – Care, Advice, Support and Education. This project saw the birth of our Specialist Huntington’s Disease Advisory service that continues to be a valued resource and focus for development to this day.

The Huntington’s Disease Association provides support to anyone affected by Huntington’s or anyone involved in their care and support across England and Wales. We also work closely with other Huntington’s disease charities across the UK and Ireland. We now have 36 staff members from a wide range of backgrounds. From nursing and social care to fundraising and administration, all united in our dedication to supporting people living with and affected by Huntington’s.

What we do

Specialist Advisory Service

The Specialist Huntington's disease Advisory service provides practical information, advice and emotional support to people with Huntington’s and their families across England and Wales. Our advisers promote local services, assist with the organisation of care packages and answer crisis calls to ensure people affected by Huntington’s receive the best possible care and support available. They also offer training, advice and support to professionals involved in the care of people with Huntington’s to improve quality of care.

Juvenile Huntington’s disease support

We are the only Huntington’s disease charity with a dedicated Specialist Juvenile Huntington’s Adviser in the world, supporting people affected by the juvenile form of the disease and their families across England and Wales.

Youth Services

We have a Huntington’s Disease Youth Engagement service (HDYES) providing support to young people aged 8-25 living in families affected by Huntington’s. HDYES is co-ordinated by a Youth Engagement Co-ordinator currently covering the whole of England and Wales.

Membership

We have a membership of over 5,000 people, made up of both families living with Huntington’s disease and health and social care professionals caring for people with Huntington’s.

Branches and Support Groups

We are linked to a number of local Huntington’s Disease Association branches and support groups, all led by dedicated volunteers. These groups provide invaluable peer support on a local level. They support many aspects of the Huntington’s Disease Association’s work.

Partnership working

We are a charity with limited resources, so we work closely with other organisations for maximum impact and influence. Organisations we regularly work with include the Neurological Alliance, Genetic Alliance UK and Rare Disease UK. We also work with other Huntington’s disease charities including the European and International Huntington’s Associations. We are part of an alliance with the Scottish Huntington Association, Huntington’s Disease Alliance Northern Ireland, and the Huntington's Disease Association of Ireland.

Research projects

We work with scientific, clinical and social researchers and experts in the field of Huntington’s in their search for ways to improve care and treatment. One day, we hope for a cure for the disease.

Supporters

We have an army of committed supporters who dedicate their time and energy to raising awareness, supporting those affected by the disease and fundraising to help ensure we can continue supporting those who need our help.

Achievements and performance

Highlights 2022/23

As we begin our new five-year strategy, this year’s annual report is a reflection on our key achievements over the past year. This year we consulted with the community on what they wanted our priorities to be.

After an increase in fundraising last year investment has been made into the charity infrastructure this year, so we can continue our ambitious aims whilst continuing to offer support to the Huntington's disease community.

Key investment achievements included:

- The Helpline Advisor role quickly made an impact enabling people accessing the services the ability to speak to a person sooner.
- The Policy and Public Affairs Manager established positive relationships with Parliament, with Hilary Benn agreeing to be a Parliamentary Champion for us, leading to a Westminster Hall Debate is November 2022. To have a role that can help people advocate for Huntington’s disease is an exciting time, we want to be able to create change for people affected by Huntington’s disease.
- A new youth worker means we can support more young people and new advisers meaning we can directly support more young people.

Our campaign for Huntington's Disease Awareness Month in 2022 was called Huntington’s in Mind, its objective was to raise awareness of mental health and Huntington’s disease.

The three main target audiences the campaign wants to engage with:

1. Huntington’s community; those with symptoms, those at risk, those who are gene-positive, carers and family members
2. Policy makers and parliamentarians
3. Health care professionals

The campaign was used as a call to action across the year, raising the understanding that mental health is an important part of people affected by Huntington’s disease.

We celebrated two Award wins this year:

1. Charitable Campaign of the Year Award at the Communiqué Awards 2022
2. Best Campaign Award at the Gene People Awards 2022

This was for a campaign involving the Alliance Partnership for the ‘My Family Matters’ campaign which took place in May 2021.

As we came to the end of our five year strategy, we began consultation on how people had found their support from our charity. The consultation included a questionnaire and a number of focus group sessions, all conducted by an external agency to prevent bias.

The results were positive with the charity receiving a Net Promoter Score (a customer satisfaction score) of 75, meaning people are highly likely to recommend us.

As said by one participant
“Facing this extremely difficult illness with an uncertain future ahead, we are confident in the knowledge that the Huntington's Disease Association is beside us for this journey.”

The respondents used a mix of services showing the variety of ways people access our services.

- 87% of respondents had used the service by telephone or in person
- 78% had used our services digitally
- 43% had engaged through in person events, branches and support groups

Comments where people thought we could improve have been taken into consideration for the next strategy. This included an online chat or email service and difficulty in accessing the service for those for whom English is not their first language. Other feedback was the loss of face-to-face contact that many felt was needed, at the time of the survey some of the comments were made at times when we couldn't risk face-to-face situations due to Covid. However, it is good to understand how people would like to access our services when planning for the future.

Using information gained in this report, consulting with staff and trustees led to the creation of our new five-year strategy, our promise on how we will support anyone affected by Huntington's disease.

Summary of Huntington's Disease Association Annual Report:

Goal 1: Improved Quality Care and Support

•The advisory service has provided crucial support, education, and help for families affected by Huntington's disease.
•Quality Assured accreditation ensures better care in care homes, with several homes receiving recognition.
•In-person events like the JHD Weekend resumed in June 2022, fostering connections among families facing Huntington's disease.

Goal 2: Better Knowledge and Understanding of Huntington’s disease

•Professionals attended courses and webinars, enhancing their knowledge of Huntington's disease.
•Support for professionals, training sessions, and attendance at professional meetings significantly increased.
•Webinars for families covered various topics, and a Family Voices webinar series featured lived experiences.
•The HD Champions Pilot program expanded knowledge-sharing through online learning.

Goal 3: Greater Opportunity for Peer Support and Community Involvement

•The AGM and Family Conference adapted to online formats, engaging the community and featuring key speakers.
•A new Volunteer Manager role was introduced to support branches and support groups.
•In-person family events returned, strengthening connections among community members.
•Peer support groups and Narrative Therapy sessions offered valuable support.

Goal 4: Improved Understanding of Huntington’s and the Association's Role with the General Public

•The '#HuntingtonsInMind' campaign raised awareness about the mental health impact of the disease.
•Collaboration with the BBC showcased Huntington's disease on prime-time TV.
•An Early Day Motion in Parliament furthered awareness and support.
•The website was updated for better community navigation, and social media engagement increased significantly.

Goal 5: A Strong Charity to Better Champion the Needs of Our Community

•New roles, including a Helpline Adviser, Policy and Public Affairs Manager, and Youth Team Worker, increased the charity's effectiveness.
•Income from community fundraising and events grew significantly.
•Individual giving and regular donations also increased, ensuring stable funding.
•Trusts, foundations, and corporate supporters contributed to the charity's growth.

Goal 6: Supporting Huntington’s Research

•The Association continued to support research studies and drug trials, keeping the community informed.
•HD Voice provided valuable feedback on research projects and played a role in communication and fundraising.
•Attendance at the European Huntingtons Disease Network (EHDN) conference facilitated international collaboration.
•Fundraising efforts, including the Christmas Appeal, and Jingle Jam, contributed to funding.

In conclusion, the Huntington's Disease Association achieved its goals of providing support and education, fostering community involvement, and contributing to research. The report highlights the dedication and impact of the Association in improving the lives of those affected by Huntington's disease.

The following pages show in detail what we have achieved in relation to our strategic aims:

Our Impact

Goal one - Improved quality care and support

Camilla talks about how the advisory service has helped her,

“I learnt about the Huntington's Disease Association after a few years of looking after her (sister). The Specialist Adviser for Cornwall was amazing. He ran sessions in the nursing homes to provide information on Huntington's disease and how best to help patients and he provided help with continuing healthcare (CHC). My great auntie wasn’t even given a Huntington's consultant or specialist Huntington's nurse due to non-compliance. Our adviser helped me to learn about the disease and give me advice at various stages when needed."

The expertise of the advisers and the understanding of Huntington’s disease that they have demonstrate the difference that knowledge can make in improving care and support.

This quote from a service user shows the difference our services make,

“Our family has had the support of the Huntington's Disease Association at a time of severe emotional stress. It was the only place that could possibly understand the complexities of a family member being diagnosed with Huntington’s disease and the impact of that on all concerned. Though one or two family members are accessing the service, it has a trickle effect which enables you to support others in the best way possible.”

Our services continue to be in demand, with our advisers working to support families across England and Wales. We offer support in a number of ways and will attend clinics to ensure all health and social care professionals are supported in providing the right care for someone with Huntington’s disease.

In numbers
Support: 8,012 people
Family visits (virtual and in person): 989
Clinic Attendance: 250

HDA Quality Assured
The Quality Assured accreditation is a mark of assurance to make choosing a care home more of a positive experience for families affected by Huntington's disease. The scheme improves choice and provides people with reassurance that core standards of care will be provided and more information to help them make a decision about the best care home for their needs.

Accreditation is a rigorous process and HDA Quality Assured was this year awarded to
•Exemplar homes - Dearnevale in Barnsley and Kavanagh Place in Liverpool.
•Fieldbay homes - Yr Ysgol and Pen Y Bont.
•Elysium Health Care - Stanley House in Herefordshire.

Juvenile Huntington’s Disease (JHD) and Young People

This year saw a return to in-person events. We were delighted to be able to hold the JHD Weekend in June 2022. The first in three years.

“We made new friends who are in the same situation as ourselves, people who can understand and empathise with us.” - Weekend attendee.

Youth Engagement Service - HDYES

Due to it’s hereditary nature Huntington’s disease affects all generations. Working with children and young people is key to offering people with Huntington’s disease the generational support they need. This year we have been working and consulting with young people to see how services can be designed to meet their needs. We worked with an external agency to consult with young people to prevent bias. The lockdown in the previous year had a huge impact on young children and how they accessed our services. Understanding we needed a fresh approach to engage with young people we worked with an external company to consult with young service users. From this, the Huntington’s Disease Youth Voice was created - a group of young people who will help us develop the services, programmes and resources that we create so that we can provide the best possible support for young people impacted by Huntington's disease. The group started in January 2023 with a residential meeting of ten young people accompanied by our Youth Coordinators. This group continue to meet and influence the way our HDYES service has transformed.

HDYES in numbers

Support by the youth service: 704
Family visits (virtual and in person): 429
New contacts: 84

Welfare Grant

Offering direct financial support through welfare grants improves people’s quality of life, and independence and reduces risks. £10,022.75 was awarded in 40 grants during 22/23. All of these grants were for people symptomatic with Huntington’s disease. Research found that the grant improved quality of life in 93% of cases, and in 81% of cases, risk had been reduced.

Communication

Understanding the importance of the website as a source of information for the community, we aim to continually improve the website. Working with the community allowed us to improve the navigation of the website and understand what information they looked for when visiting www.hda.org.uk.

Through consultation a new website was designed with an easier-to-manage content system, this meant website updates could be made more timely and the design reflected what the community told us they wanted. For example, the ‘How we support you’ area of the website now includes all information by area including all details of the local adviser, branches and support group information.

Over the year the website had 284,000 views. The most popular pages visited were ‘What is Huntington’s disease’, ‘News’ and ‘Support near you’.

Goal two - Better knowledge and understanding of Huntington’s disease

We work with families and professionals to inform and educate them about Huntington’s disease.

Educating professionals about Huntington's disease is key to increasing knowledge and understanding making it easier when families are visiting professionals as they have a better understanding of the disease.This includes offering:

Understanding Huntington’s disease - course for professionals. This three day certified course was attended by 60 attendees this year.

“I believe the training was excellent. Huntington's is such a complex disease, so I do not believe I will ever become an expert or feel confident explaining it to my colleagues. However, my knowledge of the disease has improved significantly and I believe I stand a greater chance of connecting with families suffering from Huntington's” - Course attendee.

A series of education webinars across the year, covered various topics as requested by professionals we worked with.

As commented by an attendee at a session targeting care homes,

“Staff gained more confidence to provide a high quality of care to residents with Huntington's disease. Some of us were reluctant and some were scared to provide care however, after the training the staff have now different views about it.”

Working with professionals
In numbers:
Support to professionals (email and phone): 16,720
Training sessions delivered by the advisory service: 135 sessions with 1,368 attendees
Attending professional meetings: 656
Attending HDYES professional meetings: 60
HDYES information sessions for professionals: 19 sessions delivered

We offer a number of webinars for families covering topics that the community have raised as queries, these include subjects such as voice banking, insurance, genetic testing, seating and posture, eating and drinking plus many more. Nine webinars organised attracted 285 attendees, and the YouTube version of the webinars has been watched many more times.

This year we launched the Family Voices webinar series, four webinars sharing lived experiences from well-respected people in the community. The webinars were a partnership between the Huntington’s Disease Alliance UK and Ireland. This was a positive experience of working together with people from all over the UK attending the live sessions, the webinars are now available to watch on our YouTube channel and have been viewed over 1,000 times.

With a return to more in-person events, highlights included a study afternoon in Dorset and a successful event on the Isle of Man.

The Isle of Man event was supported by Specialist Huntington's disease Advisers, Anita Daly and Theresa Westhead and was attended by 100 professionals. They also offered one to one family support sessions with a total of ten family members. *“We are just realising what we have actually achieved, it’s just truly amazing. I am so proud of the hard work and commitment from our small committee. Teamwork makes the dream work, we support and care together*” Helen Martin (Support Group Leader – Isle of Man)

Mental health study afternoon
We ran a course on mental health and Huntington’s disease as part of the '#HuntingtonsInMind' campaign attended by 80 professionals. Due to its popularity, a second session was organised and attended by 400 professionals. It was a fantastic success to reach this number of people working in an area of such importance to the charity.

•96% of attendees said that their knowledge and understanding of Huntington’s disease had increased as a result of the course
•97% of poll responders said that the webinar would help them provide better quality care and 99% said that the webinar had improved their knowledge.

HD Champions Pilot
Working with the European Huntington's Disease Network (EHDN) we piloted an online learning program with six care homes. The program was developed by the Swedish Association and was successfully trialled in five care homes that are part of the Quality Assured Scheme. The course will be run 3-4 times a year. We have been invited to give a talk, alongside the Swedish Huntington's Association who developed the online programme

Goal three - Greater opportunity for peer support and community involvement

AGM and Family Conference
The decision on whether the conference had to be held in person or online had to be made earlier in the year, due to the uncertainty of Covid. The online conference was well attended and the speakers were recorded to be shared as online webinars. We were pleased to have our patron George Rainsford join us. Nicci Robertson shared an update on Enroll HD, Chloe Holmes shared her journey with HDYES and Jenny Townhill gave a Clinical Trials update. At the conference, we premiered our new co created animation that explains 'What is Huntington's disease?' Feedback about the animation included:

"This is great"
"When can we see this on TV?"

We asked attendees what they wanted for the next AGM through online polls, making sure the community's opinions were at the heart of our decision-making for next year's conference.

Volunteer Manager
We were delighted to create a new post this year, the new Volunteer Manager whose responsibilities include supporting Branches and support groups. Branches and support groups play a big part in our community and we now need to do more to ensure these groups are supported. The role also includes supporting the wider volunteer network.

JHD weekend 3 - 5 June
This year we were excited to return to the Calvert Trust for our first in-person family event in three years! The weekend was packed full of activities for those affected with Juvenile Huntington's disease and their families. It is always very powerful to see the families all together and see them relax together as the weekend progresses. Some of the young people as well as some of the parents have made some really deep friendships which have continued outside of the weekend. A comment which regularly comes up on the evaluation forms is that this is the one environment where they feel they can completely relax.

"A welcoming and informative weekend where there is no shortage of chat and laughter as well as the opportunity to make new friends." - Weekend attendee

The year also saw a return to family days, as mentioned previously the Isle of Man held a successful event with over 100 professionals attending. Other family events included Brockenhurst and Hampshire family days. It was fantastic to see people from the community connect again.

We continued to offer online support through a mix of peer support groups for carers and families affected by JHD. These events are well-attended and offer an easy way for people to stay connected.

We trialled Narrative Therapy a respectful, non-blaming approach to counselling and community work which centres people as the experts in their own lives. The sessions were received extremely positively and narrative therapy as a tool to support people will continue to be a feature on the events calendar

"Made me realise I have a lot of skills, people, beliefs and hopes to help me when facing challenges. I felt lighter, less burdened and able to cope with difficulties in a more positive way" - Narrative therapy attendee.

Policy and Public Affairs
With a new Policy and Public Affairs Manager recruited we could begin work on our policy asks. Our top five policy asks are:

1. Access to community mental health services when psychiatric symptoms are present
2. A named care coordinator in each area to ensure people can navigate the many professionals they need and those professionals have knowledge and understanding of this disease
3. Specific NICE guidelines for Huntington's disease to ensure there is consistent care for this complex illness
4. A review of the blanket refusal to entry to the armed forces unless there has been a negative predictive test
5. Uplifting of benefits to reflect inflation as many people with Huntington's disease have higher energy and nutritional need.

Key successes already include:

•Increased awareness of the problem of mental health in people affected by Huntington's disease
•Agreement by Hilary Benn MP to become a parliamentary champion for the Huntington’s Disease Association - it an honour to have such a well respected MP supporting our cause.Hilary Benn organised a Westminster Hall debate in the Autumn of 2022, to engage MPs on the issue of Huntington’s disease and raise awareness of the issues members of the community were facing with the government. Ahead of the debate, HDA staff briefed Hilary Benn, ministerial advisors and MPs. A briefing was sent to all politicians about Huntington's disease, the main issues and our policy asks. A dozen MPs attended the debate, with a good spread of MPs from across the country and different political parties. MPs eloquently raised the big issues facing those with Huntington’s disease at present - from the postcode lottery of services, the need for NICE guidelines, to the exclusion to mental health services that so many are experiencing. Helen Whately, the Social Care Minister attended the debate on behalf of the government and agreed to take away several actions: looking into NICE guidelines for Huntington’s, the exclusions to mental health services and the possibility of having a named care coordinator for Huntington’s disease in every part of the country. While these issues were being looked into by the minister behind the scenes, the public affairs work switched to building a stronger base of support with more MPs, Lords and Baronesses.

Goal four - Improved understanding of Huntington’s and the Huntington’s Disease Association's role with the general public.

We worked with the BBC on the continuing storyline of Dr Ethan Hardy who found out he was positive for the Huntington’s disease gene. The actor George Rainsford who plays the character is now a patron of the Huntington’s Disease Association. The community were delighted to see Huntington's disease mentioned on prime-time TV. Working with the BBC helps us to ensure the disease is portrayed in the correct way.

Huntington's Disease Awareness Month May
For Huntington's disease awareness month, we highlighted the impact that Huntington’s disease has on mental health with the campaign, '#HuntingtonsInMind'.The campaign raised awareness about the mental health impact that a diagnosis of Huntington’s disease has on individuals and their families. We asked people from the Huntington’s community if they would like to share their stories, we were so thankful to the community who were so willing to do so.

The campaign '#HuntingtonsInMind' has a dual meaning, both looking at mental health and Huntington's being in the forefront of people’s minds.

Three videos were released during the month of May capturing the lived experience of people in the Huntington’s community and discussing the difficulties they had with mental health and accessing support.

A project group was set up across the charity to drive the campaign. We were delighted when George Rainsford agreed to be a spokesperson for the campaign, the timing of the campaign was a key moment in Casualty's storyline meaning George spoke about the campaign on ITV’s Loose Women and BBC Morning Live. This gave the campaign in TV terms alone a reach of over two million people. Additional press coverage included Metro papers, The Independent, Daily Express, Pick Me Up magazine an opinion piece in the Yorkshire Times and features in press aimed at professionals including The Carer, NR Times and Practice Nurse. The estimated total reach of all the press coverage was over 10.8 million people. It is an honour to be able to share people's stories as the cornerstone of the campaign. Our heartfelt thanks to everyone who contributed. The legacy of the campaign continues in the videos hosted on our YouTube channel which have been watched over 35,000 times.

During the month of May, we organised webinars about mental health as part of the '#HuntingtonsInMind' campaign. The momentum of the campaign became a call to action for the community. Working in partnership with the Scottish Huntington’s Disease Association, and Northern Ireland Association over 100 signatures were gathered for an Early Day Motion in Parliament, to look at:

“Calls on health and social care providers throughout the UK to expand specialist Huntington’s disease services and access to mental health and other essential support in order to help those living with Huntington’s disease and their families in the community.”

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Website

Thanks to funding from UniQure a pharmaceutical company, we were able to update our website, aligning it with the community's needs and preferences. The new look website was launched in April, with initial feedback positive. The new website also allows us to update information easily meaning our updates can be quicker allowing us to keep the community informed.

Social Media

With the appointment of a Social Media Officer, we were able to improve how we communicated digitally. This enabled us to develop new strategies for each social media platform. Key achievements include:

- Increased engagement - people commenting, and sharing our information
- Specific messages developed for each platform
- Development of TikTok - working with young people via the Huntington's Disease Youth Voice enabled us to reach a new audience

YouTube - Our channel continued to grow giving members of the community a chance to view webinars they were unable to attend. The platform has been used to share people's stories, the content has really resonated with the community. Through the power of sharing stories, we have been able to reach new people. Becki's story sharing her experience of living with Huntington's disease and how her Specialist Adviser has supported her has been viewed over 25,000 times. Total views for the year on our YouTube channel is over 35,000 times. With 339 subscribers and 50,632 views on our YouTube channel, social media plays a key role in increasing people's understanding of Huntington's disease.

Goal five - A strong charity to better champion the needs of our community

New roles

As the charity reported an increase in income in the previous year, we were able to recruit to new roles to increase the effectiveness of the service we offer.

Helpline Adviser - this is a responsive role. The Adviser Kim, is often the first point of contact for people who ring the helpline. Kim is a listening ear, provides emotional support and general advice/guidance and signposts/links to relevant wider services.

Policy and Public Affairs Manager - this important role has allowed us to have a voice in parliament to help fulfil our vision of 'A better life for anyone affected by Huntington's disease' Having a dedicated person to fulfil this role has meant our influence as a charity has a greater reach.

New youth team worker - due to the hereditary nature of Huntington's disease and its impact on children and young people we were delighted to be able to recruit a new youth worker further enabling the reach of the work we do. Jack has quickly established himself working with young people and has allowed the youth service to start its ambitious growth plan.

The operations team continues to support the charity to enable it to operate effectively. Their work includes HR, systems management, supporting staff, safeguarding policy and procedure management.

Goal six - Supporting Huntington's research

We continue to do all we can to continue in the fight for a cure for Huntington's disease. We have been closely working with pharmaceutical companies communicating research studies, and drug trials, and keeping the community up to date with the latest results from research studies.

We continue to fund HDBUZZ Huntington's disease research news. In plain language. Written by scientists. For the global Huntington's community

HD Voice continues to grow. HD Voice is an initiative by the Huntington's Disease Association that gives families a voice in Huntington's disease research and the internal work of the charity. They have been involved in many research projects giving valuable feedback on research. The group were also involved with supporting the communication and fundraising team. One of the HD Voice members was successfully appointed to the Clinical Research Network Kent, Surrey and Sussex (CRN KSS) as a Patient and Public Representative to the Partnership Board.

Attendance at the EHDN conference in September allowed us to meet with Huntington's disease Associations across the world as well as meet with various pharmaceutical companies. Together we work to inform the community of all developments in the drug world with the potential to help people affected by Huntington's disease.

Fundraising
In 2022/2023 our income from Community Fundraising and Events saw a huge boost bringing in £511,334.68 an increase of 16.2% on the previous year. Our largest event in the calendar year is the TCS London marathon which returned to the streets of London in October 2022 with our runners in '#TeamHDA' raising a brilliant £104,593.37. We expanded our offer to our TCS London Marathon '#TeamHDA' runners with activities over the weekend of the marathon including a pre and post-event meet up in central London. Thank you to everyone who took part and cheered '#TeamHDA' on whether it was on the TV or in person. At the other end of the country we were also thrilled to see our '#TeamHDA' take to the streets from Newcastle to South Shields in the Great North Run raising £13,805.92 towards our work.

As ever, our supporters showed imagination and ingenuity when it comes to organising their own fundraising challenges to raise funds. The fabulous Ladies Who Dare who took part in a skydive, Jess Webb not only organised a charity ball but also organised a collection at the Goodwood Super Car Day and was also the star of the BBC One Show, “One Big Thank You” in recognition of her amazing fundraising achievements for the Huntington’s Disease Association. We have an energetic lot of supporters who trained and ran for various challenge events including climbing Kilimanjaro, the Yorkshire 3 Peaks, the Rustbox Rally, the South West Coast Path Challenge and the Peaky Ramblers who covered the distance from Alnwick Castle to Bamburgh Castle.

Individual giving saw a 6.5% increase on the previous year with all donations in this area hitting £351,276. We now have over 534 regular donors who donated a total of £79,711 in the year. Donating to our work in this way is a cost-effective way for the charity to receive donations and helps the charity to plan our work. We have carried out a lot of work across individual giving across the year including an improved stewardship process for in memory donors and new fundraising products. It can be a nervous time for a charity when introducing a new fundraising product; we are conscious that we do not want to overload our supporter base, but we also want to be able to offer fundraising products which will engage and attract funding to support our work. We took the decision to introduce a charity lottery, working with Sterling Management and being part of their Unity Lottery. Our players have helped to raise £17,732 in its first full year. Thank you to everyone who has taken part in the lottery.

We would also like to thank those who invite the charity to be a part of their life celebrations, to the numerous brides and grooms and those celebrating wedding anniversaries raising funds for our work, thank you for allowing us to be a part of your special day.

Big thanks go to the community groups who supported our work. St George’s Golf Club in Surrey raised over £30,000 at their Captain’s Golf Day, Helston Cober Valley Rotary Group raised £3,000, and the Harvel Pedigree Whippet Racing Club raised over £1,000 from their pedigree whippet racing day. Our thanks go to all the choirs, churches and schools who raise funds and awareness of our work.

Our '#HD8000' challenge series continued raising over £10,000 over the course of the year. Our huge thanks to everyone who took part in '#HDMove', '#HDHike' or '#HDBike'.

In May 2022 we were thrilled to welcome people back to the Liverpool Blu Radisson for the Huntington’s Disease Association Awards, ably hosted by our friend, Charles Sabine. We introduced two new categories for this year, the Excellence in Health or Social Care to recognise the fantastic efforts of professionals who take the time to understand the complexities of Huntington’s disease to ensure that those in their care receive the best support was awarded to Alex Fisher. The Recognition award was presented to Maureen Jones and Doreen Spiers in honour of their hard work in the earlier days of the charity. Our congratulations to everyone who was nominated and our winners. It was wonderful to see you all there on the day.

Our first Christmas Appeal took place in December 2022 raising a wonderful £11,509 to support our work. Our thanks go to members of HDVoice, who helped us to shape our appeal letter and share their own stories of how to celebrate Christmas whilst living with Huntington’s.

We were delighted to continue our work with the Westerleigh Group and our thanks go to their many employees who took to the skies, ran or baked cakes raising over £40,000 towards our work. Our thanks go to other corporate supporters over the year including Strategic Dimensions who donated £2,000, Wixroyd Group who donated £3,700 in support of a ball organised by a supporter, the Phoenix Life who matched their employee's fundraising efforts with a donation of over £1,100 for the charity, the Ice Co who donated £650 following their annual family fun day, Lewis and Cooper in Northallerton continued their support with instore fundaising activities raising over £500, and Pyramid Steel whose monthly support of our work helped, to raise over £600 in the year. In total our corporate income increased 34.9% on the previous year.

Trusts and Foundations
Over the course of the year we saw a 64% increase on the previous year on income from Trusts and Foundations and Statutory. We are grateful to those Trusts and Foundations and Statutory partners whose support helps us to provide vital advice, information and support for people affected by Huntington’s disease.

In August 2022, we were delighted to be selected as one of 12 charities to benefit from the 2022 Jingle Jam Charity gaming event. Jingle Jam is the largest charity gaming event in the world and is driven by a community of volunteers, content creators, games companies, and charities all coming together over a two-week period between 1 December – 14 December 2022 to raise money. The charity was awarded £240,924.52 in support of our continued support and development of the Huntington’s Disease Association Youth Engagement Service (HDYES).

In February 2023 a full proposal worth £418,360 was submitted to the National Lottery Community Fund. This funding is to support the continued development of HDYES over the next three years.

2023 saw big changes as Clinical Commissioning Groups evolved into Integrated Care Boards/Systems. However, despite this we maintained our grant agreements for all our contracts as well as with Birmingham City Council and Dorset Healthcare University NHS Foundation. In addition, we received cost of living uplifts for three of our grant agreements as well as being successful in applying for a grant award of £31,275 from Liverpool City Council for our work support Clinically Extremely Vulnerable community members.

In 2022-23 we hosted our inaugural online Trusts and Foundations Engagement event. This virtual event brought Trust and Foundation grant-makers and funders closer to the people who their funding supports. Three speakers shared their different perspectives of Huntington’s disease and the work of the Huntington’s Disease Association. We look forward to planning more of these events in the future.
Putting people with Huntington’s disease at the heart of our work is key to letting the world know about Huntington’s disease and its effect upon individuals, families and communities. We will continue to work collaboratively with staff and supporters to share their stories and powerful messages.

We monitor return on investment on all our fundraising activities and meet or exceed all statutory and regulatory obligations.

We are members of the Fundraising Regulator and the Chartered Institute of Fundraising following best practice guidance laid down by them as well as the Charity Commission guidance for Charity Trustees (CC20). We comply with the Privacy and Electronic Communications Regulations (PECR). The Huntington’s Disease Association recognises that we may work with people in vulnerable circumstances so protection of vulnerable people is something we take seriously. We adhere to the Chartered Institute of Fundraising's guidance – ‘Treating Donors Fairly – responding to the needs of people in vulnerable circumstances’.

For the year 2022/2023 we did not receive any complaints about our fundraising practices/approaches.

Financial review

Financial review

The results for the year show an overall deficit of £104,651 (2022: surplus £742,867) made up of a deficit on the general fund of £247,758 (2022: surplus £715,699) and a surplus on the restricted funds of £142,927 (2022:surplus £27,168). The overall performance produced a deficit less than the 2022/2023 budgeted figure but the continued development of our services are anticipated to utilise reserves over the next two years to bring them in line with the Reserves Policy target.

Reserves Policy

The reserve requirement of the charity is to enable the salaries of staff members and running costs to be covered in the event of short-term income fluctuations. As a result of the uncertainties arising from the pandemic and inflationary pressures which may impact on income, it was agreed that the target for general reserves needed to be maintained at nine months recurring costs being approximately £1m.

At the year end, free reserves available excluding designated funds and tangible fixed assets stood at £1,746,363 (2022: £1,928,865) and therefore comfortably exceeded target. As noted in the Financial Review, the Trustees have agreed to utilise surplus reserves to develop the Association for the benefit of those impacted by Huntington’s disease and this is budgeted to continue over the next two years.

Risk Policy

The Trustees have assessed the major risks to which the Charity is exposed and are satisfied that systems are in place to mitigate exposure to major risks. The impact of the Coronavirus pandemic has been closely monitored by the Trustees and the Finance Committee. The success of the Reserves Policy means that the charity is well placed to make considered decisions on measures that may need to be taken as the current inflationary crisis unfolds.

Whilst working on the new strategy we looked at external and internal risks for the charity. Using two well-known strategy planning models, PESTLE and SWOT we have been able to identify potential risks to the charity. These include the rise in Cyberattacks, we have been working with our IT providers on a prevention strategy. All staff undergo mandatory training including, cyber security, data protection and Safeguarding.

The Future

We began the new financial year with the launch of our strategy. An animation was created to launch the strategy, sharing how we will make a difference.

The promises in this strategy will shape our future work. We looked at our Vision as a charity, working with the community in partnership has brought many benefits and we wanted to include this element in our updated vision by including the word ‘Together’, acknowledging that it is only by working with others we will achieve our vision.

“Together we will build a better life for anyone affected by Huntington’s disease.”

Our mission includes our commitment to advocating for change through campaigning, our continued commitment to providing education and support and demonstrating our commitment to working with the community to shape our mission:

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

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

During this time of reflection, we looked at our values, on what drives us as an organisation, again taking feedback from the community we updated and added a new value, Inspirational

Our values are:

- Tenacious
- Experienced
- Compassionate
- Inclusive
- Inspirational

Throughout the consultation process and throughout our work we often commented how it was the community that drove us, we reflected this with our new strapline to launch the strategy.

“Inspired by our community”

Our five goals for the next five years are:

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

Plans for 2023/24

We have recently submitted a bid to the lottery service to improve the expansion of the Huntington Disease Association Youth Service (HDYES), following on from the success of last year’s Jingle Jam fundraising we have big plans for the development of the service that includes:

- Developing co-production services
- Develop psychological support sessions with children and young people, including drawing and talking therapy and narrative therapy sessions
- Deliver HD Youth Voice co-production sessions, embedding our youth leadership and collaboration programme and producing new information resources for HDYES

We will continue to develop our resources adding new content using co production principles so our information is developed with the voices of people with Huntington’s.

We will work to increase the reach of all communication through all relevant social media, the website and online communications. Whilst increasing reach we will increase awareness of Huntington's disease. We will continue to develop our Ambassadors scheme so that people with Huntington’s can share their stories. We will continue to fight for a better future, making every day the best possible day with our campaign work. We will prioritise mental health and NICE guidelines and work with our parliamentary champion to gain more support in Parliament and the House of Lords.

We will continue working with other charities to ensure we have a louder voice and work to influence policymakers to address concerns of the community on concerns such as the increase in cost of living, access to appropriate treatment at the right time and access to mental health services.

Our development of the Advisory service remains a top priority, ensuring we have the right people to offer services throughout England and Wales. Understanding the complexity of Huntington’s disease and working with multiple agencies to ensure consistent care will remain a top priority of the Advisory Service. The team will expand its educational offering through the recruitment of an Education Lead, as we seek to improve professionals understanding of Huntington’s disease.

We will continue to offer in-person events where we can, although as are many other companies these can be affected by external factors such as train strikes, and adverse weather events. We have already booked our AGM and Community Conference to be held at the Radisson Blu Hotel, Derby and we are looking forward to an inspiring weekend of talks and events.

We plan to embrace the power of fundraising this year by introducing creative ways to fundraise, through gaming (after the success of this year’s Jingle Jam) and have partnered with Run for Charity to be able to offer a wider selection of events for people. We want to ensure giving is easy for people to do and are working with GOODPAYE to streamline payroll giving. We are developing the website to simplify the donation process.

As we continue to work with researchers and pharmaceutical companies to help find a cure and access to drugs to help treat the symptoms of Huntington’s disease we are driven by the resilience of the people we work with. We can not thank the community enough who tirelessly campaign with us and fundraise for us.

Structure, governance and management

Governing document

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

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

Dr G El-Nimr	
Mr N M Heath (Hon Treasurer)	
Dr E M Howard (Vice-Chairperson)	(Resigned 15 October 2022)
Professor H Rickards (Chair)	
Dr A Fryer	(Resigned 15 October 2022)
Ms C Lyon	
Ms S Barker	
Mr S Duckett	
Dr N Swales	
Ms B E Waters	
Ms H Hubberstey	(Appointed 20 October 2022)
Ms C K Holmes	(Appointed 20 October 2022)
Mr D R Thomas	(Appointed 20 October 2022)

Recruitment and appointment of trustees

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

Organisational structure

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

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

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

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

Trustee induction and training

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

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

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: 18 October 2023

STATEMENT OF TRUSTEES' RESPONSIBILITIES

FOR THE YEAR ENDED 31 MARCH 2023

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

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

In preparing these accounts, the trustees are required to:

- select suitable accounting policies and then apply them consistently;

- observe the methods and principles in the Charities SORP;

- make judgements and estimates that are reasonable and prudent;

- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the accounts; and

- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

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

INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

Opinion

We have audited the financial statements of Huntington's Disease Association (the 'charity') for the year ended 31 March 2023 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

- the information given in the trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, is consistent with the financial statements; and
- the directors' report included within the trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

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

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

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

Responsibilities of trustees

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

Auditor's responsibilities for the audit of the financial statements

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

The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

Capability of the audit in detecting irregularities, including fraud

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

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

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

Audit procedures undertaken in response to the potential risks relating to irregularities (which include fraud and non-compliance with laws and regulations) comprised of: inquiries of management and the Trustees as to whether the entity complies with such laws and regulations; enquiries with the same concerning any actual or potential litigation or claims; inspection of relevant legal correspondence; review of Trustee meeting minutes; testing the appropriateness of journal entries; and the performance of analytical review to identify unexpected movements in account balances which may be indicative of fraud.

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

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

Use of our report

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

Andrew Moss BA FCA (Senior Statutory Auditor)
for and on behalf of DSG

18 October 2023

Chartered Accountants
Statutory Auditor

Castle Chambers
43 Castle Street
Liverpool
L2 9TL

HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Income from							
Donations and legacies	2	1,298,518	74,311	1,372,829	1,723,498	27,981	1,751,479
Charitable activities	3	28,354	542,026	570,380	55,853	319,533	375,386
Other trading activities	4	18,367	-	18,367	24,975	-	24,975
Investments	5	36,267	-	36,267	12,941	-	12,941
Other income	6	5,735	-	5,735	1,544	-	1,544
Total income		1,387,241	616,337	2,003,578	1,818,811	347,514	2,166,325
Expenditure on:							
Raising funds	7	292,650	-	292,650	219,774	-	219,774
Charitable activities	8	1,268,506	473,410	1,741,916	879,401	320,346	1,199,747
Total expenditure		1,561,156	473,410	2,034,566	1,099,175	320,346	1,419,521
Net gains/(losses) on investments	12	(73,663)	-	(73,663)	(3,937)	-	(3,937)
Net movement in funds		(247,578)	142,927	(104,651)	715,699	27,168	742,867
Reconciliation of funds							
Fund balances at 1 April 2022		2,405,724	83,050	2,488,774	1,690,025	55,882	1,745,907
Fund balances at 31 March 2023		2,158,146	225,977	2,384,123	2,405,724	83,050	2,488,774

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

HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
BALANCE SHEET

AS AT 31 MARCH 2023

		2023		2022	
	Notes	**£**	**£**	**£**	**£**
Fixed assets					
Tangible assets	**14**		20,359		20,137
Investments	**15**		875,147		948,810
			895,506		968,947
Current assets					
Stocks	**16**	9,007		10,174	
Debtors	**17**	390,793		677,503	
Cash at bank and in hand		1,243,672		962,916	
		1,643,472		1,650,593	
Creditors: amounts falling due within one year	**18**	(154,855)		(130,766)	
Net current assets			1,488,617		1,519,827
Total assets less current liabilities			2,384,123		2,488,774
Income funds					
Restricted funds	**20**		225,977		83,050
<u>Unrestricted funds</u>					
Designated funds	**21**	391,424		456,722	
General unrestricted funds		1,766,722		1,949,002	
			2,158,146		2,405,724
			2,384,123		2,488,774

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

The financial statements were approved by the Trustees on 18 October 2023

N M Heath

Mr N M Heath (Hon Treasurer)
Trustee

Company registration number 02021975

HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2023

		2023		2022	
	Notes	**£**	**£**	**£**	**£**
Cash flows from operating activities					
Cash generated from operations	**26**		254,329		473,153
Investing activities					
Purchase of tangible fixed assets		(9,840)		(23,289)	
Purchase of investments		-		(501,462)	
Proceeds from disposal of investments		-		1,462	
Investment income received		36,267		12,941	
Net cash generated from/(used in) investing activities			26,427		(510,348)
Net cash used in financing activities			-		-
Net increase/(decrease) in cash and cash equivalents			280,756		(37,195)
Cash and cash equivalents at beginning of year			962,916		1,000,111
Cash and cash equivalents at end of year			1,243,672		962,916

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.

1 Accounting policies **(Continued)**

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

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

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

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

1.5 Expenditure

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

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

1.6 Tangible fixed assets

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

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

Fixtures and fittings	25% straight line

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

1.7 Fixed asset investments

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

1.8 Impairment of fixed assets

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

1.9 Stocks

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

1.10 Cash and cash equivalents

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

1 Accounting policies (Continued)

1.11 Financial instruments

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

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

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

Basic financial assets

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

Impairment of financial assets

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

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

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

Derecognition of financial assets

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

Basic financial liabilities

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

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

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

Derecognition of financial liabilities

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

1 Accounting policies (Continued)

1.12 Employee benefits

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

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

1.13 Retirement benefits

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

1.14 Branch funds

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

2 Donations and legacies

	Unrestricted funds	**Restricted funds**	**Total**	Unrestricted funds	Restricted funds	Total
	2023	**2023**	**2023**	2022	2022	2022
	£	**£**	**£**	£	£	£
Donations and gifts	968,144	70,121	1,038,265	888,814	23,381	912,195
Legacies receivable	297,406	-	297,406	805,537	3,000	808,537
Branch income	32,968	4,190	37,158	29,147	1,600	30,747
	1,298,518	74,311	1,372,829	1,723,498	27,981	1,751,479

3 Charitable activities

	2023	**2022**
	£	**£**
Grants received	548,026	345,633
Merchandise	15,708	19,812
Other income	6,646	9,941
	570,380	375,386
Analysis by fund		
Unrestricted funds	28,354	55,853
Restricted funds	542,026	319,533
	570,380	375,386

4 Other trading activities

	Unrestricted funds	**Unrestricted funds**
	2023	**2022**
	£	**£**
Consultancy	18,367	24,975

5 Investments

	Unrestricted funds	**Unrestricted funds**
	2023	**2022**
	£	**£**
Income from listed investments	25,241	12,615
Interest receivable	11,026	326
	36,267	12,941

6 Other income

	Unrestricted funds	**Unrestricted funds**
	2023	**2022**
	£	**£**
Miscellaneous income	5,735	1,544

7 Raising funds

	Unrestricted funds	Unrestricted funds
	2023	2022
	£	£
<u>Fundraising and publicity</u>		
Fundraising events	24,195	4,683
Other fundraising costs	94,196	43,830
Staff costs	174,259	171,261
Fundraising and publicity	292,650	219,774

8 Charitable activities

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication - Policy & Public Affairs	Youth Workers & Juvenile	Branch	Total 2023	Total 2022
	£	£	£	£	£	£	£	£
Staff costs	793,743	882	882	120,739	72,432	17,588	1,006,266	783,674
Welfare grants	-	12,734	-	-	-	8,058	20,792	19,551
Research	-	-	20,180	-	-	-	20,180	91
Recruitment	2,386	-	-	257	764	-	3,407	1,028
Travel and training	37,722	-	-	2,490	7,961	687	48,860	14,623
Telephone and internet	18,965	-	-	690	675	236	20,566	20,862
Other costs	49,406	63	63	54,925	25,143	20,987	150,587	65,098
Newsletter	-	-	-	24,669	-	-	24,669	5,334
Website	-	-	-	23,945	-	-	23,945	15,379
Event costs	7,712	-	-	706	23,659	-	32,077	4,855
	909,934	13,679	21,125	228,421	130,634	47,556	1,351,349	930,495
Share of support costs (see note 9)	204,472	19,338	-	77,352	38,676	38,676	378,514	257,598
Share of governance costs (see note 9)	12,053	-	-	-	-	-	12,053	11,654
	1,126,459	33,017	21,125	305,773	169,310	86,232	1,741,916	1,199,747
Analysis by fund								
Unrestricted funds	779,438	24,100	1,125	297,715	79,896	86,232	1,268,506	879,401
Restricted funds	347,021	8,917	20,000	8,058	89,414	-	473,410	320,346
	1,126,459	33,017	21,125	305,773	169,310	86,232	1,741,916	1,199,747

8 Charitable activities

(Continued)

For the year ended 31 March 2022

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication - Policy & Public Affairs	Youth Workers & Juvenile	Branch	Total 2022
	£	£	£	£	£	£	£
Staff costs	604,237	2,608	795	79,203	86,831	10,000	783,674
Welfare grants	-	11,536	-	-	-	8,015	19,551
Research	-	-	91	-	-	-	91
Recruitment	593	-	-	435	-	-	1,028
Travel and training	14,332	-	-	160	131	-	14,623
Telephone and internet	19,949	-	1	504	408	-	20,862
Other costs	23,954	38	38	16,366	4,635	20,067	65,098
Newsletter	-	-	-	5,334	-	-	5,334
Website	-	-	-	15,379	-	-	15,379
Event costs	4,504	-	-	-	351	-	4,855
	667,569	14,182	925	117,381	92,356	38,082	930,495
Share of support costs (see note 9)	141,678	12,880	-	30,912	20,608	51,520	257,598
Share of governance costs (see note 9)	11,654	-	-	-	-	-	11,654
	820,901	27,062	925	148,293	112,964	89,602	1,199,747
Analysis by fund							
Unrestricted funds	547,694	17,608	834	148,293	75,370	89,602	879,401
Restricted funds	273,207	9,454	91	-	37,594	-	320,346
	820,901	27,062	925	148,293	112,964	89,602	1,199,747

9 Support costs

	Support costs	Governance costs	2023	Support costs	Governance costs	2022
	£	£	£	£	£	£
Staff costs	215,284	-	215,284	124,021	-	124,021
Depreciation	9,618	-	9,618	7,771	-	7,771
Head office costs	153,612	-	153,612	125,806	-	125,806
Audit fees	-	8,250	8,250	-	8,000	8,000
EC meeting costs	-	3,803	3,803	-	3,654	3,654
	378,514	12,053	390,567	257,598	11,654	269,252
Analysed between						
Charitable activities	378,514	12,053	390,567	257,598	11,654	269,252

Support costs are allocated of the basis of time spent.

10 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year (2022: £nil). Two trustees were reimbursed expenses totalling £179 for a subscription and part payment of a training course (2022: two trustees were reimbursed £112).

11 Employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
Specialist HD Advisors	22	19
Management	1	1
Fundraising	5	5
Youth Worker	2	1
Administration	8	5
Communications	3	2
Total	41	33

Employment costs	2023	2022
	£	£
Wages and salaries	1,240,304	963,553
Social security costs	121,121	89,010
Other pension costs	34,384	26,393
	1,395,809	1,078,956

11 Employees (Continued)

The number of employees whose annual remuneration was more than £60,000 is as follows:

	2023 Number	2022 Number
£60,001 - £70,000	-	1
£70,001 - £80,000	1	-

12 Net gains/(losses) on investments

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Revaluation of investments	(73,663)	(3,937)

13 Taxation

The charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxationof Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects.

14 Tangible fixed assets

	Fixtures and fittings £
Cost	
At 1 April 2022	96,747
Additions	9,840
Disposals	(60,438)
At 31 March 2023	46,149
Depreciation	
At 1 April 2022	76,610
Depreciation charged in the year	9,618
Eliminated in respect of disposals	(60,438)
At 31 March 2023	25,790
Carrying amount	
At 31 March 2023	20,359
At 31 March 2022	20,137

15 Fixed asset investments

	Listed investments £
Valuation	
At 1 April 2022	948,810
Valuation changes	(73,663)
At 31 March 2023	875,147
Carrying amount	
At 31 March 2023	875,147
At 31 March 2022	948,810

16 Stocks

	2023 £	2022 £
Merchandise	9,007	10,174

17 Debtors

Amounts falling due within one year:	2023 £	2022 £
Trade debtors	3,309	15,455
Other debtors	297,298	608,214
Prepayments	90,186	53,834
	390,793	677,503

Other debtors include £252,932 (2022: £575,845) of legacies receivable.

18 Creditors: amounts falling due within one year

	2023 £	2022 £
Other taxation and social security	27,005	25,512
Trade creditors	54,744	48,286
Accruals and deferred income	73,106	56,968
	154,855	130,766

Included in accruals and deferred income is deferred income of £58,423 (2022: £37,600) relating to income received for future periods.

19 Retirement benefit schemes

Defined contribution schemes

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

The charge to the statement of financial activities in respect of defined contribution schemes was £34,384 (2022 - £26,393).

20 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

		Movement in funds			**Movement in funds**		
	Balance at 1 April 2021	**Incoming resources**	**Resources expended**	**Balance at 1 April 2022**	**Incoming resources**	**Resources expended**	**Balance at 31 March 2023**
	£	**£**	**£**	**£**	**£**	**£**	**£**
Research	16,700	9,795	(91)	26,404	7,980	(20,000)	14,384
Specialist HD Advisory Service (SHDA)	-	268,674	(268,674)	-	347,021	(347,021)	-
Children in Need	4,757	-	-	4,757	-	(4,757)	-
Lancashire Training Events	4,849	-	-	4,849	-	-	4,849
Juvenile Huntingtons Disease	-	135	(135)	-	1,500	(1,500)	-
JHD Weekend	24,624	1,000	(152)	25,472	-	(25,472)	-
Youth Services	3,048	52,500	(37,307)	18,241	1,524	(19,765)	-
BUPA Old Carers	1,904	-	(1,904)	-	-	-	-
B & Q Foundation	-	5,000	(4,533)	467	5,000	(2,768)	2,699
Welfare Fund	-	10,410	(7,550)	2,860	4,329	(6,149)	1,040
Website	-	-	-	-	8,058	(8,058)	-
Jingle Jam	-	-	-	-	240,925	(37,920)	203,005
	55,882	347,514	(320,346)	83,050	616,337	(473,410)	225,977

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

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

20 Restricted funds (Continued)

Children in Need
This grant is to fund a youth worker.

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

Juvenile HD
This fund relates to income raised by a supporter who requested the funds be used to raise awareness of Juvenile Huntingtons Disease.

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

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

Bupa Old Carers
We were awarded funding by BUPA UK Foundation to create an online area to support older carers aged 65+.

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

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

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

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

21 Designated funds

The income funds of the charity include the following designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes:

		Movement in funds				Movement in funds		
	Balance at 1 April 2021	**Incoming resources**	**Resources expended**	**Transfers**	**Balance at 1 April 2022**	**Incoming resources**	**Resources expended**	**Balance at 31 March 2023**
	£	**£**	**£**	**£**	**£**	**£**	**£**	**£**
Special projects fund	214,000	-	-	(30,000)	184,000	-	(41,110)	142,890
Branch funds	72,265	20,992	(27,535)	-	65,722	26,276	(26,996)	65,002
Huntington’s Disease Youth Engagement Service	-	-	-	207,000	207,000	-	(23,468)	183,532
	286,265	20,992	(27,535)	177,000	456,722	26,276	(91,574)	391,424

A designated special projects fund of £400,000 was established as a result of generous legacies received during 2013. It is intended that the fund be used for special projects, which, once instituted, may be developed in accordance with the long-term objectives of the charity. During 2015 and 2016 £130,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support. A further £40,000 of the fund was used to support the new communication initiative in 2017/18 and £16,000 was used in 2018/19 to complete the Care Home Accreditation project. In 2021/22, £30,000 was released to cover costs associated with changes necessitated by the pandemic including reducing the office size, software improvement and project development. The balance of the fund amounting to £184,000 has been allocated in part to cover a substantial portion of the 2022/23 budget deficit arising from new posts covering National Support, Policy and Public Affairs, Data Management and Volunteer Support.

We have been successful in obtaining funding from the National Lottery for a 3 year project for the expansion of the Huntington’s Disease Youth Engagement Service (Youth Project). The project began on 1 June 2023 and as part of the project we have committed to spending £183,532 of our own resources over the 3 years.

22 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2023	**2023**	**2023**	**2022**	**2022**	**2022**
	£	**£**	**£**	**£**	**£**	**£**
Fund balances at 31 March 2023 are represented by:						
Tangible assets	20,359	-	20,359	20,137	-	20,137
Investments	875,147	-	875,147	948,810	-	948,810
Current assets/(liabilities)	1,262,640	225,977	1,488,617	1,436,777	83,050	1,519,827
	2,158,146	225,977	2,384,123	2,405,724	83,050	2,488,774

23 Operating lease commitments

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

	2023 **£**	**2022** **£**
Within one year	34,627	28,580
Between two and five years	70,926	96,233
	105,553	124,813

24 Related party transactions

Remuneration of key management personnel

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

	2023 **£**	**2022** **£**
Aggregate remuneration	298,495	217,690

Transactions with related parties

During the year, one trustee donated £116 (2022: £120).

There were no other related party transactions in the year.

25 Branch funds

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

	2023 **£**	**2022** **£**
Cash balances		
At 1 April 2022	65,722	72,265
Receipts in year	37,158	30,747
Less :		
Local welfare grants	(8,058)	(7,468)
Sent to head office	(10,882)	(9,755)
Branch activities, local newsletters, equipment, research etc	(18,938)	(20,067)
At 31 March 2023	65,002	65,722

26 Cash generated from operations

	2023 £	2022 £
(Deficit)/surpus for the year	(104,651)	742,867
Adjustments for:		
Investment income recognised in statement of financial activities	(36,267)	(12,941)
Fair value gains and losses on investments	73,663	3,937
Depreciation and impairment of tangible fixed assets	9,618	7,771
Movements in working capital:		
Decrease/(increase) in stocks	1,167	(615)
Decrease/(increase) in debtors	286,710	(293,777)
Increase in creditors	24,089	25,911
Cash generated from operations	254,329	473,153

27 Acknowledgements

B&Q Foundation
Baron Davenport Charitable Trust
Birmingham City Council
Chapman Charitable Trust
Cheshire Community Foundation
Chrysalis Trust
Dorset Healthcare University NHS Foundation
Douglas Arter Foundation
Dryden Family Foundation
Edith Murphy Foundation
Edward Cadbury Charitable Trust
Elizabeth L Rathbone Charitable Trust
Fowler Smith and Jones Trust
Garfield Weston Foundation
Gay and Peter Hillard Hartley Charitable Trust
Hampshire and the Isle of Wight Community Foundation
Jingle Jam
John James Bristol Foundation
Liverpool City Council
Lord Leverhulmes Charitable Trust
Milles Charitable Foundation
Mrs Gladys Lancaster Will Trust
NHS Cambridgeshire & Peterborough Integrated Care Board
NHS Cornwall and Isles of Scilly Integrated Care Board
NHS Devon Integrated Care Board
NHS Lancashire and South Cumbria Integrated Care Board
North East and North Cumbria Integrated Care Board
PF Charitable Trust
PH Holt Foundation
PIB Community Trust
ShareGift (Orr Mackintosh Foundation)
Sovereign Healthcare
The Alan Higgs Charity
The Barbour Foundation
The Barratt Foundation
The Benham Charitable Settlement
The Charles Jacob Charitable Trust
The Charles Littlewood Charitable Trust
The Cumber Family Charitable Trust
The D'Oyly Carte Charitable Trust
The Dyers' Company Charitable Trust
The Earmark Trust
The Eveson Charitable Trust
The Februrary Foundation
The Florence Turner Trust
The Frederick and Phyllis Cann Trust
The George A Moore Foundation
The Goldcrest Charitable Trust
The Grace Trust
The Hadfield Charitable Trust
The Hadrian Trust
The Hull and East Riding Charitable Trust
The J Reginald Corah Foundation Fund
The Jeniffer & Jonathan Charitable Trust
The Joseph and Lena Randall Charitable Trust
The Lawson Trust

27 Acknowledgements continued

The Sir James Knott
The Sir James Reckitt Charity
The Sir James Roll Charitable Trust
The Strangwards Trust
The Sunrise (sidmouth) Charitable Trust
The Sylvia and Colin Shepherd Charitable Trust
The Thomas Sivewright Catto Charitable Settlement
The Ursula Keys Trust
The William Leech Charity
The Wixamtree Trust
The WO Street Charitable Foundation
The Lord Cozens-Hardy Trust
The Maud Elkington Charitable Trust
The May 1961 Charitable Trust
The Michael and Anna Wix Charitable Trust
The Miss Pannett Charitable Trust
The Mollie Croysdale Charitable Trust
The Norman Family Charitable Trust
The Paul Bassham Charitable Trust
The Peter Stebbing Memorial Charity
The Proven Family Trust
The Roger De Haan Charitable Trust
The Simon and Philip Cohen Charitable Trust