

**Charity Registration No. 296453**

**Company Registration No. 02021975 (England and Wales)**

**HUNTINGTON'S DISEASE ASSOCIATION  
ANNUAL REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2021**

# HUNTINGTON'S DISEASE ASSOCIATION

## LEGAL AND ADMINISTRATIVE INFORMATION

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

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# HUNTINGTON'S DISEASE ASSOCIATION

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# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT)

**FOR THE YEAR ENDED 31 MARCH 2021**

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The Trustees present their report and financial statements for the year ended 31 March 2021.

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

### **Objectives and activities**

#### **Charity objects**

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

#### **Huntington's disease, a brief overview**

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

#### **Vision**

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

#### **Mission**

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

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

#### **Values**

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive

#### **Who we are**

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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The Huntington's Disease Association provides support to anyone affected by Huntington's or anyone involved in their care and support across England and Wales. We also work closely with other Huntington's disease charities across the UK and Ireland. We now have 31 staff members from a wide range of backgrounds. From nursing and social care to fundraising and administration, all united in our dedication to supporting people living with and affected by Huntington's.

#### What we do

##### Specialist Advisory Service

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

##### Juvenile Huntington's disease support

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

##### Youth Services

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

##### Membership

We have a membership of over 5000 people, made up of both families living with Huntington's disease and health and social care professionals caring for people with Huntington's.

##### Branches and Support Groups

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

##### Partnership working

We are a charity with limited resources and so we work closely with other organisations for maximum impact and influence. Organisations we regularly work with include the Neurological Alliance and Genetic Alliance UK. We also work with other Huntington's disease charities including the European and International Huntington's Associations.

##### Research projects

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

##### Supporters

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

#### **Aims and objectives in 2020/21**

The following goals underpin the Huntington's Disease Association's five-year strategy and were the focus of the charity's work throughout 2020/21:

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

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

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### Achievements and performance

#### Our impact in 2020/21

##### *Improved quality care and support*

As the COVID-19 pandemic continued in 2020/21, the whole of the UK faced unprecedented social and economic challenges - isolation, financial uncertainty, difficulty accessing health services and losing loved ones to mention just a few. These difficulties were felt profoundly by millions of people during the year but for the Huntington's community, they are regrettably commonplace. As a rare, progressive and degenerative condition, Huntington's is often misunderstood and frequently misdiagnosed with many people, healthcare professionals and the general public alike, never having encountered the condition and its complexities. With such a reliance on the UK's health services as a result of the pandemic, our mission to champion the needs of those affected by Huntington's disease and improve quality care and support was imperative. We worked hard throughout the year trying to ensure the needs of those affected by Huntington's were understood and adequately met at a time when nationally, healthcare resources were limited and facing acute disruption.

Our Specialist Huntington's Disease Advisers provided information and advice to 4,148 people affected by Huntington's disease throughout 2020/21, which included 759 new referrals to our advisory service. 51% were adults with Huntington's who were either experiencing symptoms or were not yet symptomatic, 8% were adults at risk of developing the condition, 1% were adults who had tested negative for the condition, 2% were young people with Juvenile Huntington's, 26% were carers, 5% were young people living in families affected by the disease and 7% were people who didn't tell us their connection to Huntington's. We also supported a small number of people with rare conditions akin to Huntington's for which there is no dedicated charity support, such as Dentatorubral-pallidoluysian atrophy (DPRLA) and Neuroacanthocytosis.

With the country in national lockdown for large parts of the year and many members of the Huntington's community shielding for their own safety, we had to move swiftly to adapt our support services, processes and resources to make sure we could continue to provide information and advice to those that needed it. In-person contact, unfortunately, had to stop, but this meant less extensive travel across the country and more advisers manning our telephone and email helpline ready to help. During the year, our Huntington's helpline responded to 9,849 calls and 26,812 emails to both people affected by Huntington's and health and social care professionals involved in their care. Other communication methods, such as eNewsletters, direct messages via our website or social media and texts, continued to be utilised as a means of accessing and providing advice and support. Various remote communication methods were introduced during the year to facilitate face-to-face contact for more complex cases, including video support calls and virtual Multi-Disciplinary Team meetings. Virtual Specialist Huntington's Disease Adviser surgeries were also successfully trialled to allow our advisers to use their time most effectively to help more people.

People made contact with us for many reasons throughout the year, whether to obtain emotional support, seek advice or learn more about Huntington's. 95% of those who completed our post-contact survey informed that we were able to help them, 86% informed that we were able to provide them with information and advice and 74% felt their knowledge and understanding of Huntington's had improved as a result of the contact. With increased isolation and people facing a variety of challenging situations throughout the year, our advisers proactively reached out to people in the Huntington's community to help ensure they didn't feel they were facing the pandemic and the progression of the condition alone. 53% of those who had contact with an adviser said that they felt more able to cope, 49% reported feeling less isolated and 33% told us we helped them with a crisis situation.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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2020/21 was a difficult year for many, not least for children and young people who also had to contend with home-schooling, isolation from loved ones and missing milestone moments, such as starting a new school or completing an important examination, completely virtually in many cases. For young people in the Huntington's community, these challenges were in addition to those they were already facing through living with a loved one affected by Huntington's and seeing them gradually deteriorate. Our Specialist Huntington's Disease Youth Engagement service (HDYES) supported 212 young people between the ages of 8-25 throughout the year, including 56 new referrals. They also provided information and advice to many of their parents, guardians and schools. With in-person visits unable to take place during the year, our Youth Engagement Co-ordinator provided online drop-in sessions for young people and those involved in their care, covering topics such as COVID-19 queries and coping with being home from school. A HDYES Facebook page was also created during the year to help widen virtual communication and support for young people during this difficult period.

Our website continued to be used extensively throughout the year as an accurate source of information about Huntington's disease, particularly as a result of the pandemic which encouraged more people than ever towards the use of digital resources. With 150,272 visits to our site between April 2020 to March 2021, 18,682 of which entered via our social media channels, it became clear that our digital resources were integral to many people's Huntington's journey. Throughout the year, we took steps to develop our website and social channels further, increasing our use of informative blogs, creating more downloadable resources and improving the site's functionality thus creating useful information that is more easily accessible to a wider audience. We also received our blue verification tick on Facebook highlighting that we are a recognised and reputable organisation that people can trust.

We were able to continue to provide financial support to the Huntington's community via our welfare grants programme. A total of £4,527 grant funding was spent in 2020/21, in providing 13 grants for items such as, a wheelchair battery pack, a bicycle and a laptop. Such items were provided on the basis that they would greatly help to improve people's quality of life.

Specialist healthcare services for people affected by Huntington's disease vary greatly across the country culminating in a complex post-code lottery for quality care. This can range from no services at all to inconsistent services with different team names, varying referral criteria and support offered. As an organisation, we are committed to addressing this inequality and throughout the year we worked to begin mapping services across England and Wales to build a clear picture of what support is available to the Huntington's community. This information is invaluable in helping us to evidence service gaps, highlight best practice and ultimately work towards achieving equal and consistent access to quality care and support for people affected by Huntington's.

As part of our commitment to challenging disparity and gaps in services, we worked with a group of like-minded health and social care professionals on a project to review and take steps to improve support for people affected by Huntington's and other neurological conditions in prisons. Mental health support was another unmet need identified during the year that we worked hard to improve. Mental illness is a common feature of Huntington's disease but the symptoms are often viewed as part and parcel of Huntington's and not as a mental health need that could be individually treated. As a result, many people affected by Huntington's do not receive the most appropriate support when it comes to their mental health. To help combat this, we were involved in consultation for the Mental Health Act and a scoping exercise looking at unmet mental health needs for the Mental Health Implementation Programme to assist in NHS England's planning. We also worked closely with members of the British Psychological Society who created guidelines relating to psychological services that include Huntington's to look at ways of better informing people what psychological services can offer and how this support can be accessed.

As a small charity representing a rare condition, it is important that we join with like-minded organisations to provide the Huntington's community with a stronger voice to ensure they are well represented in discussions with key policy and decision-makers. We continued to work closely with the Neurological Alliance, joining more than 80 other organisations representing varying neurological conditions, to collectively influence policy and ensure joined-up care for people at each stage of their condition. Throughout 2020/21, we represented Huntington's in a number of subgroups relating to mental health, rare diseases and COVID-19's impact on neurological conditions. Our Chief Executive joined the Neurological Alliance's board as a trustee; all of which helped us to propel the needs of the Huntington's community to the forefront of discussions and push for change.

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# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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We represented Huntington's at National Neurosciences Advisory Group meetings in 2020/21, focussing on future development of more clearly defined care pathways for neurology and capturing patient experience. We also attended a meeting with NHS England Chief, Sir Simon Stevens, during the year to bring his attention to COVID-19's effect on neurological services. Our links with Rare Disease UK continued during the year and we attended a Rare Disease Patient Round table. Here we looked at the future of the Rare Disease Strategy and have been invited to become a patient representative for the Department of Health and Social Care for the stakeholder engagement they plan to undertake in creating the UK Rare Diseases Framework. We continued to align ourselves with the NCVO to ensure the Huntington's Disease Association was represented in key discussions affecting the charity sector, particularly in relation to the impact of the COVID-19 pandemic.

Our collaborative work with the Department of Work and Pensions and Personal Independence Payments (PIP) assessors at both Capita and the Independent Assessment Service (IAS), continued to be invaluable during the year in helping us to assist people affected by Huntington's disease in obtaining the financial support they are entitled to but sometimes struggle to access.

#### ***Better knowledge and understanding of Huntington's***

Educating people about Huntington's remained a key priority for the Huntington's Disease Association throughout the year. With a number of COVID-related hospital admissions for people with Huntington's and many facing difficulties in adhering to the safety measures of the pandemic, such as social distancing and wearing a mask, knowledge and understanding of the condition by medical professionals and the general public was of paramount importance in 2020/21. The COVID-19 resource hub created on our website to provide information, advice and resources continued to be updated and developed as each change in national policies for England and Wales occurred throughout the year to ensure accurate information and resources relevant to the Huntington's community were available. Resources included mask exemption cards and leaflets explaining Huntington's to help educate people in public settings such as supermarkets and emergency departments. These pages were visited 9,692 times throughout the year.

We added to our information guides during the year with the creation of a genetic testing guide aimed at those going through or considering a genetic Huntington's test, and a wellbeing guide for older carers as part of the BUPA UK funded Older carers project. Our suite of guides focussing on various aspects of Huntington's were viewed and downloaded 8,843 times throughout the year.

We made improvements to our website in 2020/21 during the year, creating an information resource landing page in which all of our guides, magazines, webinars and useful downloadable resources can be found and accessed quickly to make learning about Huntington's easier.

With in-person training events suspended and an increased reliance on digital technology, we worked hard throughout 2020/21 to develop a series of webinars to educate more people about the complexities of Huntington's disease. The webinars were aimed at Huntington's families and health and social care professionals alike and covered a range of topics, such as coping with loss, speech and language therapy, research, physical activity at home and various Q & A's; all delivered by experts in their respective fields. A total of 28 webinars were delivered during this period which were well received and attended by over 500 people.

In addition to the webinar series, our advisers continued to deliver training and advice to health and social care professionals. The social distancing restrictions associated with the pandemic meant that this training had to be moved online and delivered virtually for the first time. 47 training sessions and 22 informal information sessions about Huntington's were delivered to 391 health and social care professionals throughout 2020/21. Survey evaluations of these sessions revealed that 100% of those who attended training with us felt that their knowledge and understanding had improved and that they were in a better position to provide quality care and support moving forward.

We produced our twice-yearly magazine/newsletter throughout the year containing informative articles about Huntington's, personal stories, upcoming events and fundraising activities to enable our membership to keep up to date with upcoming opportunities for involvement, learn practical tips for care management and find out about developments in Huntington's research.



# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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We continued to work with the Association of British Insurers (ABI) during the year on guidance they are creating regarding insurance, making sure that it was clear and applicable to the Huntington's community by reviewing its content and providing information about the condition. Through our work with the ABI, we hope that this will help both improve access to affordable insurance products for people affected by Huntington's and also make guidance much clearer to help create a smoother application process.

#### ***Greater opportunity for peer support and community involvement***

The Huntington's community understand the condition the most and it is important that they are given the opportunity to connect to share their knowledge and support each other. We were committed throughout the year to creating peer support and community involvement opportunities.

Many professionals who support and care for people affected by Huntington's have little or no prior knowledge of the condition. In addition to providing training and information resources to expand their knowledge, we strongly encouraged peer support amongst the professional community to share best practice knowledge and to promote better standards of care. During the year we created a 'professional hub' on our online message board, specifically for Occupational Therapists in the first instance, as a secure forum in which they can ask questions of each other and seek peer support to enhance their knowledge, understanding and practice in caring for people affected by Huntington's.

Our volunteer branch and support group network played an integral part in supporting people affected by Huntington's throughout the year. Despite the challenges that the various COVID-19 lockdowns brought, our branch and support group volunteers showed tremendous resilience with many groups using video-calling to continue running support meetings and social get-togethers safely. They really were a lifeline for many people during the year in times of extreme isolation. We also introduced a regular virtual meeting with branch and support group leaders throughout 2020/21 for training, reviewing and communicating process changes and sharing ideas and upcoming opportunities for involvement.

Our planned in-person support events for 2020/21 were cancelled, like all events across the UK, as a result of the COVID-19 pandemic in order to adhere to social distancing requirements and keep our vulnerable community safe. We were however thrilled to take many of our events online during the year, such as our information and peer support event for young adults aged 18-45 affected by Huntington's and our Annual General Meeting in which the accounts and work of the charity during the year were presented to the membership. Whilst there are undeniable benefits to in-person events, there were also positive aspects to having moved these online, not least because they were accessible to more people and more cost-effective without expensive accommodation and travel costs included.

We also introduced a number of new online events in 2020/21 to bring members of the Huntington's community together. These events included regular Zoom calls for families affected by Juvenile Huntington's disease, quarterly virtual coffee mornings that were open to all, both national and local online peer support meetings for carers, Christmas quizzes for adults and children alike, a virtual pantomime and a circus skills session aimed at the children and young people in our community.

Patient and public involvement group, HD Voice, went from strength to strength during the year, increasing its membership to 39 members. Our volunteers continued to review and comment on a number of internal and external projects to help strengthen and develop work by both the charity and external researchers. HDVoice ensured the needs and experiences of the Huntington's community were well represented. The group introduced monthly virtual meetings for the first time in 2020/21 which proved to be successful for learning, sharing and discussing different projects. We also expanded our volunteer opportunities in 2020/21 with a social media volunteer role which was carried out by a young graduate who brought invaluable ideas and created engaging content which was shared on our social channels throughout the year.

With limited in-person interaction possible due to the pandemic, it was more important than ever that we continued to develop our online peer support platforms as a way of helping people stay in touch. Our online message board continued to provide a forum for people seeking peer support. As we worked to provide varied and engaging content across our social channels, our followers grew steadily to 14,374 on Facebook, 3,506 on Twitter, 1,556 on Instagram, 675 on LinkedIn by year-end March 2021. Our social channels also provided an opportunity for our followers to connect and interact with each other.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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Through the circulation of eNewsletters, including quarterly communications to our branches and support groups and quarterly editions of Incoming!, our dedicated fundraising communication, we kept the community up to date with upcoming opportunities.

Our dedicated supporters spent the year organising imaginative fundraising initiatives from virtual sweepstakes to online quiz nights and solo endurance challenges, joining together to raise vital funds to support the Huntington's Disease Association through the financial uncertainty of the pandemic. We are incredibly grateful for their continued support.

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

Raising awareness of Huntington's disease and the work and services of our charity continued to be a key focus for us in 2020/21.

Huntington's Disease Awareness Month in May provided us with an opportunity to raise the profile of Huntington's bringing understanding to those that knew very little or nothing at all before. The timing of the first national lockdown meant that our plans had to be quickly amended so that people could take part from home and maintain COVID-19 social distancing. During the month, we encouraged the Huntington's community to Hashtag SpeakOut4HD by sharing our videos, blogs and social media posts far and wide, holding virtual events to raise awareness and adding an awareness banner to their social media profile pictures. We shared information about Huntington's throughout the month, including informative videos, personal stories about life with Huntington's and live Q & A opportunities with key staff at the charity. A number of people in the Huntington's community also took part in virtual and socially distanced picnics to raise vital awareness of the condition during the month.

We continued to advise on scripts and storylines for prime-time tv shows, including BBC's Casualty and ITV's Emmerdale throughout the year to ensure their ongoing Huntington's storylines were true to life and to bring knowledge and understanding of this little known disease to millions throughout the country.

In a year of such uncertainty and restriction, our focus was clear, we needed to ensure our support services remained accessible to all and that the Huntington's community knew we would be there for them if they needed our help. We encouraged people to join our mailing list to ensure we could keep people updated. We increased our electronic communications, sharing updates on how we were adapting our services and new resources to help with the challenges faced by the community.

We joined together with many other charities as part of the Directory of Social Change and National Council for Voluntary Organisations led campaigns- HashtagSaveOurSector, HashtagEveryDayCounts and HashtagNeverMoreNeeded, to highlight to the UK government the financial uncertainty and difficulties facing the third sector as a direct result of COVID-19 restrictions. With key income generators such as events and fundraising activities stopped almost overnight, the sector needed financial support from the government. Such support would have permitted the retention of staff to deliver services that were potential lifelines for isolated and vulnerable communities, as opposed to the furlough scheme that meant a reduction in workforce at a time when they were needed most. We urged the Huntington's community to get behind the campaign and write to their local MPs to raise maximum awareness.

During the year, we worked with folk singer, Sylvie Lewis to launch a social media campaign, Hashtag Sing4HD to raise both awareness of Huntington's and vital funds for our charity during the first COVID-19 lockdown. As part of the campaign, musicians recorded themselves singing then challenged another person to sing whilst asking those watching to donate. Sylvie sang first and was followed by 11 other professional musicians, many of whom had a large following bringing important awareness to many.

Throughout the year we were approached by a number of authors wishing to include Huntington's in fictional storylines to review and ensure an accurate portrayal, including a children's book 'Owlbert explains Huntington's' and 'Coming back to you' by Lilly Hayden who donated sales royalties to us and included information about the charity in the back of her book. We also reviewed and commented on Dr Oliver Quarrell's latest edition of 'HD, the facts' that also included information about the charity to bring greater knowledge of our services to many readers.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### **FOR THE YEAR ENDED 31 MARCH 2021**

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We created new media guidance for members of the Huntington's community speaking to the media on our behalf to help ensure consistent messaging in relation to the condition and the work of the charity.

Our Chief Executive wrote articles about Huntington's that were published with Orphanet and in the Neuro Rehab Times during 2020/21 to raise further awareness within the professional community.

We introduced new merchandise throughout the year in the form of branded face masks which were well received by the community, allowing them to support our work and continue to raise awareness during the pandemic.

We took part in RAREfest20 during the year, a free, virtual, interactive science, technology, advocacy and arts exhibition with a focus on rare diseases, organised by the Cambridge Rare Disease Network. We had a short video explaining Huntington's disease featured during the event and took part in a question and answer session to provide further information about the condition to those that wanted to learn more.

Summer 2020 saw the Huntington's Disease Alliance UK and Ireland, a collation of Huntington's associations, ourselves included, begin work on a national Huntington's awareness campaign, Hashtag FamilyMatters, to provide greater insight into the condition and what it is like to live with Huntington's disease. In February 2021, on Rare Disease Day, the Huntington's community were informed of the campaign plans, how they could get involved and the expected launch during awareness month in May 2021. An incredible awareness opportunity that will bring greater knowledge and understanding of Huntington's disease to the general public.

#### ***A strong charity to better champion the needs of our community***

COVID-19 brought many challenges to the charity during the year, from financial uncertainty and home-working to almost overnight service delivery changes, however, our mission and commitment to supporting the Huntington's community never wavered and we adapted to meet these challenges head-on.

2020/21 was the third year of our five year strategic plan and as a result of the pandemic, a number of our plans were paused, such as the expansion of our care home accreditation scheme which was unfeasible during lockdown with increased social distancing measures in place in care homes across the country. However, other elements of the strategy, such as widening our digital support, digitising processes and reducing our environmental footprint, were achieved ahead of schedule. Important changes had to be made to our fundraising and communications strategies to adapt to the changing fundraising landscape with the postponement of most fundraising events and the increased reliance on digital communication during the year.

We made the difficult decision in 2020/21 to utilise the government's Coronavirus Job Retention Scheme, furloughing 15 staff members across the Advisory, Fundraising and Operations departments of the charity. This provided much needed financial support at a time of great uncertainty and allowed us to continue delivering support and advice services to the Huntington's community when it was needed most. This action helped ensure the running costs of the charity could be met in the absence of key income streams, such as fundraising events, and ensured we would emerge from COVID-19 restrictions in a strong position to better champion the needs of those affected by Huntington's.

With our staff working almost entirely from home during the pandemic and facing unprecedented pressures both at work and at home, staff welfare and wellbeing was of paramount importance. We ensured regular communication with our teams via meetings, telephone check-ins and eNewsletters, provided access to exercise classes during the working day, shared wellbeing resources and encouraged staff to move away from their desks and spend time outdoors, whilst observing government guidelines around outdoor activities, during their breaks. With a number of employees caring for loved ones who were shielding or home-schooling young children, we encouraged a flexible approach to the working day to allow staff to navigate these new challenges more easily alongside their existing workloads. Furloughed staff were contacted regularly and on return to work were allocated a 'buddy' to help them transition back to work and learn the new processes implemented whilst they were away. We ensured all relevant COVID-19 processes and procedures were set up and we ensured our central office base was COVID-secure.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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With the support of the Huntington's community, our communications became almost entirely digital, with our member magazine moving online only for the first time. The benefits of this were threefold, the magazine content was shared more widely, our carbon footprint was reduced and the money we saved in removing the printing element of such communications were reallocated to help fund vital advice and support services to help ensure no one has to face Huntington's alone.

We made improvements to our website during the year, moving to a new web agency who have worked with our communications team to improve webpage functionality and navigation and ensure our site remains secure.

A number of our workforce made the decision to retire or move on to new ventures during the year. Additionally, our Chair of trustees, Andrew Bickerdike stood down at the 2020 AGM after five years in the role and longer as a trustee. We are incredibly thankful to all for their dedication in supporting families affected by Huntington's during their time with the charity. This provided us with an opportunity to review our services, identify gaps and agree on the roles required to best meet the current needs of the Huntington's community. We were pleased to welcome Professor Hugh Rickards as our new Chair of trustees, an existing trustee on our board, who will be an incredible figurehead and spokesperson for the charity as we move through the changing landscape of Huntington's care, support and research.

Data security and protection remained a priority throughout the year to ensure GDPR compliance. Our databases were regularly reviewed and our outsourced I.T company ensured our I.T and information systems were fully protected. We began the process of reviewing the data we hold as a charity during the year with an external consultant to gain a better understanding of our services and the people we support. We also took steps to improve our monitoring and evaluation processes, setting up quarterly review meetings, further developing our evaluation surveys and improving our impact reporting.

Relevant training was carried out by employees and trustees throughout 2020/21 in line with their individual roles for their continued professional development.

Our board of trustees met frequently throughout the year to monitor the charity's performance both financially and operationally and ensure compliance with the charity governance code and the charity commission's good practice guidelines. In addition to scheduled meetings, the board and finance sub-committee met on a number of occasions throughout the year to safely navigate the charity through the challenges of the pandemic.

#### ***Supporting Huntington's research***

Huntington's research faced a disappointing setback in 2020/21 with the ending of the GENERATION-HD1 and PRECISION-HD trials as the drugs being trialled didn't perform as hoped. We ensured that the Huntington's community were kept up to date and informed as and when we learned more about the reasons for the premature conclusion of the trials and what the next steps would be. Whilst this was a disappointing outcome, it is widely regarded in the research community that these trials helped provide invaluable information that will be integral in driving future research forward to develop an effective treatment.

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

With the possibility of an effective treatment for Huntington's still very much on the horizon, it was a key focus for our charity to continue supporting the work of Huntington's researchers, make links with pharmaceutical companies and take steps towards gathering further data about the condition. In 2020/21, we continued our work with HCD Economics, Shift Healthcare and Tessella respectively on Huntington's health economics and burden of illness projects. These projects are helping us to learn more about the financial impact of Huntington's and will help build supportive evidence to present to policy and decision-makers so that they can make more informed choices and ensure fair and equal access to future treatments.

During the year, our staff team received training from pharmaceutical company, Roche, on clinical trials including how they work, criteria for entry and the process of licensing and funding any future treatments. This knowledge and insight is invaluable for our team so that they can better support members of the Huntington's community interested in or already taking part in clinical trials.

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# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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HD Voice, our patient and public participation group, continued to provide a voice for the Huntington's community in relation to research and service development. Two HDVoice members took part in a rare disease co-ordination project led by University College London during the year. They also represented the charity on HDCOPE, the European Patient and Public Participation group; on HEALTHE-RND, a European project looking to develop an eHealth Care model for rare and neurodegenerative diseases; and DOMINO-HD, a European study looking at the relationship between genetic and lifestyle factors and Huntington's symptom progression.

Throughout the year, we helped to facilitate regular meetings of the UK Huntington's Disease Network, chaired by Professor Hugh Rickards, which brought key clinicians and researchers together to discuss plans, projects and challenges being faced by the Huntington's research community. These meetings were invaluable in sharing best practice, seeking solutions and gaining understanding of the issues facing research sites and lay organisations across the UK and Europe.

#### **Fundraising**

As COVID-19 took hold across the UK and the first lockdown took place in March 2020, it became clear our fundraising strategy for the year would have to be significantly adjusted to ensure our services could remain open and operational during what was to be a tough year ahead for many people living with Huntington's disease.

Early in the year, we launched a COVID-19 appeal raising £25,950; adding to the annual growth we have seen in donations from individuals which overall totalled £285,074.

In 2020/2021 our income from Community Fundraising and Events was severely disrupted by the effects of COVID-19. However, thanks to our committed supporters we saw this income stream pick up from the third quarter onwards bringing the total raised overall to £221,648. During the lockdowns of 2020/2021, committed supporters came up with new and imaginative ways to support our work including Mr and Mrs Winser who raised £2,110 from sales of homemade chutney and Julie Hayden who organised driveway sales raising £4,100. Our thanks go to these and the hundreds of fundraisers who came out to support our work.

Our HashtagTeamHDA of runners coped amazingly with the postponement of the Virgin Money London Marathon 2020 just one month before it was due to take place. The event moved to October 2020 before it was postponed once again. However, many of our runners carried on with their training and fundraising taking part in the Virtual London Marathon in October 2020. We are so grateful and proud of HashtagTeamHDA. Likewise, many nationally organised events were cancelled including parachute jumps, Great North Run and almost all national and overseas challenges. However, we saw people organising and taking on their own challenges such as the Manchester United RTC Under 11 Squad who took on the fantastic challenge of covering 200 miles through walking, running or cycling and raising a fantastic £7,372, Tom Crowder who took on the Three Peaks Challenge in between lockdowns raising over £5,000 and Harvey Scowcroft who raised over £5,000 with a 24-hour Strava Zwift indoor bike ride on a smart trainer.

Working through the pandemic allowed us to examine some of our practices around fundraising, giving us an opportunity to develop our new fundraising challenge, HashtagHD8000, with the first in the series, HashtagHDMove raising £13,854 in January 2021. We look forward to HashtagHD8000 becoming our flagship annual fundraising activity for the charity.

Our work with corporates and local businesses saw Marks and Spencer, Edge Lane in Liverpool raising £4,192 and continuing to support our work well into 2020. Our thanks go to employees at Brit Insurance for nominating us for their Employee Charity Scheme with a donation of £10,000. We were also delighted to receive a donation of £2,000 from Ixico PLC. We formed a new partnership with Marshalls Garden with the development of the Christmas Amaryllis, which retailed in the period leading up to Christmas 2020 raising just over £1,524. These are just a few of the businesses and their employees who supported our work.

In a year unlike any other, we are thankful to the various Trusts and Foundations who supported our work in 2020/2021. Their support helped us continue our work offering advice, information and support for people affected by Huntington's disease.

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# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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All the funding we received was, and continues to be, important; however, we were particularly grateful for the funding we received from the various COVID-19 emergency funding programmes. This included £92,751 from the Julia and Hans Rausing Trust, £80,976 administered by The National Lottery Community Fund on behalf of the Office for Civil Society, £20,025 from various Community Foundations and additional support from many long-term Trust and Foundation supporters.

In statutory funding, we continued to deliver services through grant agreements across a number of Clinical Commissioning Group areas including Blackburn with Darwen, Cambridgeshire and Peterborough, Devon, Kernow and Sunderland. In addition, we successfully delivered year one of our two-year contract with Birmingham City Council for delivering services for people affected by Huntington's disease across the city.

Our three-year Children in Need grant came to an end in 2020/2021. We are incredibly thankful for their support enabling us to establish HDYES - such an important service for children and young people affected by Huntington's disease.

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

We also turned our attention to understanding our data management across the department and wider organisation identifying ways to improve our communications with supporters.

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

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

For the year 2020/2021 we did not receive any complaints about our fundraising practices/approaches

#### **Financial review**

The results for the year show an overall surplus of £656,775 (2020: £61,383) made up of a surplus on the general fund of £630,030 (2020: £54,943) and a surplus on the restricted funds of £26,745 (2020: £6,440).

The surplus arose during the first 12 months of the pandemic which caused a major disruption to our services and a substantial reduction in costs due to restrictions imposed. This can be seen from the accounts which also show income boosted by the £161,450 Coronavirus Job Retention Scheme, which enabled us to retain staff during the first lockdown, and substantial one-off grants and individual donations. In addition, investment gains of £77,920 reflected the bounce back from the depressed Stock Market levels of March 2020.

The Trustees, through the Finance Committee, have monitored developments closely and considered how the surplus should be utilised taking account of the uncertainties arising from the pandemic and the consequent need to boost reserves. Budgeted expenditure has been increased by boosting the number of Specialist Huntington's Advisors and strengthening the data management, impact assessment and policy and communications operations. It is anticipated that the underlying deficit for 2021/22 and the subsequent two years will be approximately £200,000 per annum.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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#### **Reserves Policy**

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

At the year end, free reserves available excluding the designated project reserve and funds held by branches stood at £1,403,760 (2020: £751,954) and therefore comfortably exceeded target. As noted in the Financial Review, the Trustees have agreed a policy to utilise surplus reserves over the next three years to develop the Association for the benefit of those impacted by Huntington's Disease.

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

#### **Future plans 2021/22**

After a year like no other, we are pleased to have emerged from the pandemic in a strong position that will allow us to continue in our mission to enable everyone affected by Huntington's disease to live life to their full potential. In the year ahead we plan to learn from the challenges of the last year and as COVID-19 restrictions begin to ease, use this knowledge to adapt our services to include best practice from both before and during the pandemic.

We will continue to offer and expand the ways in which people can access support from us through the year, with the video support call option offered during the pandemic becoming a permanent feature. As COVID-19 restrictions ease, our advisers will return to in-person support through attendance at clinics and home visits in some circumstances, recognising that not everyone will access remote support and more complex cases may be better-discussed face to face.

We will recommence our ongoing projects that were put on hold during the pandemic. The BUPA UK funded Older Carers project will be brought to a conclusion in 2021/22 with resources developed to enhance support and access to information for older generations who may be less confident utilising digital technology. HD Quality Assured, our care home accreditation scheme, will be re-opened as social distancing restrictions begin to ease, with a number of care homes having already expressed an interest in taking part in the scheme in the year ahead.

We will begin a new project, in conjunction with Roche, to map Huntington's services across England and Wales to gain a better understanding of Huntington's care and support provision, identify service gaps and work towards the implementation of a best-practice care model for the condition. This will expand on the mapping work we carried out in 2020/21 and will help to improve standards of care.

Our youth support materials will also be developed during the year with funding sourced to create guides aimed specifically at teenagers living in families affected by Huntington's, and teaching staff supporting children from families affected by the condition.

Online training has been so successful during the year that we plan to develop this further by trialling our Huntington's certificated course for professionals as a digital event for the first time in June 2021. We will also recruit an education lead in the year to allow us to become more proactive and further develop our training offer to provide greater knowledge and understanding of Huntington's to the health and social care sector. We will also continue to develop our series of webinars to shine a light on all aspects of Huntington's disease for families affected by the condition and health and social care professionals alike.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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We plan to embrace digital further, making changes to our website's capabilities including improving the search functionality and user experience from mobile devices, streamlining and improving website content, and developing our digital communications further. A role dedicated to managing the charity's social media channels will be recruited during the year to help us reach more people who need our support or want to know more about Huntington's. This role will also provide our existing communications team with more scope to develop our eNewsletters, member magazines, guides and other resources throughout the year.

We will continue to raise awareness and understanding of Huntington's with the Huntington's Disease Alliance UK and Ireland's HashtagFamilyMatters campaign set to raise the profile of Huntington's disease in 2021/22 and highlight our services to more people to help us reach those who need our support.

We will continue to work with our branch and support group network throughout the year and explore ways in which we can improve the support and resources we provide to help them deliver peer support to a greater number of people affected by Huntington's in local communities throughout England and Wales. Opportunities for community involvement and peer support will also continue to be developed throughout the year, from in-person and online events to digital platforms and volunteer roles.

We plan to recruit to the teams who lost staff to retirement and new job opportunities in 2020/21 to relieve pressure and return the workforce to full capacity as the country begins to return to more normal times without COVID-19 restrictions. This will ensure we can continue to meet the needs of the Huntington's community and develop our services further through the year.

We plan to expand our fundraising team in 2021/22 to develop individual giving for the charity and make improvements to our charity membership offer. With many public events postponed until 2022, we will continue to develop new and innovative ways people can get involved in supporting our work.

Continuing with our data review, we plan to develop our use and understanding of the data we hold and recruit a Data Manager to manage our client and supporter databases and oversee the transition to a new database system.

We will also explore equipment and technology to better facilitate our work, such as call handling systems and cloud-based information management systems, and invest as appropriate. We also plan to introduce a hybrid working model for our office-based staff to reduce our office space and overheads and use these funds more effectively to support the community.

We will continue to work in partnership with other organisations that allow us to provide the Huntington's community with a stronger voice to their needs and the challenges they face better known. We will explore further how we as a charity can work more proactively and become more influential with policy and decision-makers to help bring an effective treatment for Huntington's a step closer and improve standards of care and support.

Our board of trustees will join together for a strategy planning weekend in the year ahead to begin looking at the charity's priorities for our next strategic plan set to launch in 2023/24. A skills audit for the board will also be undertaken to identify any recruitment needs to ensure the charity is safely guided through the years ahead. Consultation with our community will also begin in 2021/22 to assess their needs and requirements to help inform our future strategic direction.



# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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#### Structure, governance and management

##### Governing document

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

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

Mr A Bickerdike (Chairperson) (Resigned 18 November 2020)

Dr G El-Nimr

Mr M Ellison (Resigned 20 July 2021)

Mr N M Heath (Hon Treasurer)

Dr E M Howard (Vice-Chairperson)

Professor H Rickards (Chair)

Ms A C Clarke

Dr A Fryer

Ms C Lyon

Ms S Barker

Mr S Duckett

Dr N Swales

(Appointed 18 November 2020)

Ms B E Waters

(Appointed 18 November 2020)

##### Recruitment and appointment of trustees

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

##### Organisational structure

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

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

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

*FOR THE YEAR ENDED 31 MARCH 2021*

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### **Trustee induction and training**

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

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

### **Remuneration policy**

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

### **Auditor**

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

### **Disclosure of information to auditor**

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

The Trustees report was approved by the Board of Trustees.

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

Dated: 27 September 2021

# HUNTINGTON'S DISEASE ASSOCIATION

## STATEMENT OF TRUSTEES RESPONSIBILITIES

*FOR THE YEAR ENDED 31 MARCH 2021*

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

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

In preparing these accounts, the Trustees are required to:

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT

### TO THE TRUSTEES OF HUNTINGTON'S DISEASE ASSOCIATION

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#### Opinion

We have audited the financial statements of Huntington's Disease Association (the 'Charity') for the year ended 31 March 2021 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and the notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2021 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### Basis for opinion

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

#### Conclusions relating to going concern

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

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

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

#### Other information

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

We have nothing to report in this regard.

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

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT (CONTINUED)

### TO THE TRUSTEES OF HUNTINGTON'S DISEASE ASSOCIATION

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

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

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

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

#### **Responsibilities of Trustees**

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

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

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT (CONTINUED)

### TO THE TRUSTEES OF HUNTINGTON'S DISEASE ASSOCIATION

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

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

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

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

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

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

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

#### **Use of our report**

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

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

27 September 2021

**Chartered Accountants**  
**Statutory Auditor**

Castle Chambers  
43 Castle Street  
Liverpool  
L2 9TL

# HUNTINGTON'S DISEASE ASSOCIATION

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2021

		Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 2020 £
	<b>Notes</b>						
<b>Income and endowments from:</b>							
Donations and legacies	2	1,290,255	13,436	1,303,691	1,151,744	38,828	1,190,572
Charitable activities	3	140,633	399,134	539,767	91,930	373,938	465,868
Other trading activities	4	17,510	-	17,510	10,258	-	10,258
Investments	5	12,266	-	12,266	12,385	-	12,385
Other income	6	6,935	-	6,935	2,035	-	2,035
<b>Total income</b>		<b>1,467,599</b>	<b>412,570</b>	<b>1,880,169</b>	<b>1,268,352</b>	<b>412,766</b>	<b>1,681,118</b>
<b>Expenditure on:</b>							
Raising funds	7	182,804	-	182,804	177,950	-	177,950
Charitable activities	8	732,685	385,825	1,118,510	993,538	409,621	1,403,159
<b>Total resources expended</b>		<b>915,489</b>	<b>385,825</b>	<b>1,301,314</b>	<b>1,171,488</b>	<b>409,621</b>	<b>1,581,109</b>
Net gains/(losses) on investments	12	77,920	-	77,920	(38,626)	-	(38,626)
Gross transfers between funds		-	-	-	(3,295)	3,295	-
<b>Net movement in funds</b>		<b>630,030</b>	<b>26,745</b>	<b>656,775</b>	<b>54,943</b>	<b>6,440</b>	<b>61,383</b>
Fund balances at 1 April 2020		1,059,995	29,137	1,089,132	1,005,052	22,697	1,027,749
<b>Fund balances at 31 March 2021</b>		<b>1,690,025</b>	<b>55,882</b>	<b>1,745,907</b>	<b>1,059,995</b>	<b>29,137</b>	<b>1,089,132</b>

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

# HUNTINGTON'S DISEASE ASSOCIATION

## BALANCE SHEET

AS AT 31 MARCH 2021

	Notes	2021		2020	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	13		4,619		9,317
Investments	14		452,747		374,827
			<u>457,366</u>		<u>384,144</u>
<b>Current assets</b>					
Stocks	16	9,559		5,891	
Debtors	15	383,726		271,334	
Cash at bank and in hand		1,000,111		579,341	
		<u>1,393,396</u>		<u>856,566</u>	
<b>Creditors: amounts falling due within one year</b>	17	(104,855)		(136,060)	
Net current assets			<u>1,288,541</u>		<u>720,506</u>
<b>Total assets less current liabilities</b>			<u>1,745,907</u>		<u>1,104,650</u>
<b>Creditors: amounts falling due after more than one year</b>	18		-		(15,518)
<b>Net assets</b>			<u><u>1,745,907</u></u>		<u><u>1,089,132</u></u>
<b>Income funds</b>					
Restricted funds	20		55,882		29,137
<u>Unrestricted funds</u>					
Designated funds	21	286,265		308,081	
General unrestricted funds		1,403,760		751,914	
			<u>1,690,025</u>		<u>1,059,995</u>
			<u><u>1,745,907</u></u>		<u><u>1,089,132</u></u>

The financial statements were approved by the Trustees on 27 September 2021

Mr N M Heath (Hon Treasurer)  
Trustee

Professor H Rickards (Chair)  
Trustee

Company Registration No. 02021975



# HUNTINGTON'S DISEASE ASSOCIATION

## STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2021

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	Notes	2021 £	£	2020 £	£
<b>Cash flows from operating activities</b>					
Cash generated from operations	27		408,504		160,881
<b>Investing activities</b>					
Purchase of tangible fixed assets		-		(5,340)	
Purchase of investments		-		(75,000)	
Investment income received		12,266		12,385	
<b>Net cash generated from/(used in) investing activities</b>			12,266		(67,955)
<b>Net cash used in financing activities</b>			-		-
<b>Net increase in cash and cash equivalents</b>			420,770		92,926
Cash and cash equivalents at beginning of year			579,341		486,415
<b>Cash and cash equivalents at end of year</b>			1,000,111		579,341

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# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS

**FOR THE YEAR ENDED 31 MARCH 2021**

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### 1 Accounting policies

#### Charity information

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

#### 1.1 Accounting convention

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

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

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

#### 1.2 Going concern

The Trustees have reviewed the effect of the Coronavirus pandemic which has had an impact on fundraising streams and the costs of delivering services.

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

#### 1.3 Charitable funds

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

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

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

#### 1.4 Income

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

Investment income consists of interest and dividends received and receivable.

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

**FOR THE YEAR ENDED 31 MARCH 2021**

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### **1 Accounting policies**

**(Continued)**

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

#### **1.5 Expenditure**

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

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

#### **1.6 Tangible fixed assets**

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

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

Fixtures and fittings	25% straight line
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The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year..

#### **1.7 Fixed asset investments**

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

#### **1.8 Impairment of fixed assets**

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

#### **1.9 Stocks**

Stocks are valued at the lower of cost or net realisable value after making due allowance for obsolete and slow-moving items. Cost is calculated using the first-in first-out basis of valuation.

Net realisable value is the estimated selling price less all estimated costs of completion and costs to be incurred in marketing, selling and distribution.

#### **1.10 Cash and cash equivalents**

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

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

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### 1 Accounting policies

(Continued)

#### 1.11 Financial instruments

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

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

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

#### **Basic financial assets**

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

#### **Impairment of financial assets**

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

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

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

#### **Derecognition of financial assets**

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

#### **Basic financial liabilities**

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

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 1 Accounting policies

(Continued)

#### *Derecognition of financial liabilities*

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

#### 1.12 Employee benefits

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

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

#### 1.13 Retirement benefits

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

#### 1.14 Leases

Rentals payable under operating leases, including any lease incentives received, are charged as an expense on a straight line basis over the term of the relevant lease.

#### 1.15 Branch funds

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

### 2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2021	2021	2021	2020	2020	2020
	£	£	£	£	£	£
Donations and gifts	727,805	13,436	741,241	804,671	26,272	830,943
Legacies receivable	364,922	-	364,922	254,495	3,305	257,800
Grants	171,450	-	171,450	-	-	-
Other	26,078	-	26,078	92,578	9,251	101,829
	<u>1,290,255</u>	<u>13,436</u>	<u>1,303,691</u>	<u>1,151,744</u>	<u>38,828</u>	<u>1,190,572</u>
<b>Donations and gifts</b>						
Community Fundraising	226,038	-	226,038	554,853	6,222	561,075
Other	501,767	13,436	515,203	249,818	20,050	269,868
	<u>727,805</u>	<u>13,436</u>	<u>741,241</u>	<u>804,671</u>	<u>26,272</u>	<u>830,943</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 2 Donations and legacies (Continued)

#### Grants

Coronavirus Job Retention Scheme	161,450	-	161,450	-	-	-
Coronavirus Discretionary Grant	10,000	-	10,000	-	-	-
	<u>171,450</u>	<u>-</u>	<u>171,450</u>	<u>-</u>	<u>-</u>	<u>-</u>

### 3 Charitable activities

	2021 £	2020 £
Grants received	525,292	423,438
Merchandise	13,877	10,901
Other income	598	31,529
	<u>539,767</u>	<u>465,868</u>
Analysis by fund		
Unrestricted funds	140,633	91,930
Restricted funds	399,134	373,938
	<u>539,767</u>	<u>465,868</u>

### 4 Other trading activities

	Unrestricted funds 2021 £	Unrestricted funds 2020 £
Raffle and sponsorship	-	308
Company sponsorships	-	9,950
Consultancy	17,510	-
	<u>17,510</u>	<u>10,258</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 5 Investments

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	<b>£</b>	£
Income from listed investments	11,819	10,896
Interest receivable	447	1,489
	<u>12,266</u>	<u>12,385</u>

### 6 Other income

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	<b>£</b>	£
Miscellaneous income	6,935	2,035
	<u>6,935</u>	<u>2,035</u>

### 7 Raising funds

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	<b>£</b>	£
<u>Fundraising and publicity</u>		
Fundraising events	9,349	16,775
Other fundraising costs	25,608	20,050
Staff costs	147,847	141,125
	<u>182,804</u>	<u>177,950</u>
Fundraising and publicity	182,804	177,950
	<u>182,804</u>	<u>177,950</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 8 Charitable activities

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication	Youth Worker & Juvenile	Branch	Total 2021	Total 2020
	£	£	£	£	£	£	£	£
Staff costs	691,877	691	691	46,753	43,735	10,000	793,747	872,441
Welfare grants	-	18,521	-	-	-	-	18,521	38,608
Research	-	-	144	-	-	-	144	11,998
Juvenile	-	-	-	-	-	-	-	2,816
Branch activities	-	-	-	-	-	3,953	3,953	48,324
Travel and training	1,278	-	-	27	605	-	1,910	71,919
Camps, conferences and AGM	-	-	-	-	-	-	-	36,894
Telephone and internet	24,074	-	-	440	525	-	25,039	25,625
Other costs	12,866	24	24	15,828	5,089	-	33,831	35,672
Newsletter	-	-	-	6,391	-	-	6,391	9,453
Publications and merchandise	-	-	-	-	-	-	-	9,066
Event costs	4,211	-	-	-	3,621	-	7,832	-
	<u>734,306</u>	<u>19,236</u>	<u>859</u>	<u>69,439</u>	<u>53,575</u>	<u>13,953</u>	<u>891,368</u>	<u>1,162,816</u>
Share of support costs (see note 9)	120,627	10,967	-	26,320	17,547	43,865	219,326	228,860
Share of governance costs (see note 9)	7,816	-	-	-	-	-	7,816	11,483
	<u>862,749</u>	<u>30,203</u>	<u>859</u>	<u>95,759</u>	<u>71,122</u>	<u>57,818</u>	<u>1,118,510</u>	<u>1,403,159</u>

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



# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 8 Charitable activities

(Continued)

For the year ended 31 March 2020

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication	Youth Worker & Juvenile	Branch	Total 2020
	£	£	£	£	£	£	£
Staff costs	758,251	688	688	46,010	56,804	10,000	872,441
Welfare grants	-	38,608	-	-	-	-	38,608
Research	-	-	11,998	-	-	-	11,998
Juvenile	-	-	-	-	2,816	-	2,816
Branch activities	-	-	-	-	-	48,324	48,324
Travel and training	61,530	-	-	374	10,015	-	71,919
Camps, conferences and AGM	16,612	-	-	-	20,282	-	36,894
Telephone and internet	24,215	-	-	329	1,081	-	25,625
Other costs	29,126	60	60	3,948	1,041	1,437	35,672
Newsletter	-	-	-	9,453	-	-	9,453
Publications and merchandise	-	-	-	9,066	-	-	9,066
	<u>889,734</u>	<u>39,356</u>	<u>12,746</u>	<u>69,180</u>	<u>92,039</u>	<u>59,761</u>	<u>1,162,816</u>
Share of support costs (see note 9)	137,316	11,443	-	16,020	16,020	48,061	228,860
Share of governance costs (see note 9)	11,483	-	-	-	-	-	11,483
	<u><u>1,038,533</u></u>	<u><u>50,799</u></u>	<u><u>12,746</u></u>	<u><u>85,200</u></u>	<u><u>108,059</u></u>	<u><u>107,822</u></u>	<u><u>1,403,159</u></u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 9 Support costs

	Support costs £	Governance costs £	2021 £	Support costs £	Governance costs £	2020 £
Staff costs	89,189	-	89,189	89,352	-	89,352
Depreciation	4,698	-	4,698	4,062	-	4,062
Head office costs	125,439	-	125,439	135,446	-	135,446
Audit fees	-	7,750	7,750	-	7,608	7,608
EC meeting costs	-	66	66	-	3,875	3,875
	<u>219,326</u>	<u>7,816</u>	<u>227,142</u>	<u>228,860</u>	<u>11,483</u>	<u>240,343</u>
Analysed between Charitable activities	<u>219,326</u>	<u>7,816</u>	<u>227,142</u>	<u>228,860</u>	<u>11,483</u>	<u>240,343</u>

### 10 Employees

The average monthly number of employees during the year was:

	2021 Number	2020 Number
Specialist HD Advisors	21	21
Management	1	2
Fundraising	5	3
Youth Worker	1	2
Administration	4	5
Communications	1	1
Total	<u>33</u>	<u>34</u>

#### Employment costs

	2021 £	2020 £
Wages and salaries	940,269	1,004,671
Social security costs	67,878	75,173
Other pension costs	22,636	23,074
	<u>1,030,783</u>	<u>1,102,918</u>

The number of employees whose annual remuneration was £60,000 or more were:

	2021 Number	2020 Number
£60,000 - £69,999	<u>1</u>	<u>-</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

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### 11 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the Charity during the year.

### 12 Net gains/(losses) on investments

	<b>Unrestricted funds</b>	Unrestricted funds
	<b>2021</b>	2020
	£	£
Revaluation of investments	77,920	(38,626)
	<u>77,920</u>	<u>(38,626)</u>

### 13 Tangible fixed assets

	<b>Fixtures and fittings</b>
	£
<b>Cost</b>	
At 1 April 2020	73,458
	<u>73,458</u>
At 31 March 2021	73,458
	<u>73,458</u>
<b>Depreciation and impairment</b>	
At 1 April 2020	64,141
Depreciation charged in the year	4,698
	<u>68,839</u>
At 31 March 2021	68,839
	<u>68,839</u>
<b>Carrying amount</b>	
At 31 March 2021	4,619
	<u>4,619</u>
At 31 March 2020	9,317
	<u>9,317</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

### 14 Fixed asset investments

	Listed investments £
<b>Cost or valuation</b>	
At 1 April 2020	374,827
Valuation changes	77,920
At 31 March 2021	<u>452,747</u>
<b>Carrying amount</b>	
At 31 March 2021	<u>452,747</u>
At 31 March 2020	<u>374,827</u>

### 15 Debtors

	2021 £	2020 £
<b>Amounts falling due within one year:</b>		
Trade debtors	270	34,572
Other debtors	361,545	205,601
Prepayments and accrued income	21,911	31,161
	<u>383,726</u>	<u>271,334</u>

Other debtors include £304,539 (2020: £154,000) of legacies receivable.

### 16 Stocks

	2021 £	2020 £
Merchandise	9,559	5,891
	<u>9,559</u>	<u>5,891</u>

### 17 Creditors: amounts falling due within one year

	2021 £	2020 £
Other taxation and social security	19,116	24,869
Trade creditors	40,524	26,080
Accruals and deferred income	45,215	85,111
	<u>104,855</u>	<u>136,060</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

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<b>18 Creditors: amounts falling due after more than one year</b>	<b>2021</b>	<b>2020</b>
	£	£
Accruals and deferred income	-	15,518
	<u>          </u>	<u>          </u>

### **19 Retirement benefit schemes**

#### **Defined contribution schemes**

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

The charge to profit or loss in respect of defined contribution schemes was £22,636 (2020 - £23,074).

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 20 Restricted funds

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

	Movement in funds				Movement in funds			
	Balance at 1 April 2019 £	Incoming resources £	Resources expended £	Transfers £	Balance at 1 April 2020 £	Incoming resources £	Resources expended £	Balance at 31 March 2021 £
Research	-	8,703	(11,998)	3,295	-	16,844	(144)	16,700
Specialist HD Advisory Service (SHDA)	-	292,955	(292,955)	-	-	334,744	(334,744)	-
Children in Need	-	38,196	(37,351)	-	845	42,133	(38,221)	4,757
Lancashire Training Events	-	-	-	-	-	4,849	-	4,849
JHD Weekend	22,697	19,482	(21,555)	-	20,624	4,000	-	24,624
Publications (Mazars)	-	12,000	(10,500)	-	1,500	-	(1,500)	-
Youth Services	-	20,000	(20,000)	-	-	10,000	(6,952)	3,048
BUPA Old Carers	-	20,930	(14,762)	-	6,168	-	(4,264)	1,904
Events	-	500	(500)	-	-	-	-	-
	<u>22,697</u>	<u>412,766</u>	<u>(409,621)</u>	<u>3,295</u>	<u>29,137</u>	<u>412,570</u>	<u>(385,825)</u>	<u>55,882</u>

#### Research

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

#### Specialist HD Advisory Service (SHDA)

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

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

*FOR THE YEAR ENDED 31 MARCH 2021*

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### 20 Restricted funds

(Continued)

#### **Children in Need**

This grant is to fund a youth worker.

#### **Lancashire Training Events**

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

#### **JHD Weekend**

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

#### **Publications (Mazars)**

This was an award of £12,000 to update five of our publications

#### **Youth Services**

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

#### **Bupa Old Carers**

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

#### **Events**

A branch donation with a request that it is to be spent on HDA Events and Activities

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

#### 21 Designated funds

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

	Movement in funds			Movement in funds			Balance at 31 March 2021 £
	Balance at 1 April 2019 £	Incoming resources £	Resources expended £	Balance at 1 April 2020 £	Incoming resources £	Resources expended £	
Special projects fund	214,000	-	-	214,000	-	-	214,000
Branch funds	111,215	101,829	(118,963)	94,081	26,078	(47,894)	72,265
	<u>325,215</u>	<u>101,829</u>	<u>(118,963)</u>	<u>308,081</u>	<u>26,078</u>	<u>(47,894)</u>	<u>286,265</u>

A designated special projects fund of £400,000 was established as a result of generous legacies received during 2013. It is intended that the fund be used for special projects, which, once instituted, may be developed in accordance with the long-term objectives of the charity. During 2015 and 2016 £130,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support. A further £40,000 of the fund was used to support the new communication initiative in 2017/18 and £16,000 was used in 2018/19 to complete the Care Home Accreditation project.

The Trustees have not released any of the designated funds in 2020/21 but anticipate that a re-evaluation in 2021/22 will be required to reflect the impact of the pandemic and research developments on future requirements.

#### 22 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	2021 £	2021 £	2021 £	2020 £	2020 £	2020 £
Fund balances at 31 March 2021 are represented by:						
Tangible assets	4,619	-	4,619	9,317	-	9,317
Investments	452,747	-	452,747	374,827	-	374,827
Current assets/ (liabilities)	1,232,659	55,882	1,288,541	691,369	29,137	720,506
Long term liabilities	-	-	-	(15,518)	-	(15,518)
	<u>1,690,025</u>	<u>55,882</u>	<u>1,745,907</u>	<u>1,059,995</u>	<u>29,137</u>	<u>1,089,132</u>



# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

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### 23 Related party transactions

#### Remuneration of key management personnel

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

	2021 £	2020 £
Aggregate compensation	241,187	168,042

#### Transactions with related parties

During the year a donation of £4,625 (2020: £25,000) was received from a Trustee.

### 24 Operating lease commitments

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

	2021 £	2020 £
Within one year	17,752	48,129
Between two and five years	10,620	28,655
	<u>28,372</u>	<u>76,784</u>

### 25 Contingent asset

Following the death of the life tenant, the contingent asset has now been recognised.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

### 26 Branch funds

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

	2021 £	2020 £
Cash balances at 1 April 2020	94,081	111,215
Receipts in year	26,078	101,829
Less :		
Local welfare grants	(12,108)	(27,293)
Sent to head office	(31,833)	(43,346)
Branch activities,local newsletters,equipment,research etc	(3,953)	(48,324)
Cash balances at 31 March 2021	<u>72,265</u>	<u>94,081</u>

### 27 Cash generated from operations

	2021 £	2020 £
Surplus for the year	656,775	61,383
Adjustments for:		
Investment income recognised in statement of financial activities	(12,266)	(12,385)
Fair value gains and losses on investments	(77,920)	38,626
Depreciation and impairment of tangible fixed assets	4,698	4,062
Movements in working capital:		
(Increase) in stocks	(3,668)	(1,087)
(Increase)/decrease in debtors	(112,392)	71,522
(Decrease) in creditors	(46,723)	(1,240)
<b>Cash generated from operations</b>	<u>408,504</u>	<u>160,881</u>

### 28 Analysis of changes in net funds

The Charity had no debt during the year.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2021

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#### 29 Acknowledgements

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

BBC Children in Need  
Birmingham City Council  
Bruce Wake Charitable Trust  
Cambridgeshire County Council  
Chapman Charitable Trust  
Charles S French Charitable Trust  
Community Foundation for Merseyside  
Community Foundation Tyne & Wear and Northumberland  
County Durham Community Foundation  
Douglas Arter Foundation  
Funding from Suffolk Community Foundation through the Private Fund - JA  
Liverpool City Council  
Milles Charitable Foundation Limited  
Milton Damerel Trust  
Mr and Mrs J A Pye's Charitable Settlement  
NHS Blackburn with Darwen Clinical Commissioning Group  
NHS Cambridge & Peterborough Clinical Commissioning Group  
NHS Devon Clinical Commissioning Group  
NHS Kernow Clinical Commissioning Group  
NHS Sunderland Clinical Commissioning Group  
P F Charitable Trust  
P H Holt Charitable Trust  
Sir James Knott Trust  
Steve Morgan Foundation  
Tanner Trust  
The Adint Charitable Trust  
The Alan Edward Higgs Charity  
The Ardwick Trust  
The Barbour Foundation  
The Barratt Development PLC Charitable Foundation  
The Benham Charitable Settlement  
The Birmingham District Nursing Charitable Trust  
The Charles Jacob Charitable Trust  
The Chrysalis Trust  
The Clive and Sylvia Richard Charitable Trust  
The Community Foundation for Lancashire  
The Dyers Company Charitable Trust  
The Edgar E Lawley Foundation  
The Edward and Dorothy Cadbury Trust  
The Eleanor Rathbone Charitable Trust  
The Ernest Kleinwort Charitable Trust  
The Eveson Charitable Trust  
The February Foundation  
The Frederick & Phyllis Cann Trust  
The George A. Moore Foundation  
The Goldcrest Charitable Trust  
The Grace Trust  
The Hadrian Trust  
The Hemby Trust  
The Ian Askew Charitable Trust  
The J Reginald Corah Fund

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

**FOR THE YEAR ENDED 31 MARCH 2021**

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### 29 Acknowledgements

(Continued)

The J.G. Graves Charitable Trust  
The James Tudor Foundation  
The John Avins Trust  
The John James Bristol Foundation  
The Joseph and Annie Cattle Trust  
The Joseph And Lena Randall Charitable Trust  
The Julia and Hans Rausing Trust  
The Lawson Trust  
The Leach Fourteenth Trust  
The London Community Foundation  
The Lord Cozens-Hardy Trust  
The National Lottery Community Fund  
The Neighbourly Community Fund  
The Peter Stebbings Memorial Charity  
The Roger De Haan Charitable Trust  
The Simon And Philip Cohen Charitable Trust  
The Sir James Reckitt Charity  
The Sobell Foundation  
The Sovereign Health Care Charitable Trust  
The Sunrise (Sidmouth) Charitable Trust  
The Sylvia And Colin Shepherd Charitable Trust  
The Thomas Sivewright Catto Charitable Settlement  
The Valentine Charitable Trust  
The Wilfred And Elsie Elkes Charity Fund  
The William Leech Foundation  
The Wixamtree Trust  
Tory Family Foundation

We would also like to thank all supporters who helped the Huntington's Disease Association during the year to bring us closer to our vision - a better life for anyone affected by Huntington's disease.