

Charity registration number 296453

Company registration number 02021975 (England and Wales)

HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE

LEGAL AND ADMINISTRATIVE INFORMATION

| | |
|--------------------------|--|
| Patrons | Tony Hadley Shane Richie George Rainsford |
| Trustees | Dr G El-Nimr Mr N M Heath (Hon Treasurer) Dr E M Howard (Vice-Chairperson) Professor H Rickards (Chair) Dr A Fryer Ms C Lyon Ms S Barker Mr S Duckett Dr N Swales Ms B E Waters |
| 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 |

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HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2022

The trustees present their annual report and financial statements for the year ended 31 March 2022.

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

Objectives and activities

Charity objects

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

Huntington's disease, a brief overview

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

Vision

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

Mission

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

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

Values

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive

Who we are

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

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

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

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

What we do

Specialist Advisory Service

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

Juvenile Huntington's disease support

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

Youth Services

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

Membership

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

Branches and Support Groups

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

Partnership working

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

Research projects

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

Supporters

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

Aims and objectives in 2021/22

The following goals underpin the Huntington's Disease Association's five-year strategy and were the focus of the charity's work throughout 2021/22:

- Improved quality care and support
- Better knowledge and understanding of Huntington's
- Greater opportunity for peer support and community involvement
- Improved understanding of Huntington's and the Huntington's Disease Association's role with the general public
- A strong charity to better champion the needs of our community
- Supporting Huntington's research

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

Achievements and performance

Our impact in 2021/2022

Improved quality care and support

This year we continued with lessons learned from the pandemic. With in-person contact still not advisable, we carried on offering our services online and, on the phone, to provide the Huntington's disease community with the support it needs. We continued to deliver online webinars, and this year we recorded them to give people the chance to watch on-demand via our YouTube channel.

Our support services were available mainly through phone calls, emails and virtual meetings, although 2021 saw some return to in-person meetings. Our 19 Specialist Huntington's Disease Advisers provided information and advice to 4,060 individuals and we supported 1,026 families. Throughout the year we held 18,740 conversations with families, by email or phone.

"The Adviser is an incredible part of the Huntington's disease team, I feel blessed to have her support. I'm very thankful for the time she gave me and feel a great rapport has been built. She's thoroughly trustworthy and caring in her manner. A brilliant asset to the Huntington's Disease Association."

In addition to the support available, online webinars continued to offer support on subjects requested by the community. We were fortunate to hear from well-known people in the Huntington's disease community who shared their expert advice and knowledge on topics including keeping active at home and health. In total, 26 webinars were attended by 612 people, as well as being held live the webinars were also uploaded to our YouTube channel giving everyone in the community the opportunity to watch them. Virtual carers groups continued with a total of 57 meetings, attended by over 300 people. 41 people with Juvenile Huntington's Disease were also supported through nine peer support sessions.

We continued to expand our digital communications and improve our website. The newly developed knowledge area of the website saw 1,823 visitors downloading our resources and guides. Our social media continued to share knowledge and resources resulting in an engagement rate of over 20,000 people reacting to our posts across all platforms.

Our project aimed at older carers funded by BUPA resulted in specific guides and information, additional resources, an older carers area of the website, a number of webinars, ongoing educational and peer events, and long-term peer support.

The Youth Engagement Co-ordinator supported 317 children and young people. Understanding that young people's needs have increased and changed over the last two years, particularly during the pandemic, we worked with a company to consult with young people to see what thought of our current support offer and how we can improve this. The feedback was incredibly positive and the information we gained will help us to shape future services. The children and young people we spoke with told us that they felt supported by the charity and that the Youth Engagement Service was central to this. Securing an additional youth worker to build on the existing support was a clear priority for young people, although a number of other suggestions came from the consultation, including activity days and weekends, as well as more active involvement of young people in developing the charity's services.

"I truly don't know where I'd be without the support the Youth Co-ordinator has given me over the last year or so. He's educated me on Huntington's disease and been there to listen when no-one in my family was, and just generally been really empowering for me to make choices for myself. My mental health took a big hit last year due to the impacts of being at risk of Huntington's and he was the first person I opened up to about this and he encouraged me to get further support for my mental health. He somehow manages to turn really hard conversations into a positive somewhere and is the friendliest person I know. He truly is an asset to the charity and his support will have a lifelong impact on me."

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When looking at the data collected about the Advisory Service, 90% of contact made this year was either by phone, text, email or video call. 27% of people contacting us this year hadn't been in contact with us before. When asked how they felt after they had been in touch, 97% of respondents felt it had been useful. 56% felt their understanding of Huntington's disease had increased after contact was made. In terms of emotional well-being, 66% said their well-being had improved and 69% reported feeling less isolated. 68% of people asked felt they had more knowledge about where to turn to for professional help. 49% of contact made was to ask for support in a crisis or potential crisis situations.

Due to the ongoing uncertainty of COVID-19 and continued restrictions in care homes we were only able to open our Care home accreditation scheme, HDA Quality Assured, later on in the year and one care home was accredited. Dearnevale care home has now joined a number of care homes who have demonstrated that they meet a high standard in the care and support they provide for people and families affected by Huntington's disease

Thirty one welfare grants were awarded during the year, totalling £9,000. In addition, we were able to provide an additional £5,000 gifted by B&Q. 100% of recipients reported that the grant had improved their quality of life, and 71% reported that risks had been reduced.

We are delighted that due to partnership with Surrey Heartlands, Kent Surrey Sussex Academic Health Science Network and Roche Products Ltd, we were able to help produce a Service Model and Care Pathway for Huntington's disease. This work also culminated in the commissioning of a Care Co-ordinator in Surrey. We believe this will make a big difference and improve care and support for people with Huntington's disease in the area.

During the year, we worked closely with the Neurological Alliance, with our CEO now a trustee. This has led to a stronger voice for people with Huntington's disease as we have been able to collaborate on projects. The partnership meant we could input into best practice guidelines in neuropsychiatry and advise practices for the forthcoming Integrated Care System (ICS) changes to commissioning.

We also worked with the Rare Disease Industry group during the year who had direct input into NICE who have been reviewing the mechanisms by which new drugs are approved. We are part of the National Neuroscience Advisory Group who reviewed how neurology sits within Integrated Care Systems during the year with a view to ensuring neurological services are a priority within this new structure.

Our website had a record 268,766 visitors over the year with 537,060 pages read. Our top visited pages on the website were 'What is Huntington's disease', 'what is Juvenile Huntington's disease', 'Symptoms' and 'Genetics' suggesting people reached out to the website as a source of information for Huntington's disease. The engagement rates on our social media grew along with the number of followers, demonstrating the need for social media to increase our engagement with the community. Statistics demonstrated that visitors to the website who came from social media were the people who stayed the longest on the website. We changed video platforms, moving from Vimeo to a new YouTube account and all of our online webinars throughout the year were recorded, edited, and uploaded. This gave people who wanted to watch the webinars, but who may not have been able to attend, the ability to watch them at any time they wanted. This led to 74 subscribers to the YouTube channel by year-end and the videos have been watched over 2,500 times.

Better knowledge and understanding of Huntington's

Educating people about Huntington's remained a key priority for the Huntington's Disease Association throughout the year.

Over three days in June we held our first virtual certificated professional course. 'Understanding Huntington's disease - a certificated course for professionals' gave Health and Social Care professionals an opportunity to learn about the disease in-depth. The course covered topics from genetics, behaviour, and therapies to research and all sessions were delivered by experts in their fields. The opportunity to also hear from someone with lived experience of the condition was invaluable for those that attended. Running this course virtually for the first time, made it more accessible to those who might not usually be able to attend. Following the success of the course in June, we ran a further course in November with a total of 84 people attending across the two events.

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

In addition, we delivered 103 training sessions attended by 891 Health and Social Care professionals and held 102 information sessions attended by 967 people. 82% of training was delivered online. 100% of attendees stated their knowledge of Huntington's disease had changed and the quality of care and support they give will change. All who attended said they would now know where to go to find out more about Huntington's disease.

Our website also saw some improvements, with a professional specific section created containing detailed resources to provide accurate and up-to-date advice for professionals working with people affected by Huntington's. We also set up a 'professional hub' on our messageboard as a secure space for Occupational Therapists to share knowledge, information and resources. It is likely that this will be rolled out to other disciplines in the future.

"We have all gained lots of knowledge about Huntington's and the different aspects of it. We have a lot of residents with Huntington's disease and this has helped more people gain an understanding."

Greater opportunity for peer support and community involvement

Local branches and support groups continued to provide vital support to the community, and in the year, we had 39 branches and support groups across England and Wales.

Our social media channels continued to grow in popularity, with follower numbers increasing. A more accurate metric demonstrating how the community interacts with our pages is engagement rate. This figure demonstrates the number of interactions on each platform:

| Social Media | Followers | Engagement |
|--------------|-----------|------------|
| Facebook | 15,286 | 117,393 |
| Instagram | 2,216 | 78,469 |
| Twitter | 3,840 | 8,812 |
| LinkedIn | 1,312 | 5,310 |

Our co-production group, HD Voice has consulted on 13 projects this year, lending their lived experience to help shape Huntington's disease services as well as input into research.

During the year we held our Family Conference and AGM online, due to continuing COVID-19 restrictions. 120 people enjoyed the virtual event, during which we were also able to celebrate our 50th year as a charity.

Improved understanding of Huntington's and the Huntington's Disease Association's role with the general public

During the year, we worked with the BBC on the script for the TV Show Casualty, which continued its storyline of the character, Ethan Hardy, who has the Huntington's gene and is beginning to show symptoms. The show was a brilliant opportunity for the disease to be talked about on prime-time TV and we received wonderful feedback from the community. We were delighted when the actor who plays Ethan, George Rainsford agreed to become our Patron. George took part in a fundraising challenge helping us raise both awareness of the disease and money through his fundraising. George said of becoming a patron,

"I am honoured to become a patron and help raise awareness of Huntington's disease so that the public understand not only how devastating the disease can be but also to celebrate the amazing strength and positivity that some families with Huntington's have."

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This year for Huntington's disease awareness month in May we were delighted to work as 'The Huntington's Disease Alliance', a combination of four charities; ourselves, the Scottish Huntington Disease Association, the Huntington's Disease Association for Northern Ireland, and the Huntington Disease Association of Ireland. Established to promote awareness of Huntington's disease and improve support for families across the UK and Ireland, the Alliance has worked together on many projects over the years, but 2020/21 saw incredible strides made. With funding received from Roche, together we created a campaign called 'My Family Matters'. The campaign was designed to show the enormous 'ripple effect' of Huntington's within a family unit, to help the public realise the impact of this disease. It celebrated the resilience of many of the families affected to help inspire and support the community, and to recognise that every family has a different experience. The campaign featured a living wall, on the My Family Matters website, of people's experiences of living with Huntington's disease with hundreds sharing their stories, poems, and art. The campaign is a testament to the community's spirit and dedication to raising awareness of Huntington's disease. It achieved outstanding results. The films alone achieved over 5,297 views and 288 hours in total watch time on YouTube. Media coverage was also extensive across both national and regional outlets. Broadcast coverage netted over six million opportunities to see the campaign, and print and online coverage brought a further 380 million opportunities to see the story. The social media programme reached over 1.5 million people. The month-long campaign resulted in four Huntington's disease questions being tabled in parliament. The campaign has also been nominated for an award and we are looking forward to finding out the result.

This year we launched Right Market, an online design platform, through which our supporters, staff and branch and support group volunteers can develop on-brand materials such as posters and flyers. 50th anniversary templates were also made available for fundraisers to share. The platform will help us establish our branding.

Our website continued to improve with navigation made easier and a number of new blogs and stories featuring people from the community. 5,243 people visited the stories webpage, and one of the stories featured, Mark's Story, was read 5,927 times. Total visits for 2021/22 to the website were 268,766, a 42% increase from the year before.

On social media we introduced a popular giving people the opportunity to share their fundraising stories. This proved to be successful and helped people achieve their fundraising targets. It also gave us the opportunity to get to know more about our supporters and create a successful online community.

We continued to grow our audiences on Facebook, Twitter, Instagram, and LinkedIn, giving us a chance to really connect with our community. We did a soft launch of our TikTok channel, and plan to explore this further as part of next year's strategy.

A strong charity to better champion the needs of our community

During the year we made the decision to downsize our central office, reviewing working practices and opting for a hybrid model. This allowed us to significantly reduce our overheads and redirect these funds back into directly supporting the Huntington's community. In addition, we reviewed several software products and have moved to a cloud-based Human Resources system which has enabled us to operate much more efficiently, as well as significantly reducing our paper usage and carbon footprint.

With staff returning to work after the COVID-19 Job retention scheme finished, we were able to continue to grow as a charity. We were able to strengthen teams with additional people joining during the year. Due to some staff retirement and a period of recruitment, our advisory team finished the year with 19 Specialist Huntington's Disease Advisers. Other new roles in 2021/22 included, Head of Communication and Marketing, Social Media Officer, Data Manager, Operations Assistant and Senior Individual Giving Co-ordinator.

Relevant training was carried out by employees and trustees throughout 2021/22 in line with their individual roles for their continued professional development. Safeguarding and lone working training was introduced for all staff with supporting policies developed.

Our board of trustees met frequently throughout the year to monitor the charity's performance both financially and operationally and ensure compliance with the charity governance code and the charity commission's good practice guidelines.

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Supporting Huntington's research

With confirmation of the withdrawal of the GENERATION-HD1 trial brought disappointment to the community, new analysis released of GENERATION HD1 suggests that the drug tominersen may have potential benefit to some patients. Roche are at the early stages of designing a new Phase 2 clinical trial in younger adult patients with lower disease burden, meaning someone in the earlier stages of the disease. During the year, as results were released, we acted quickly to ensure the community had access to accurate and easy to understand information as updates emerged.

Our volunteer patient and public involvement group, HD Voice, were consulted on a number of research and service development projects throughout the year ensuring that the needs and viewpoints of the Huntington's community remained at the forefront of development and decision-making. Some of the projects they were involved in included:

- Domino-HD – a volunteer-led virtual meeting looking at issues with engagement on this project, which studies how digital technologies, such as wearable fitness trackers, can be used to support people with Huntington's disease.
- BUPA older carers project – ongoing support and consultation for this in-house project to improve support for older carers.
- HD-Drum – trialling a drumming app built specifically for people in early stages of the condition.
- PIVOT-HD – with Cardiff University – working with use of volunteers in exercise promotion in collaboration with Disability Sport Wales.
- Quality Assured - two members of HD Voice were on the panel for the assessment of a care home
- Kim's Friends - assistance given on our resources for those who've tested negative, including a web page, guides and a private Facebook group.

We continued to financially support and promote HD Buzz, a website that explains current Huntington's research in plain English and encourages people to participate in Enroll-HD, the world's largest observational study for Huntington's disease to enable researchers to gain better insight into the condition.

We worked collaboratively throughout the year with HCD Economics, with funding from Roche and UniQure, on a burden of illness study, to try to demonstrate the impact of the disease on individuals affected and their carers. Findings from this study have been presented in poster format at various conferences throughout the world and there is a manuscript planned to formally publish the results. This will help raise awareness of the significant effect the condition has on the families affected.

We have worked with Hugh Rickards, Chair of the board of trustees and Consultant and Honorary Professor in Neuropsychiatry, on developing a collaborative working group of experts in the fields of pharmacology and drug treatment regulation. This group has been created to act in an advisory capacity to enable us to understand how pharmaceutical companies operate and the regulation process new treatments have to take so we can be prepared to act quickly when new treatments emerge to best support the Huntington's community.

It is important for our charity to understand current services for people affected by Huntington's to help us highlight the disparity in the support and care available across the UK. We worked with HCD Economics, in another project funded by Roche, involving the circulation of questionnaires to services that provide care and support for people with Huntington's. This was then followed up by in-depth interviews to get a better understanding of the breadth of service that individual centres provide and any gaps in service. These findings will be published in the year ahead and will be used by the charity as evidence to advocate for and fight for better quality access to services, care and support for the Huntington's community.

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Fundraising

As we moved into the second year of living with COVID-19, we continued with our fundraising to ensure that the charity remained operational, offering information and advice to those who needed it most.

In 2021/2022, our income from Community Fundraising and Events saw a huge boost bringing in a magnificent £440,710. In October 2021, we were thrilled that the majority of '#TeamHDA' were back on the streets of London with the TCS London Marathon as well as the streets around their local towns through the Virtual TCS London Marathon. Although we could not be there in person, our London runners coped amazingly with the new restrictions put in place to ensure the event could go ahead. In total all our TCS London Marathon runners raised an astonishing £113,457. We were also thrilled to see the Great North Run return in 2021 with our team of runners raising £15,935.

As ever, our supporters came through for us in 2021/2022 with many organising and taking on their own challenges, such as Suzanna Mavity who as a part of her 'Do it for Dom' group, spent Christmas 2021 climbing Kilimanjaro raising an amazing £11,487, Ella Doheny who cycled 100 miles from Coventry to Abergavenny raising £1,235, Molly and Isla who raised £2,671 with a marathon walk and our new Patron, George Rainsford took on the three-day ultra-marathon, The Druids Challenge, raising an astonishing £6,185.

'#HD8000', our flagship fundraising challenge series continued into the year with '#HDHike' taking place in May raising £31,100 and '#HDBike' taking place in August raising £5,808. In total '#HD8000', with the first in the series, '#HDMove' in January 2021 raising £13,854, raised over £50,000.

For the first time we had to move our Volunteer Awards online, our event celebrating our fundraisers and supporters, took place on Friday 11 June 2021 and we were delighted to welcome many people to share in their success. Our thanks to everyone who took part and congratulations to the winners on the day.

2021 also saw the 50th anniversary of the founding of the Huntington's Disease Association and our fundraising challenge '#50MyWay' encouraged supporters to take up challenges based around the number 50. We are grateful to everyone who took part and helped to raise over £9,701.

In January 2022, we were delighted to be named 'Charity of the Year' for the Westerleigh Group who kicked off their fundraising with a fantastic donation of £22,000 towards our work. We look forward to continuing to work with the Westerleigh Group into the next year. Our thanks go to other corporate supporters over the year, including Perenco who donated £2,000, Iceland Foods Ltd in Worksop who raised £724, Centre Parcs at Whinfell Forest who donated £1,000, the Maldon Salt Company with their donation of £500, Lewis and Cooper in Northallerton who held an in-store fundraising and awareness event raising £484 and the continued support of Mazars with their donation of £1,000.

As we moved out of the shadow of COVID-19 the support provided by Trusts and Foundations became even more important to continuing our work in 2021/2022. Their support has helped us adapt to the needs of our community throughout the pandemic and continue to provide vital advice, information and support for people affected by Huntington's disease.

All the funding we received was, and continues to be, important; however, we were particularly grateful for the £20,000 funding we received from Garfield Weston Foundation in support of our work across the North West and the Moondance Foundation who provided a grant of £20,000 for our work across South Wales. In addition, we successfully applied to the B&Q Foundation for a £5,000 grant to enable us to provide welfare grants for families. In statutory funding, we continued to deliver services through grant agreements across a number of Clinical Commissioning Group areas including Blackburn with Darwen, Cambridgeshire and Peterborough, Devon, Kernow and Sunderland. In addition, we successfully delivered our two-year contract with Birmingham City Council. We are happy to report that this contract has been extended for a further two years.

In 2021/2022 two incredibly important funding relationships came to an end. First, our six-year relationship with the Clive Richards Foundation came to an end as they revised their funding criteria. Second, our six-year relationship with the Milton Damerel Trust was paused. We are incredibly thankful for their support that has enabled us to establish our services for adults and children and young people affected by Huntington's disease.

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Putting people with Huntington's disease at the heart of our work is key to letting the world know about Huntington's disease and its effect upon individuals, families and communities. We will continue to work collaboratively with staff and supporters to share their stories and powerful messages.

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

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

For the year 2021/2022 we did not receive any complaints about our fundraising practices or approaches.

Financial review

The results for the year show an overall surplus of £742,867 (2021: £656,775) made up of a surplus on the general fund of £715,699 (2021: £630,030) and a surplus on the restricted funds of £27,168 (2021: £26,745).

As discussed elsewhere in the Trustees' Report, the pandemic continued to cause disruption to our service delivery and a reduction in costs continued due to restrictions imposed. However, as a result of a substantial increase in legacies, income rose to over £2m from £1.88m despite the absence of furlough support and specific pandemic recovery grants.

The Trustees, through the Finance Committee, have monitored developments closely and considered how the surplus should be utilised taking account of the uncertainties arising from the pandemic and the consequent need to boost reserves. Budgeted expenditure has been increased by boosting the number of Specialist Huntington's Advisors and strengthening the data management, impact assessment and policy and communications operations. The Trustees have also committed to a major expansion of the Youth Engagement Service for which funds have been designated. As a result of the continuing impact of the pandemic and the exceptional legacy income, the anticipated deficit for 2021/22 did not arise. However, in the absence of generous bequests, the budget anticipates a deficit of £300,000 in 2022/23 and the subsequent two years.

Reserves Policy

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

At the year end, free reserves available excluding designated funds and tangible fixed assets stood at £1,928,865 (2021: £1,399,141) and therefore comfortably exceeded target. As noted in the Financial Review, the Trustees have agreed a policy to utilise surplus reserves over the next two years to develop the Association for the benefit of those impacted by Huntington's Disease.

Risk Policy

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

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Future plans 2022/23

As a charity, we emerged stronger than ever after the pandemic, due to our incredible fundraisers, and successful grant bids we are now looking forward to how we can grow in 2022/23 to enable us to offer more to our community.

Early indicators from the mapping project demonstrate a lack of service provision for people's mental health with Huntington's. Our plans for Huntington's disease awareness month in May 2022 will be about mental health and Huntington's. The campaign will feature people's lived experiences as we continue to put people at the heart of our charity.

We will make a difference to national policy with plans for a new role of Policy and Public Affairs Manager, that will help us make our campaigns really make a difference to those whose life is affected by Huntington's disease.

The team will continue to grow with a number of new roles planned. We hope to recruit a Volunteer Manager to assist with our growing number of volunteers and branch and support groups, and a Helpline Adviser to become the first point of contact for people calling or emailing us for advice and support. The communication team is also looking to expand with one new post.

We have plans to extend our Huntington's Disease Youth Engagement Service (HDYES) over the forthcoming year. The recent consultation report with young people has given us some fantastic information on how we can develop this service. We hope to employ a further youth worker to help us as we design this new service with children and young people, and their views and ideas, at the heart of its development.

This year our JHD weekend will return as an in-person event for the first time since the pandemic. This is an invaluable opportunity for families affected by the Juvenile form of the condition, to meet and enjoy activities together.

Due to the success of this year's training for professionals, we will continue in the year ahead to offer both in-person and online training, including bespoke presentations, informative webinars, our flagship certified course for professionals, and a new online information event specifically for mental health teams.

We will extend our reach into digital fundraising and are looking at how we can get involved in the Gaming for Good campaign. We are keen to celebrate our fundraisers at in-person events and plan to support our London marathon runners this year as the event returns live.

We plan to further improve our social media presence, developing different targeting strategies for each digital platform. We will also include paid advertising in our social media.

We will expand and develop our TikTok channel to engage with a new audience. The website will continue to evolve and we will use data and consultation to ensure we are communicating with people in the way they want. We will continue with our monthly email newsletter but also explore other ways of engaging with our community. We will continue to use our Google Ad grant to expand our website reach.

We look forward to our Family conference and AGM this year in which we have invited our patron, George Rainsford, to speak, this will be held virtually giving people the opportunity to attend from across England and Wales.

As we enter the final year of our strategic plan, our Board of trustees are looking ahead to develop our strategy for the next five years. Staff consultation events will be held to see where our strengths and weaknesses have been over the last five years. We will also work with our community to ask them how we can best support them on their Huntington's journey. Their voice will help us reflect on what we as a charity have achieved and identify the key priorities for the Huntington's community to enable us to build our strategy around them.

As we plan and develop our new strategy, we will make sure our Board of trustees have the skills and expertise to guide the charity through the years ahead, fulfilling relevant training needs and recruiting trustees with particular expertise to fill any skill gaps identified. The board of trustees supported by the Finance and Audit subcommittee will meet throughout 2022/23 to ensure the strong governance of our charity, activities, and finances.

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

Structure, governance and management

Governing document

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

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

| | |
|----------------------------------|----------------------------|
| Dr G El-Nimr | |
| Mr M Ellison | (Resigned 21 July 2021) |
| Mr N M Heath (Hon Treasurer) | |
| Dr E M Howard (Vice-Chairperson) | |
| Professor H Rickards (Chair) | |
| Ms A C Clarke | (Resigned 16 October 2021) |
| Dr A Fryer | |
| Ms C Lyon | |
| Ms S Barker | |
| Mr S Duckett | |
| Dr N Swales | |
| Ms B E Waters | |

Recruitment and appointment of trustees

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

Organisational structure

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

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

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

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

Trustee induction and training

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

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

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

Remuneration policy

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

Auditor

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

Disclosure of information to auditor

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

Small company provisions

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

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

Mr N M Heath (Hon Treasurer)

Dated: 9 September 2022

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
STATEMENT OF TRUSTEES' RESPONSIBILITIES
*FOR THE YEAR ENDED 31 MARCH 2022***

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

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

In preparing these accounts, the trustees are required to:

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

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

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

Opinion

We have audited the financial statements of Huntington's Disease Association (the 'charity') for the year ended 31 March 2022 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2022 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT (CONTINUED) TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

Matters on which we are required to report by exception

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

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

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

Responsibilities of trustees

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

Auditor's responsibilities for the audit of the financial statements

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

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

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE INDEPENDENT AUDITOR'S REPORT (CONTINUED) TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

Capability of the audit in detecting irregularities, including fraud

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

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

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

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

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

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

Use of our report

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

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

9 September 2022

Chartered Accountants
Statutory Auditor

Castle Chambers
43 Castle Street
Liverpool
L2 9TL

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
STATEMENT OF FINANCIAL ACTIVITIES
INCLUDING INCOME AND EXPENDITURE ACCOUNT
FOR THE YEAR ENDED 31 MARCH 2022**

| | | Unrestricted funds 2022 £ | Restricted funds 2022 £ | Total 2022 £ | Unrestricted funds 2021 £ | Restricted funds 2021 £ | Total 2021 £ |
|---------------------------------------|-------|------------------------------------|----------------------------------|--------------------|------------------------------------|----------------------------------|--------------------|
| | Notes | | | | | | |
| <u>Income from</u> | | | | | | | |
| Donations and legacies | 2 | 1,723,498 | 27,981 | 1,751,479 | 1,290,255 | 13,436 | 1,303,691 |
| Charitable activities | 3 | 55,853 | 319,533 | 375,386 | 140,633 | 399,134 | 539,767 |
| Other trading activities | 4 | 24,975 | - | 24,975 | 17,510 | - | 17,510 |
| Investments | 5 | 12,941 | - | 12,941 | 12,266 | - | 12,266 |
| Other income | 6 | 1,544 | - | 1,544 | 6,935 | - | 6,935 |
| Total income | | 1,818,811 | 347,514 | 2,166,325 | 1,467,599 | 412,570 | 1,880,169 |
| <u>Expenditure on:</u> | | | | | | | |
| Raising funds | 7 | 219,774 | - | 219,774 | 182,804 | - | 182,804 |
| Charitable activities | 8 | 879,401 | 320,346 | 1,199,747 | 732,685 | 385,825 | 1,118,510 |
| Total expenditure | | 1,099,175 | 320,346 | 1,419,521 | 915,489 | 385,825 | 1,301,314 |
| Net gains/(losses) on investments | 12 | (3,937) | - | (3,937) | 77,920 | - | 77,920 |
| Net movement in funds | | 715,699 | 27,168 | 742,867 | 630,030 | 26,745 | 656,775 |
| <u>Reconciliation of funds</u> | | | | | | | |
| Fund balances at 1 April 2021 | | 1,690,025 | 55,882 | 1,745,907 | 1,059,995 | 29,137 | 1,089,132 |
| Fund balances at 31 March 2022 | | 2,405,724 | 83,050 | 2,488,774 | 1,690,025 | 55,882 | 1,745,907 |

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

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE BALANCE SHEET

AS AT 31 MARCH 2022

| | Notes | 2022 £ | £ | 2021 £ | £ |
|---|-------|-----------|-----------|-----------|-----------|
| Fixed assets | | | | | |
| Tangible assets | 13 | 20,137 | | 4,619 | |
| Investments | 14 | 948,810 | | 452,747 | |
| | | | 968,947 | | 457,366 |
| Current assets | | | | | |
| Stocks | 16 | 10,174 | | 9,559 | |
| Debtors | 17 | 677,503 | | 383,726 | |
| Cash at bank and in hand | | 962,916 | | 1,000,111 | |
| | | 1,650,593 | | 1,393,396 | |
| Creditors: amounts falling due within one year | 18 | (130,766) | | (104,855) | |
| Net current assets | | | 1,519,827 | | 1,288,541 |
| Total assets less current liabilities | | | 2,488,774 | | 1,745,907 |
| Income funds | | | | | |
| Restricted funds | 21 | 83,050 | | 55,882 | |
| <u>Unrestricted funds</u> | | | | | |
| Designated funds | 22 | 456,722 | | 286,265 | |
| General unrestricted funds | | 1,949,002 | | 1,403,760 | |
| | | | 2,405,724 | | 1,690,025 |
| | | | 2,488,774 | | 1,745,907 |

The financial statements were approved by the Trustees on 9 September 2022

Mr N M Heath (Hon Treasurer)
Trustee

Company registration number 02021975

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE**
STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 MARCH 2022

| | Notes | 2022 £ | £ | 2021 £ | £ |
|---|-------|-----------|-----------|-----------|-----------|
| Cash flows from operating activities | | | | | |
| Cash generated from operations | 26 | | 473,153 | | 408,504 |
| Investing activities | | | | | |
| Purchase of tangible fixed assets | | (23,289) | | - | |
| Purchase of investments | | (501,462) | | - | |
| Proceeds from disposal of investments | | 1,462 | | - | |
| Investment income received | | 12,941 | | 12,266 | |
| Net cash (used in)/generated from investing activities | | | (510,348) | | 12,266 |
| Net cash used in financing activities | | | - | | - |
| Net (decrease)/increase in cash and cash equivalents | | | (37,195) | | 420,770 |
| Cash and cash equivalents at beginning of year | | | 1,000,111 | | 579,341 |
| Cash and cash equivalents at end of year | | | 962,916 | | 1,000,111 |

HUNTINGTON'S DISEASE ASSOCIATION COMPANY LIMITED BY GUARANTEE

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

1 Accounting policies

Charity information

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

1.1 Accounting convention

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

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

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

1.2 Going concern

The Trustees have reviewed the effect of the Coronavirus pandemic which has had an impact on fundraising streams and the costs of delivering services and have also considered the potential effects of current inflationary pressures and general economic uncertainty on the charity.

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

1.3 Charitable funds

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

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

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

1.4 Income

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

Investment income consists of interest and dividends received and receivable.

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

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

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

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

1 Accounting policies

(Continued)

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

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

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

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

1.5 Expenditure

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

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

1.6 Tangible fixed assets

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

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

| | |
|-----------------------|-------------------|
| Fixtures and fittings | 25% straight line |
|-----------------------|-------------------|

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

1.7 Fixed asset investments

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

1.8 Impairment of fixed assets

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

1.9 Stocks

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

1.10 Cash and cash equivalents

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

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

1 Accounting policies

(Continued)

1.11 Financial instruments

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

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

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

Basic financial assets

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

Impairment of financial assets

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

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

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

Derecognition of financial assets

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

Basic financial liabilities

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

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

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

Derecognition of financial liabilities

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

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

1 Accounting policies

(Continued)

1.12 Employee benefits

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

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

1.13 Retirement benefits

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

1.14 Branch funds

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

2 Donations and legacies

| | Unrestricted funds | Restricted funds | Total | Unrestricted funds | Restricted funds | Total |
|----------------------------------|-----------------------|---------------------|------------------|-----------------------|---------------------|------------------|
| | 2022 £ | 2022 £ | 2022 £ | 2021 £ | 2021 £ | 2021 £ |
| Donations and gifts | 888,814 | 23,381 | 912,195 | 727,805 | 13,436 | 741,241 |
| Legacies receivable | 805,537 | 3,000 | 808,537 | 364,922 | - | 364,922 |
| Grants | - | - | - | 171,450 | - | 171,450 |
| Branch income | 29,147 | 1,600 | 30,747 | 26,078 | - | 26,078 |
| | <u>1,723,498</u> | <u>27,981</u> | <u>1,751,479</u> | <u>1,290,255</u> | <u>13,436</u> | <u>1,303,691</u> |
| Grants | | | | | | |
| Coronavirus Job Retention Scheme | - | - | - | 161,450 | - | 161,450 |
| Coronavirus Discretionary Grant | - | - | - | 10,000 | - | 10,000 |
| | <u>-</u> | <u>-</u> | <u>-</u> | <u>171,450</u> | <u>-</u> | <u>171,450</u> |

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE**
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

3 Charitable activities

| | 2022 | 2021 |
|--------------------|----------------|----------------|
| | £ | £ |
| Grants received | 345,633 | 525,292 |
| Merchandise | 19,812 | 13,877 |
| Other income | 9,941 | 598 |
| | <u>375,386</u> | <u>539,767</u> |
| Analysis by fund | | |
| Unrestricted funds | 55,853 | 140,633 |
| Restricted funds | 319,533 | 399,134 |
| | <u>375,386</u> | <u>539,767</u> |

4 Other trading activities

| | Unrestricted funds | Unrestricted funds |
|-------------|---------------------------|---------------------------|
| | 2022 | 2021 |
| | £ | £ |
| Consultancy | 24,975 | 17,510 |
| | <u>24,975</u> | <u>17,510</u> |

5 Investments

| | Unrestricted funds | Unrestricted funds |
|--------------------------------|---------------------------|---------------------------|
| | 2022 | 2021 |
| | £ | £ |
| Income from listed investments | 12,615 | 11,819 |
| Interest receivable | 326 | 447 |
| | <u>12,941</u> | <u>12,266</u> |

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE**
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

6 Other income

| | Unrestricted funds | Unrestricted funds |
|----------------------|-------------------------------|-----------------------|
| | 2022 | 2021 |
| | £ | £ |
| Miscellaneous income | 1,544 | 6,935 |
| | <u> </u> | <u> </u> |

7 Raising funds

| | Unrestricted funds | Unrestricted funds |
|----------------------------------|-------------------------------|-----------------------|
| | 2022 | 2021 |
| | £ | £ |
| <u>Fundraising and publicity</u> | | |
| Fundraising events | 4,683 | 9,349 |
| Other fundraising costs | 43,830 | 25,608 |
| Staff costs | 171,261 | 147,847 |
| | <u> </u> | <u> </u> |
| Fundraising and publicity | 219,774 | 182,804 |
| | <u> </u> | <u> </u> |

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

| 8 Charitable activities | Specialist HD Advisory Service | | Welfare and Respite Care | | Research | | Communication | | Youth Worker & Juvenile | | Branch | | Total 2022 | | Total 2021 | |
|--|--------------------------------|---|--------------------------|---|----------|---|---------------|---|-------------------------|---|--------|---|------------|---|------------|---|
| | £ | £ | £ | £ | £ | £ | £ | £ | £ | £ | £ | £ | £ | £ | £ | £ |
| Staff costs | 604,237 | | 2,608 | | 795 | | 79,203 | | 86,831 | | 10,000 | | 783,674 | | 793,747 | |
| Welfare grants | - | | 11,536 | | - | | - | | - | | 8,015 | | 19,551 | | 18,521 | |
| Research | - | | - | | 91 | | - | | - | | - | | 91 | | 144 | |
| Recruitment | 593 | | - | | - | | 435 | | - | | - | | 1,028 | | - | |
| Branch activities | - | | - | | - | | - | | - | | - | | - | | 3,953 | |
| Travel and training | 14,332 | | - | | - | | 160 | | 131 | | - | | 14,623 | | 1,910 | |
| Telephone and internet | 19,949 | | - | | 1 | | 504 | | 408 | | - | | 20,862 | | 25,039 | |
| Other costs | 23,954 | | 38 | | 38 | | 16,366 | | 4,635 | | 20,067 | | 65,098 | | 33,831 | |
| Newsletter | - | | - | | - | | 5,334 | | - | | - | | 5,334 | | 6,391 | |
| Website | - | | - | | - | | 15,379 | | - | | - | | 15,379 | | - | |
| Event costs | 4,504 | | - | | - | | - | | 351 | | - | | 4,855 | | 7,832 | |
| | 667,569 | | 14,182 | | 925 | | 117,381 | | 92,356 | | 38,082 | | 930,495 | | 891,368 | |
| Share of support costs (see note 9) | 141,678 | | 12,880 | | - | | 30,912 | | 20,608 | | 51,520 | | 257,598 | | 219,326 | |
| Share of governance costs (see note 9) | 11,654 | | - | | - | | - | | - | | - | | 11,654 | | 7,816 | |
| | 820,901 | | 27,062 | | 925 | | 148,293 | | 112,964 | | 89,602 | | 1,199,747 | | 1,118,510 | |
| | | | | | | | | | | | | | | | | |
| Analysis by fund | | | | | | | | | | | | | | | | |
| Unrestricted funds | 547,694 | | 17,608 | | 834 | | 148,293 | | 75,370 | | 89,602 | | 879,401 | | 732,685 | |
| Restricted funds | 273,207 | | 9,454 | | 91 | | - | | 37,594 | | - | | 320,346 | | 385,825 | |
| | 820,901 | | 27,062 | | 925 | | 148,293 | | 112,964 | | 89,602 | | 1,199,747 | | 1,118,510 | |
| | | | | | | | | | | | | | | | | |

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

| 8 Charitable activities | | (Continued) | | | | | | | |
|--|---------|---------------|---------|-------------|----------|---------------|----------|--------|-----------|
| For the year ended 31 March 2021 | | Specialist HD | | Welfare and | Research | Communication | Youth | Branch | Total |
| | | Advisory | Respite | Care | | | Worker & | | 2021 |
| | | Service | | | | | Juvenile | | |
| | £ | £ | £ | £ | £ | £ | | £ | £ |
| Staff costs | 691,877 | 691 | | | 691 | 46,753 | 43,735 | 10,000 | 793,747 |
| Welfare grants | - | 18,521 | | | - | - | - | - | 18,521 |
| Research | - | - | - | 144 | 144 | - | - | - | 144 |
| Branch activities | - | - | - | - | - | - | - | 3,953 | 3,953 |
| Travel and training | 1,278 | - | - | - | - | 27 | 605 | - | 1,910 |
| Telephone and internet | 24,074 | - | - | - | - | 440 | 525 | - | 25,039 |
| Other costs | 12,866 | 24 | | 24 | 24 | 15,828 | 5,089 | - | 33,831 |
| Newsletter | - | - | - | - | - | 6,391 | - | - | 6,391 |
| Event costs | 4,211 | - | - | - | - | - | 3,621 | - | 7,832 |
| | 734,306 | 19,236 | | 859 | | 69,439 | 53,575 | 13,953 | 891,368 |
| Share of support costs (see note 9) | 120,627 | 10,967 | | - | | 26,320 | 17,547 | 43,865 | 219,326 |
| Share of governance costs (see note 9) | 7,816 | - | | - | | - | - | - | 7,816 |
| | 862,749 | 30,203 | | 859 | | 95,759 | 71,122 | 57,818 | 1,118,510 |

Expenditure on charitable activities was £1,118,510 (2020: £1,403,159) of which £732,685 (2020: £993,538) was unrestricted and £385,825 (2020: £409,621) was restricted.

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COMPANY LIMITED BY GUARANTEE**
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

9 Support costs

| | Support costs | Governance costs | 2022 | Support costs | Governance costs | 2021 |
|---|----------------|------------------|----------------|----------------|------------------|----------------|
| | £ | £ | £ | £ | £ | £ |
| Staff costs | 124,021 | - | 124,021 | 89,189 | - | 89,189 |
| Depreciation | 7,771 | - | 7,771 | 4,698 | - | 4,698 |
| Head office costs | 125,806 | - | 125,806 | 125,439 | - | 125,439 |
| Audit fees | - | 8,000 | 8,000 | - | 7,750 | 7,750 |
| EC meeting costs | - | 3,654 | 3,654 | - | 66 | 66 |
| | <u>257,598</u> | <u>11,654</u> | <u>269,252</u> | <u>219,326</u> | <u>7,816</u> | <u>227,142</u> |
| Analysed between Charitable activities | <u>257,598</u> | <u>11,654</u> | <u>269,252</u> | <u>219,326</u> | <u>7,816</u> | <u>227,142</u> |

Support costs are allocated on the basis of time spent.

10 Employees

The average monthly number of employees during the year was:

| | 2022 Number | 2021 Number |
|------------------------|----------------|----------------|
| Specialist HD Advisors | 19 | 21 |
| Management | 1 | 1 |
| Fundraising | 5 | 5 |
| Youth Worker | 1 | 1 |
| Administration | 5 | 4 |
| Communications | 2 | 1 |
| Total | <u>33</u> | <u>33</u> |

Employment costs

| | 2022 £ | 2021 £ |
|-----------------------|------------------|------------------|
| Wages and salaries | 963,553 | 925,269 |
| Social security costs | 89,010 | 82,878 |
| Other pension costs | 26,393 | 22,636 |
| | <u>1,078,956</u> | <u>1,030,783</u> |

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

| | 2022 Number | 2021 Number |
|-------------------|----------------|----------------|
| £60,001 - £70,000 | <u>1</u> | <u>1</u> |

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE**
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

11 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year (2021: £nil). Two trustees were reimbursed expenses totalling £112 for a subscription and part payment of a training course (2021: no trustees).

12 Net gains/(losses) on investments

| | Unrestricted funds | Unrestricted funds |
|----------------------------|-------------------------------|-----------------------|
| | 2022 | 2021 |
| | £ | £ |
| Revaluation of investments | (3,937) | 77,920 |
| | <u> </u> | <u> </u> |

13 Tangible fixed assets

| | Fixtures and fittings |
|----------------------------------|------------------------------|
| | £ |
| Cost | |
| At 1 April 2021 | 73,458 |
| Additions | 23,289 |
| | <u> </u> |
| At 31 March 2022 | 96,747 |
| | <u> </u> |
| Depreciation | |
| At 1 April 2021 | 68,839 |
| Depreciation charged in the year | 7,771 |
| | <u> </u> |
| At 31 March 2022 | 76,610 |
| | <u> </u> |
| Carrying amount | |
| At 31 March 2022 | 20,137 |
| | <u> </u> |
| At 31 March 2021 | 4,619 |
| | <u> </u> |

**HUNTINGTON'S DISEASE ASSOCIATION
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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

14 Fixed asset investments

| | Listed investments £ |
|------------------------|-------------------------------------|
| Valuation | |
| At 1 April 2021 | 452,747 |
| Additions | 501,462 |
| Valuation changes | (3,937) |
| Disposals | (1,462) |
| | <hr/> |
| At 31 March 2022 | 948,810 |
| | <hr/> |
| Carrying amount | |
| At 31 March 2022 | 948,810 |
| | <hr/> <hr/> |
| At 31 March 2021 | 452,747 |
| | <hr/> <hr/> |

| 15 Financial instruments | 2022 £ | 2021 £ |
|--|-------------------|-------------------|
| Carrying amount of financial assets | | |
| Debt instruments measured at cost | 1,567,032 | 1,312,051 |
| Instruments measured at fair value through the statement of financial activities | 947,551 | 452,747 |
| | <hr/> | <hr/> |
| Carrying amount of financial liabilities | | |
| Measured at cost | 90,253 | 85,739 |
| | <hr/> | <hr/> |
| 16 Stocks | 2022 £ | 2021 £ |
| Merchandise | 10,174 | 9,559 |
| | <hr/> | <hr/> |
| 17 Debtors | 2022 £ | 2021 £ |
| Amounts falling due within one year: | | |
| Trade debtors | 15,455 | 270 |
| Other debtors | 608,214 | 361,545 |
| Prepayments | 53,834 | 21,911 |
| | <hr/> | <hr/> |
| | 677,503 | 383,726 |
| | <hr/> | <hr/> |

Other debtors include £575,845 (2021: £304,539) of legacies receivable.

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

18 Creditors: amounts falling due within one year

| | 2022 | 2021 |
|------------------------------------|----------------|----------------|
| | £ | £ |
| Other taxation and social security | 25,512 | 19,116 |
| Trade creditors | 48,286 | 40,524 |
| Accruals and deferred income | 56,968 | 45,215 |
| | <u>130,766</u> | <u>104,855</u> |

Included in accruals and deferred income is deferred income of £37,600 (2021: £5,600) relating to income received for future periods.

19 Retirement benefit schemes

Defined contribution schemes

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

The charge to the statement of financial activities in respect of defined contribution schemes was £26,393 (2021 - £22,636).

20 Operating lease commitments

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

| | 2022 | 2021 |
|----------------------------|----------------|---------------|
| | £ | £ |
| Within one year | 28,580 | 17,752 |
| Between two and five years | 96,233 | 10,620 |
| | <u>124,813</u> | <u>28,372</u> |

**HUNTINGTON'S DISEASE ASSOCIATION
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FOR THE YEAR ENDED 31 MARCH 2022**

21 Restricted funds

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

| | Movement in funds | | | Movement in funds | | | Movement in funds | | |
|---------------------------------------|---------------------------------|----------------------------|----------------------------|---------------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------------|
| | Balance at 1 April 2020 £ | Incoming resources £ | Resources expended £ | Balance at 1 April 2021 £ | Incoming resources £ | Resources expended £ | Incoming resources £ | Resources expended £ | Balance at 31 March 2022 £ |
| Research | - | 16,844 | (144) | 16,700 | 9,795 | (91) | 9,795 | (91) | 26,404 |
| Specialist HD Advisory Service (SHDA) | - | 334,744 | (334,744) | - | 268,674 | (268,674) | 268,674 | (268,674) | - |
| Children in Need | 845 | 42,133 | (38,221) | 4,757 | - | - | - | - | 4,757 |
| Lancashire Training Events | - | 4,849 | - | 4,849 | - | - | - | - | 4,849 |
| Juvenile Huntingtons Disease | - | - | - | - | 135 | (135) | 135 | (135) | - |
| JHD Weekend | 20,624 | 4,000 | - | 24,624 | 1,000 | (152) | 1,000 | (152) | 25,472 |
| Publications (Mazars) | 1,500 | - | (1,500) | - | - | - | - | - | - |
| Youth Services | - | 10,000 | (6,952) | 3,048 | 52,500 | (37,307) | 52,500 | (37,307) | 18,241 |
| BUPA Old Carers | 6,168 | - | (4,264) | 1,904 | - | (1,904) | - | (1,904) | - |
| B & Q Foundation | - | - | - | - | 5,000 | (4,533) | 5,000 | (4,533) | 467 |
| Welfare Fund | - | - | - | - | 10,410 | (7,550) | 10,410 | (7,550) | 2,860 |
| | 29,137 | 412,570 | (385,825) | 55,882 | 347,514 | (320,346) | 347,514 | (320,346) | 83,050 |

Research

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

Specialist HD Advisory Service (SHDA)

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

**HUNTINGTON'S DISEASE ASSOCIATION
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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

| | | |
|-----------|---|--------------------|
| 21 | Restricted funds | (Continued) |
| | <p>Children in Need This grant is to fund a youth worker.</p> <p>Lancashire Training Events Money raised towards an awareness/training event in the Fylde Coast area.</p> <p>Juvenile HD This fund relates to income raised by a supporter who requested the funds be used to raise awareness of Juvenile Huntingtons Disease.</p> <p>JHD Weekend These relate to individual donations and grants that have been or are to be spent on the JHD weekend.</p> <p>Publications (Mazars) This was an award of £12,000 to update five of our publications</p> <p>Youth Services This relates to Trusts funding received to fund the work of our Youth Worker</p> <p>Bupa Old Carers We were awarded funding by BUPA UK Foundation to create an online area to support older carers aged 65+.</p> <p>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</p> <p>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.</p> | |

**HUNTINGTON'S DISEASE ASSOCIATION
COMPANY LIMITED BY GUARANTEE
NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022**

22 Designated funds

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

| | Balance at 1 April 2020 £ | Movement in funds | | | Balance at 1 April 2021 £ | Movement in funds | | | Transfers £ | Balance at 31 March 2022 £ |
|---|---------------------------------|----------------------------|----------------------------|--|---------------------------------|----------------------------|----------------------------|--|----------------|----------------------------------|
| | | Incoming resources £ | Resources expended £ | | | Incoming resources £ | Resources expended £ | | | |
| Special projects fund | 214,000 | - | - | | 214,000 | - | - | | (30,000) | 184,000 |
| Branch funds | 94,081 | 26,078 | (47,894) | | 72,265 | 20,992 | (27,535) | | - | 65,722 |
| Huntington's Disease Youth Engagement Service | - | - | - | | - | - | - | | 207,000 | 207,000 |
| | 308,081 | 26,078 | (47,894) | | 286,265 | 20,992 | (27,535) | | 177,000 | 456,722 |

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

The Trustees have now committed £207,000 for the expansion of the highly successful Huntington's Disease Youth Engagement Service (Youth Project). Funding will be sought from external sources and it is anticipated that the commitment of our own resources shall enhance the viability of the Project.

**HUNTINGTON'S DISEASE ASSOCIATION
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NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2022

23 Analysis of net assets between funds

| | Unrestricted funds | Restricted funds | Total | Unrestricted funds | Restricted funds | Total |
|--|-----------------------|---------------------|------------------|-----------------------|---------------------|------------------|
| | 2022 | 2022 | 2022 | 2021 | 2021 | 2021 |
| | £ | £ | £ | £ | £ | £ |
| Fund balances at 31 March 2022 are represented by: | | | | | | |
| Tangible assets | 20,137 | - | 20,137 | 4,619 | - | 4,619 |
| Investments | 948,810 | - | 948,810 | 452,747 | - | 452,747 |
| Current assets/(liabilities) | 1,436,777 | 83,050 | 1,519,827 | 1,232,659 | 55,882 | 1,288,541 |
| | <u>2,405,724</u> | <u>83,050</u> | <u>2,488,774</u> | <u>1,690,025</u> | <u>55,882</u> | <u>1,745,907</u> |

24 Related party transactions

Remuneration of key management personnel

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

| | 2022 £ | 2021 £ |
|------------------------|----------------|----------------|
| Aggregate remuneration | <u>217,690</u> | <u>241,187</u> |

Transactions with related parties

During the year, one trustee donated £120 (2021: £4,625).

There were no other related party transactions in the year.

**HUNTINGTON'S DISEASE ASSOCIATION
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FOR THE YEAR ENDED 31 MARCH 2022

25 Branch funds

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

| | 2022 | 2021 |
|---|---------------|---------------|
| | £ | £ |
| Cash balances | | |
| At 1 April 2021 | 72,265 | 94,081 |
| Receipts in year | 30,747 | 26,078 |
| Less : | | |
| Local welfare grants | (7,468) | (12,108) |
| Sent to head office | (9,755) | (31,833) |
| Branch activities, local newsletters, equipment, research etc | (20,067) | (3,953) |
| | <u>65,722</u> | <u>72,265</u> |
| At 31 March 2022 | <u>65,722</u> | <u>72,265</u> |

26 Cash generated from operations

| | 2022 | 2021 |
|---|----------------|----------------|
| | £ | £ |
| Surplus for the year | 742,867 | 656,775 |
| Adjustments for: | | |
| Investment income recognised in statement of financial activities | (12,941) | (12,266) |
| Fair value gains and losses on investments | 3,937 | (77,920) |
| Depreciation and impairment of tangible fixed assets | 7,771 | 4,698 |
| Movements in working capital: | | |
| (Increase) in stocks | (615) | (3,668) |
| (Increase) in debtors | (293,777) | (112,392) |
| Increase/(decrease) in creditors | 25,911 | (46,723) |
| Cash generated from operations | <u>473,153</u> | <u>408,504</u> |