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 2020

HUNTINGTON'S DISEASE ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Patrons	Tony Hadley Shane Richie
Trustees	Mr A Bickerdike (Chairperson) Dr G El-Nimr Mr M Ellison Mr N M Heath (Hon Treasurer) Dr E M Howard (Vice-Chairperson) Professor H Rickards Ms A C Clarke Dr A Fryer Ms C Lyon Ms S Barker Mr S Duckett
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Charity number	296453
Company number	02021975
Registered office	Suite 24 Liverpool Science Park Innovation Centre 131 Mount Pleasant Liverpool L3 5TF
Auditor	DSG Castle Chambers 43 Castle Street Liverpool L2 9TL
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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 2020

The Trustees present their report and financial statements for the year ended 31 March 2020.

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 person’s 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 an inherited, genetic and rare neurological disorder that affects the central nervous system. It is a degenerative condition that causes progressive cognitive deterioration and changes in behaviour and movement. It is often described as like having motor neurone disease, schizophrenia, Parkinson’s and Alzheimer’s disease all at the same time. Each child of a parent with Huntington’s has a 50% chance of inheriting the faulty gene. It is estimated that around 8,000 people are living with Huntington’s and 32,000 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 Association was founded in 1971 after a family who had been given a diagnosis of Huntington’s put an advert in the local paper asking if anyone knew of any other families in a similar situation. It began as a self-help group with 76 members and was known initially as the Association to Combat Huntington’s Chorea, later becoming the Huntington’s Disease Association.

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

The Huntington’s Disease Association provides support to anyone affected by Huntington’s or working with people affected by Huntington’s in England and Wales. We also work closely with other organisations with similar interests in Scotland and Ireland. We have 36 staff members from a wide range of backgrounds. From nursing and social care to fundraising and administration, all are united in their dedication to supporting people living with and affected by Huntington’s.

What we do

Specialist Advisory Service

The Specialist Huntington’s Disease Advisory service is made up of 23 Specialist Huntington’s Advisers, each covering different areas of England and Wales. Our advisers provide practical information, advice and emotional support to individuals with Huntington’s and their families. They promote local services, assist with the organisation of care packages and answer crisis calls to ensure people with Huntington’s receive the best possible care and support. 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 children 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.

Membership

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

Branches and Support Groups

We are linked to 22 local Huntington’s Disease Association branches and 25 support groups all led by dedicated volunteers. These groups provide invaluable peer support on a local level. They work tirelessly to help in all aspects of the Huntington’s Disease Association’s work and enable governance and administration costs to be kept at a minimum.

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 impacted by the disease and fundraising to help ensure we can continue supporting those who need our help.

Aims and objectives in 2019/20

The following goals underpin the Huntington’s Disease Association’s five-year strategy and were the focus of the charity’s work throughout 2019/20:

- 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

Achievements and performance

Our impact in 2019/20

Improved quality care and support

As a rare condition, often shrouded in misconception and misunderstanding, it can be challenging for people affected by Huntington's to access appropriate services and find health and social care professionals who understand the complexities of the condition. Throughout the year, at the Huntington's Disease Association, we took steps to improve the quality of care and support people with Huntington's receive; educating and correcting inaccurate information, signposting to services that understand and challenging inequality and poor standards.

In 2019/20 our Specialist Huntington's Disease Advisory service provided information and advice to 5,258 people affected by Huntington's disease. 57% of the people we supported were adults with Huntington's who were either experiencing symptoms or were not yet symptomatic, 1% were adults who had tested negative for the condition, 1% were young people with Juvenile Huntington's, 10% were adults at risk of developing the condition, 27% were carers and 4% were young people living in families affected by the disease. Throughout the year, we received 1,261 new referrals to our Specialist Huntington's Disease Advisory service.

We were able to support people in a variety of ways. Our dedicated helpline responded to 14,938 calls and 25,227 emails; our advisers carried out 1,990 visits to people in their own homes and we provided a face to face presence at over 242 Huntington's clinic sessions at hospitals throughout England and Wales. In addition, we communicated with service users via direct messages on our website and social media channels. Whether providing emotional support, information about future care planning, tips on symptom management or advocacy on health, financial and legal matters, our advisers were there to guide those affected by Huntington's. 97% of those who completed our family feedback survey told us that contact with an adviser helped them, with 80% feeling less isolated, 83% were better able to cope with their condition and 77% felt more informed about organisations and services available to help them.

For a number of people referred to our service, English is not their first language and they can sometimes struggle to access support. During the year, we took steps to ensure we are able to provide information and advice about Huntington's to those in these circumstances, linking with a translation service that we are able to call on when needed. We are committed to ensuring our services are as accessible as possible to ensure no one faces Huntington's disease alone.

During the year, our Huntington's Disease Youth Engagement Service (HDYES) supported 209 young people between the ages of 8-25 living in families affected by Huntington's and provided advice to a number of parents and guardians. For these young people, life can be difficult and confusing. They may be seeing a loved one with Huntington's gradually deteriorate, taking on a caring role, worrying about Huntington's affecting them in the future, all while trying to juggle school work and friends. Our Youth Workers expanded their range of support throughout the year, visiting young people at school to talk with them about their experiences and concerns, developing a workbook to help parents / teachers talk to young people about Huntington's and running a number of social events to allow young people to meet and make friends with others their age who are facing similar situations.

As the year progressed, both the charity and the Huntington's community faced new challenges as the COVID-19 pandemic took hold. When the UK Prime Minister announced lockdown measures on 23 March 2020, we put strategies in place to ensure we could continue to provide our Huntington's disease advisory service on a more remote basis to ensure the safety of those we support and that of our staff. Struggling to access essential items and services due to shielding measures, increased cases of domestic violence due to more time spent together at home and difficulty understanding and complying with social distancing guidelines were just some of the many challenges people were facing. In March alone, 13% of all telephone and email queries our advisory service received related to COVID-19. With advice from the UK Government in relation to COVID-19 changing frequently, we created a dedicated COVID-19 resource hub on our website to provide accurate, easy to understand information and helpful resources relevant to people affected by Huntington's, including information sheets to help explain Huntington's to those that might not understand it in public settings from supermarkets to Emergency departments.

With digital technology becoming a favoured method for accessing immediate, accurate information and advice, especially now when faced with COVID-19, we understand the importance of ensuring older generations of people, who may not be digitally confident, don't miss out on important support and resources. After successfully receiving funding from the Bupa UK Foundation last year, we were able to significantly develop our online carer support for people over the age of 65 throughout 2019/20. Through extensive engagement with 'older' carers, we were able to learn how we could make information more accessible to them using digital technology. This resulted in the creation of easy to use webpages on our website that house accessible resources such as guides and videos, all written in plain English language with no technical jargon and with clear visual cues to help people easily navigate the pages. In addition, guidance on how to use the pages was created as well as an online forum where the older generation could seek advice from each other both in relation to their caring roles and accessing support online. We also offered support with using the resources via phone if people were struggling.

During the year we were able to provide 28 welfare grants of approximately £250 each to people affected by Huntington's who were experiencing financial hardship. The grants awarded were for items or activities that would go on to significantly improve the person's quality of life, including household items such as washing machines or carpets, technology to help with communication and respite breaks.

Our HDA Quality Assured Care Home Accreditation Scheme awarded accreditation to two care homes in 2019/20 - Fairburn Mews in Castleford was the first home in England to achieve this accreditation and Yr Ysgol in Swansea, was the first in Wales. After extensive assessment against a criteria of best practice care standards for people with Huntington's, both care homes were able to evidence that they provide excellent quality care. It is our hope that these care homes are the first of many to achieve accreditation and that the scheme will help improve and standardise care quality and give confidence to families affected by Huntington's when a loved one has to move to a care or nursing home.

It was by working together with fellow charities, organisations and key policy and decision-makers, that we were able to give people affected by Huntington's a stronger voice through the year. Our partnership with the Department of Work and Pensions (DWP) continued in 2019/20 to facilitate and streamline the Personal Independence Payments (PIP) application process for families affected by Huntington's. We maintained good relationships with both organisations that assess PIP applications, Capita and the Independent Assessment Service (IAS), often advising on complex cases. We also attended IAS stakeholder meetings to ensure Huntington's disease was at the forefront of discussions and decision-making regarding benefits.

We continued to work alongside a number of academics and lay groups throughout the year to promote the benefits of physical activity and standardise the use of this therapy. Firstly, in partnership with a number of organisations, we continued our involvement with the Physical Activity for People with Rare Neurological Conditions (PARCC) project, attending workshops and forming important links between those leading the project and the Huntington's community. We also helped to organise a physical activity study event in partnership with UCLAN which was open to patients and carers, clinicians and UCLAN Physiotherapy/ Occupational Therapy students. The study focussed specifically on the benefits for people with Huntington's disease.

We continued our work with the Neurological Alliance, a coalition of more than 80 organisations working together to improve and standardise the quality of care, support and advice for people in England who have a neurological condition. We represented Huntington's disease in various subgroups which gave us the opportunity to network with other neurological charities of varying sizes, share information and best practice, explore issues of mutual interest and work together for greater impact to effect important change. One important change during the year was the launch of the Mental Health Consensus Statement, aimed at key policymakers, that outlines what every person with a neurological condition should expect to receive in terms of treatment and care for their mental, cognitive and emotional health. The document makes a number of recommendations about what changes need to happen to make these recommended standards a reality.

During the year we represented Huntington’s disease families at the Rare Disease UK annual reception at Westminster, meeting with politicians and other stakeholders to raise awareness of rare diseases, the impact they have and the various issues people are facing, particularly around poor care co-ordination. We also attended National Neurosciences Advisory Group meetings in 2019/20 during which we emphasised the importance of clear care pathways for people with Huntington’s disease. We attended the Genetic Alliance UK annual conference and their ‘Action for Access for Medicines for Rare Diseases’ APPG, joining MPs, pharmaceutical company representatives and charity representatives to discuss the changes needed to ensure fair and equal access to potentially life-changing treatments for people affected by rare diseases. We were invited to speak at a Westminster Forum event on end of life care, to provide key information relating to Huntington’s disease to members of the Houses of Lords and Commons and a number of NHS England representatives which gave us opportunity to make important links. We were also invited to advise Parkinson’s UK on some of the particular aspects of Huntington’s care and support and best practice to help inform their work with NHS England on trying to create a pathway relevant to all movement disorders.

Better knowledge and understanding of Huntington’s

Improving knowledge and understanding of Huntington’s formed a key part of our work in 2019/20. Through training, information resources and education we were able to raise the profile of this rare disease and bring greater understanding to those with Huntington’s, their loved ones and the health and social care professionals involved in their care and support.

During the year, we launched a number of new easy to read and informative guides aimed at families affected by Huntington’s on subjects such as caring, eating well, communication and behaviour changes and well-being. We also published a guide written specifically with Social Workers in mind to provide a better understanding of the condition so that they can put the relevant strategies in place from the outset of their involvement. Throughout the year, our guides were viewed and downloaded from our website over 9,000 times.

We expanded our training programme in 2019/20, refreshing and tailoring presentation content and making sessions more visual and engaging. This allowed us to provide informative, bespoke training to share knowledge and best practice guidance with specific health and social sector groups such as Social Workers and Multi-Disciplinary teams. We delivered 177 training sessions overall and 69 smaller information sessions to over 1,650 health and social care professionals throughout the year. Following the training, 100% of those that responded to our survey informed us that they felt the quality of care their teams provide would improve and we hope will go a long way to improving care standards for people affected by Huntington’s.

We continued to deliver ‘Understanding Huntington’s disease’, our flagship professional course in 2019 with two courses held over a number of days. Covering in-depth topics such as diet and nutrition in Huntington’s, speech and language, mental health and genetics, attendees were able to learn more about the condition and discover management strategies through discussion with Huntington’s experts and their fellow attendees.

During the year, we continued to produce our twice-yearly magazine / newsletter packed full of tips, sources of support, personal stories and important updates to keep the charity’s family and professional members fully informed of upcoming opportunities and to enable them to learn from the experiences of others affected by Huntington’s.

Events throughout the year such as the national Annual Family Weekend and Juvenile Huntington’s Weekend and various other locally organised events, provided families affected by Huntington’s further opportunity to learn more about the disease and ask questions relevant to their own situations.

We know that more and more people are using web resources for information and advice, particularly those at the earlier stages of their Huntington’s journey. As such, we invested a lot of time in making improvements to our website throughout the year to provide diverse, user-friendly and informative content to suit various audiences. 2019/20 saw an increase in website visitors with around 158,000 people visiting the site. Information updates, downloadable support resources, personal story blogs, important news articles and upcoming events updated on our website were shared across our social media channels in an attempt to bring accurate information about Huntington’s to a wider audience. Website sessions triggered via social media more than doubled compared to the previous year highlighting that this strategy was successful in enabling us to reach more people in 2019/20.

Our work with the Association of British Insurers (ABI) and the British Insurance Broker’s Association (BIBA) carried on into 2019/20 with further progress made in our attempts to make insurance more accessible for people with Huntington’s. In partnership with the Scottish Huntington’s Association, we provided information about Huntington’s disease and the difficulties people face when seeking an insurance product, allowing these organisations to review their processes, webpages and search tools to make finding a specialist broker much easier. In addition, we provided detailed information, including the latest research findings, to support a review into the way insurance companies assess risk when it comes to Huntington’s which is currently outdated and sometimes inaccurate. We hope this updated knowledge will help insurance companies make important changes to improve access to affordable and fair insurance costs for those who live with Huntington’s or are at risk of developing it.

We continued our fight to encourage equal and fairer access to armed forces recruitment for people at risk to Huntington’s in 2019/20. We wrote to the Ministry of Defence on multiple occasions stating occurrences of unfair and misinformed treatment to armed forces applicants within the Huntington’s community, providing up to date evidence and urging consultation with Huntington’s disease medical professionals when the recruitment policy is reviewed. We hope our efforts will ensure the most accurate information and research is taken into consideration and we will continue to challenge mistreatment and misinformation in the armed forces as occurrences are made known to us.

Greater opportunity for peer support and community involvement

Many people in the Huntington’s community have told us that spending time with others who understand what they are facing and who they can share hints and tips with to help overcome particular challenges is a real life-line. Whether in person or online, providing more opportunities for people to meet and interact with each other was a prominent focus of our work during the year.

We were able to hold a number of national events in 2019/20 that provided opportunity for young people and adults alike to seek support from each other. Our annual family weekend in October 2019 was open to all in the Huntington’s community and included both informative content in the form of interactive workshops and presentations and time to network and socialise with fun activities for the younger attendees and a dinner dance for all in the evening. In June 2019, our annual Juvenile Huntington’s weekend provided young people with the Juvenile onset form of the disease and their families opportunity to come together for an activity-filled weekend in the Lake District to form friendships, share experiences, seek support and spend time together as a family. We were able to bring our dedicated army of fundraisers together in June 2019 at our Volunteer Awards ceremony which allowed attendees to meet others with a shared dedication to the charity and celebrate each other’s fantastic achievements.

On a more local level, our Specialist Huntington’s Disease Advisers, each covering a number of counties across England and Wales, ran events specific to the needs of those affected by Huntington’s in their local communities. In Birmingham, an event took place providing male carers the opportunity to meet with others with similar caring responsibilities. In Oxfordshire, a ‘Walk and talk’ event was organised for people affected by Huntington’s in the area who were keen to meet and chat with others and improve their physical and mental wellbeing. In the Hampshire and Berkshire areas, in collaboration with a local genetics team, an event for young adults, who had tested positive for the Huntington’s gene, took place to provide a chance for them to meet and form key support links with each other.

With physical difficulties and caring duties preventing many people in the Huntington’s community from attending face to face events, we further developed our online peer support opportunities throughout the year. Our online message board continued to provide a space for members to seek advice from each other in various themed topic threads with over 1,700 posts and 398 new members joining throughout the year. With a following over 13,000 on Facebook, over 3,000 on Twitter and over 1,200 on Instagram, the number of people we reached in 2019/20 grew significantly. As well as being key communication tools for the charity, our social channels also allowed the Huntington’s community to connect and interact with each other. Our website blog also provided opportunity for our supporters affected by Huntington’s to share their stories about their fundraising endeavours, experiences of the genetic testing process and the challenges of caring for a loved one with the condition.

We increased our communication with supporters throughout the year with the launch of various eNewsletters which enabled us to bring opportunities for involvement in fundraising, events and awareness campaigns to our subscribers as and when opportunities arose which provided a much easier and more immediate way for the Huntington’s community to learn about and get involved in charity activity.

During the year, we began a partnership with an organisation specialising in interactive digital and brand innovation with whom we hope to provide an integrated web platform on our website to allow our supporters to create their own high quality and on-brand fundraising and event materials. We hope this will make it easier for people to get involved in fundraising and awareness events as well as strengthening our brand recognition. We hope to launch the platform in the coming year.

Our Patient and Public Involvement Group, HD Voice, continued to grow in 2019/20 with a total membership of 30 volunteers by year-end. By reviewing internal resources and attending external consultation events for various research projects, HD Voice ensured that the issues faced by people affected by Huntington’s in England and Wales were highlighted during the year to ensure that discussions and decisions were based on accurate and current experiences.

In 2019/20, committed volunteers throughout England and Wales continued to dedicate their time and expertise to help run our branch and support group network. From arranging guest speakers at meetings to social get-togethers, branch and group leaders helped to provide guidance, signpost to relevant services, provide welfare grants, facilitate local friendships and represent the Huntington’s Disease Association in the local community. With a longstanding volunteer structure within the charity and following various changes to the network over the years, a review of branch and support groups was commissioned in 2018/19 and this continued throughout 2019/20. During the year, a focus group met to discuss and later implement improved processes, updated paperwork and a new design web page for each branch and support group to strengthen and update group administration and make information and events more accessible.

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

The month of May 2019 provided us with the opportunity to concentrate our time and resources on raising awareness of Huntington’s disease with the general public and for the first time, our awareness efforts spanned the entire month, rather than a week, for maximum impact. Throughout Awareness Month, we shared information about Huntington’s, encouraged people to take part in fundraising and awareness-raising opportunities, ran events aimed at carers and asked our supporters to spread the word far and wide with their networks to encourage interaction and bring knowledge and understanding about Huntington’s to as many people as possible. Once again, the Huntington’s community took part in the international "LightItUp4HD" campaign which encouraged landmarks and notable buildings to light up in our charity colours, pink and green, to raise awareness. Over 25 well known buildings lit up during the month including Althorp House in Northamptonshire, Blackpool Tower and Birmingham’s Bullring Grand Central. People also took part at home, lighting up whole communities with illuminated pink and green candle bags in the windows of homes throughout England and Wales.

Storylines in popular programmes, such as Casualty, Doctors and Emmerdale, brought Huntington’s to prime time television throughout the year which was a fantastic opportunity to convey understanding about Huntington’s to the general public. We were approached to read and advise on scripts to ensure an accurate portrayal of Huntington’s disease was shown.

We were approached on a number of occasions throughout the year by journalists and authors to provide information about Huntington’s and we were able to link them to members of the Huntington’s community interested in sharing their story. This facilitated information about Huntington’s disease appearing in print, TV and radio outlets across the country throughout 2019/20. Our Chief Executive also spoke directly to the media on a number of important matters including on BBC Three Counties Radio about Huntington’s research trials, on BBC News about gene silencing and on the Victoria Derbyshire show about genetic testing; all of which brought information and awareness to many who knew little about the condition before.

Huntington’s disease even made it the silver screen at the beginning of 2020 with a documentary entitled ‘Dancing at the Vatican’ created by the organisation HDdennomore. We helped promote this documentary, showcasing the Huntington’s community’s first ever audience with the Pope and invited journalist and influencer contacts to attend the premiere to help raise maximum awareness.

A strong charity to better champion the needs of our community

Now two years into our five-year strategic plan, we continued to develop and expand our services throughout the year in line with agreed service development, fundraising and communication strategies to grow our charity and continually improve our support to best meet the needs of the Huntington’s community.

The COVID-19 pandemic had an inevitable impact on planned activities and events towards the end of 2019/20 with the introduction of social distancing, the cancellation of events, an increased reliance on digital communication and restrictions that meant fundraising for us in the usual way was impossible. Together with the Huntington’s community, we pulled together to adapt our services and activities to ensure people affected by Huntington’s remained supported. Innovative ideas from our supporters and fundraising team saw fundraising activities begin to turn digital and become social distancing safe. Our advisers stopped face to face contact and began focussing on providing advice via our telephone and email helpline. We started to explore ways in which we could continue to provide training to health and social care professionals remotely and we trialled our very first webinar as part of the Bupa Foundation UK Older Carers project. Our central office-based staff began to work from home and took steps to ensure that charity operations and administration continued to run smoothly with changes made to the telephony and computer systems and various in-house processes so that they could become digital and less paper reliant.

We continued throughout the year to improve our charity branding, updating our merchandise, guides, forms, training materials, website and social media content to ensure their style was consistent and easy to recognise as belonging to the Huntington’s Disease Association. We worked to improve our website, adding to our blog with articles on a wide range of useful topics, creating new webpages to suit emerging needs, such as a COVID-19 resource hub and older carers project, and developing the branch and support group and events pages to make local meeting and upcoming event details much more accessible.

As part of our ongoing service review, we trialled a new way of working within our Specialist Advisory Service with the creation of a Northern ‘hub’ of Specialist Huntington’s advisers based in various locations in the North of England. Through close team working and sharing their knowledge of local areas, advisers within the hub were able to provide advice and support to all callers within the North of the country and not just those living in their local area. A review of this way of working will take place in the next year to determine whether this model has been successful and whether it will be extended to other areas of the country. Even before COVID-19 lockdown, our Specialist Huntington’s Disease Advisers began reducing their travel time and connecting with people affected by Huntington’s in smarter, more efficient ways which allowed them to both reach and support a greater number of people and significantly lessen the charity’s carbon footprint. A review of the Huntington’s Disease Youth Engagement service through the year resulted in a restructure with a team leader position created to better co-ordinate the support service and peer support opportunities. A new Fundraising Assistant appointment at the beginning of 2019/20 provided greater opportunity to streamline supporter stewardship and review and improve current fundraising processes throughout the year.

Safeguarding training took place during the year to ensure that both staff and trustees were fully informed about current safeguarding practice. Additional individual training needs were identified and courses attended throughout the year to ensure the continued professional development of our staff team.

Ongoing maintenance of our client and supporter databases continued throughout the year to ensure the data held was complete, accurate and fully compliant with General Data Protection Regulations, to improve monitoring and evaluation of our work and to improve our mailing list segmentation allowing us to tailor our communication to meet individual interests. We also invested in HR software to allow us to start centralising, streamlining and digitising our employee processes and records to take greater steps forward in reducing our paper usage.

A data quality group was formed in 2019/20 compromising of representatives from each staff team, the board of trustees and the Huntington’s community. Together they worked to review the data the charity collects and the monitoring systems used to determine whether any improvements can be made to better demonstrate the impact of our services. Data security remained a key priority in 2019/20 with a security review taking place during the year and a strategy implemented to ensure relevant security precautions were in place to protect our I.T and information systems.

As a relatively small charity representing a rare and often little-known disease, we understand the importance of standing together with key partners and similar organisations representing rare and neurological conditions. This strengthens our position and provides Huntington’s with a much louder voice when highlighting issues and suggesting change to policy and decision-makers. Throughout the year, we worked closely with national and international Huntington’s charities and remained active members of Genetic Alliance UK, Rare Disease UK, the Neurological Alliance and the National Council for Voluntary Organisations.

For effective governance of the charity, the board of trustees met regularly throughout the year to closely monitor the charity’s operations and financial performance, ensuring compliance with the charity governance code and the charity commission’s good practice guidelines.

Supporting Huntington’s research

With exciting developments emerging in Huntington’s disease research and the potential for an effective treatment edging closer each day, supporting the work of researchers remained a key priority for the charity throughout the year.

We continued to actively support the work of three Huntington’s Disease Association funded research projects that entered the final stages of their studies. Dr Una Jones from Cardiff University continued her project to promote the importance of physical activity for people with Huntington’s, Professor Roger Barker’s team at the University of Cambridge continued to look at how Huntington’s affects financial decisions and Speech and Language Therapist Emma Burnip entered her final year of PhD research into a swallowing therapy for people with Huntington’s.

We recognise the importance of communicating Huntington’s research advancements to the Huntington’s community and keeping them up to date with progress made. In 2019/20 we revamped our research webpages making them easier to navigate and access up to date information. We continued to provide updates and research opportunities at our events, on social media and in our newsletters. We were also pleased to continue our funding towards HD Buzz, a website that explains current Huntington’s disease research in a way that is easier to understand for a non-medical audience.

Promoting participation in Enroll-HD continued throughout the year to encourage maximum involvement in the world’s largest observational study for Huntington’s disease to enable researchers to gain better insight into the condition.

Our Patient and Public Participation group, HD Voice, continue to comment on various research documentation and take part in important market research throughout the year to ensure the thoughts, experiences and needs of the Huntington’s community were considered at all times.

We continued to work with HCD Economics during the year and formed a new partnership with Tessella to gather Huntington’s data, including health economics and the cost of caring for someone with the condition, to provide evidence to support future discussions with key policy and decision-makers and encourage fair and equal access to future medicines or treatments. Again, with future access in mind, we worked with other Huntington’s charities within the UK and Europe during the year to determine the role charities and lay organisations might play in facilitating the process. Important links were also formed throughout the year with representatives from NICE to aid future discussions about recommended health and care guidance for Huntington’s and with a number of pharmaceutical companies responsible for bringing treatments to market, including Roche who requested our input on an advisory panel.

Fundraising

Our income continues to come from a variety of sources with individuals and grants being our largest streams.

In 2019/2020 our income from Community Fundraising and Events was strong, raising £561,075 in total. This is down to our fantastic supporters which included further backing from “Do it for Dom”. In addition, we received fabulous support from “Run for Huntington’s” who ran from Colchester to Newcastle raising £10,030.00. We have also seen fantastic growth in digital fundraising with donations via Facebook raising over £77,000 and our thanks go to everyone who has chosen to support our work in this way.

We were thrilled to be chosen as the Charity of the Year for FMP Global and were hugely impressed to see their staff take on different challenges throughout the year from a Paris to Chichester sponsored bike ride to office Guinness World Record attempts. They raised over £20,000.

Christmas 2019 saw us being one of 18 charities selected to be a partner in the Paperchase Charity Christmas Cards scheme. This saw a specially chosen card for the Huntington’s Disease Association being sold in all Paperchase high street stores and online raising over £7,000. Our thanks to Paperchase and everyone who bought a pack of our cards.

Once again, the committed support from Trusts and Foundations towards our work is welcome. We are thankful to the various Trusts and Foundations who have supported our work in 2019/2020 for recognising the valuable contribution our work makes towards people affected by Huntington’s disease. We were especially pleased to receive continuation funding from a number of Trusts including the Clive and Sylvia Richards Charity and Children in Need. We were also pleased to receive £20,930 from BUPA for development of resources for Older Carers and a donation of £5,000 from Genetic Disorders UK for the Huntington’s Disease Youth Engagement Service (HDYES).

In statutory funding, we were successful in our application for a two-year contract with Birmingham City Council for delivering services for people affected by Huntington’s disease across the city.

We believe that putting people with Huntington’s disease at the heart of our fundraising messages 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.

A new range of policies around fundraising were developed including Fundraising with the Huntington’s Disease Association, Supporter Charter and How to make a complaint. These new policies will give our supporters confidence in the work we do and how we will support them through their supporter journey with us. 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 to the Privacy and Electronic Communications Regulations (PECR). The Huntington’s Disease Association recognises that we may on certain occasions work with people in vulnerable circumstances and 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 2019/2020 we did not receive any complaints about our fundraising practices/approaches.

Financial review

The results for the year show an overall surplus of £61,383 (2019: £87,579) made up of a surplus on the general fund of £54,943 (2019: £57,774) and a surplus on the restricted funds of £6,440 (2019: £29,085). As in previous years a transfer from unrestricted fund to restricted funds was made to cover research spending.

Overall income for the year fell as a result of a decline in notified legacy income. The variable nature of this source of funds is recognised in our budgeting process and the Trustees are pleased to report that the surplus, after taking account of unrealised losses on investment, has continued to build the resilience of the charity.

Expenditure in all areas was carefully controlled and on budget in all departments. We continued to support research activities, mainly from funds previously provided for by recognising future committed costs.

Strong cashflow during the year enabled investments to be boosted by a further £75,000 placed in a Charity Common Investment Fund.

Reserves Policy

The reserve requirement of the Charity is to enable the salaries of staff members to be covered in the event of short-term income fluctuation. This policy enabled the Charity to continue its work throughout the year ended 31 March 2020. The surplus for the year built the general reserves to a level that covers six months' salary and running costs and therefore met our target in all material respects. As at the year end, free reserves available, excluding the designated project reserve and funds held by branches stood at £751,954 (2019: £679,837) against a target of £775,000. The designated project reserve stood at £214,000 at the year end.

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 2020/21

Looking to the year ahead, we plan to continue to innovate and develop our services to further improve standards of care and support, better educate people about Huntington's and its complexities, encourage community involvement and peer support and support progress in Huntington's research.

With COVID-19 and social distancing set to continue into the next year, we will explore how we can utilise technology to its maximum potential to enable us to support, educate and encourage safe interaction. We will further explore the use of webinars and video calling and plan to make improvements to our helpline telephony systems. We will continue to update our website in line with user feedback with plans to simplify the website navigation and layout in place. With a greater digital reliance, the development of our social media channels, blogs and eNewsletters to communicate with those who use and support the charity will be key priorities for the next year.

With two HDA Quality Assured care homes already on board, we plan to further expand the accreditation scheme throughout the year and encourage participation from a greater number of care homes to further promote best practice care in Huntington's disease and improve care standards.

Following the cancellation of a number of events and projects in 2020, including the Virgin London Marathon and our own Volunteer Awards and Volunteer Ambassadors programme due to the arrival of COVID-19, we will take steps in the next year to mitigate the financial impact on the charity through the furlough of staff and reconfiguring our events and community fundraising portfolio.

Further development of resources to help families affected by Huntington's and health and social care professionals working with people with the condition is planned for the next year including the creation of further guides, video content and infographics.

We will continue in our commitment to raise the profile of Huntington’s disease and the work of the Huntington’s Disease Association and bring greater knowledge to the general public by taking part in awareness campaigns, supporting scriptwriters, authors and journalists alike to feature Huntington’s stories and encouraging our followers to share information about Huntington’s and the support available.

Work will continue throughout the year with our dedicated branch and support network, providing them with the resources they need to offer peer support to a greater number of people affected by Huntington’s in their local community. We also hope to provide greater volunteer opportunities within the charity in 2020/21 to encourage people to donate their time and expertise to help us further our goals and provide greater opportunity for community involvement.

Facing a changing and uncertain landscape in 2020/21 with the continuation of the COVID-19 pandemic and anticipated Brexit progress, we plan to review our services continually throughout the year, taking a flexible approach and adapting to provide relevant advice and support to those that need us whilst utilising charity resources as effectively as possible.

Supporting Huntington’s research will remain a significant focus for the charity in the coming year. We will continue to promote research opportunities, provide up to date information about research progress and support the work of research teams across the country. We will continue to form important links and work with fellow Huntington’s and rare disease charities, pharmaceutical companies, researchers and key policy and decision-makers to help bring an effective treatment for Huntington’s a step closer.

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)
Dr G El-Nimr
Mr M Ellison
Mr N M Heath (Hon Treasurer)
Dr E M Howard (Vice-Chairperson)
Professor H Rickards
Ms A C Clarke
Dr A Fryer
Ms C Lyon
Ms S Barker
Mr S Duckett

Recruitment and appointment of trustees

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

Organisational structure

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

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

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

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

Trustee induction and training

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

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

Remuneration policy

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

Auditor

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

Disclosure of information to auditor

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

The Trustees report was approved by the Board of Trustees.

N M Heath

Mr N M Heath (Hon Treasurer)

Dated: 30 October 2020

STATEMENT OF TRUSTEES RESPONSIBILITIES

FOR THE YEAR ENDED 31 MARCH 2020

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

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

In preparing these accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;

- observe the methods and principles in the Charities SORP;

- make judgements and estimates that are reasonable and prudent;

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

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

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

INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

Opinion

We have audited the financial statements of Huntington's Disease Association (the ‘Charity’) for the year ended 31 March 2020 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2020 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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the Charity’s ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor’s report thereon. 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.

In connection with our audit of the financial statements, 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 audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. 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.

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

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.

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.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: http://www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

INDEPENDENT AUDITOR'S REPORT (CONTINUED)

TO THE MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

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

30 October 2020

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 2020

	Notes	**Unrestricted funds 2020 £**	**Restricted funds 2020 £**	**Total 2020 £**	Unrestricted funds 2019 £	Restricted funds 2019 £	Total 2019 £
Income and endowments from:							
Donations and legacies	**2**	1,151,744	38,828	1,190,572	1,251,542	19,826	1,271,368
Charitable activities	**3**	91,930	373,938	465,868	100,538	368,210	468,748
Other trading activities	**4**	10,258	-	10,258	7,061	-	7,061
Investments	**5**	12,385	-	12,385	17,288	-	17,288
Other income	**6**	2,035	-	2,035	798	-	798
Total income		1,268,352	412,766	1,681,118	1,377,227	388,036	1,765,263
Expenditure on:							
Raising funds	**7**	177,950	-	177,950	186,579	-	186,579
Charitable activities	**8**	993,538	409,621	1,403,159	1,096,540	400,649	1,497,189
Total resources expended		1,171,488	409,621	1,581,109	1,283,119	400,649	1,683,768
Net gains/(losses) on investments	**12**	(38,626)	-	(38,626)	6,084	-	6,084
Net incoming resources before transfers		58,238	3,145	61,383	100,192	(12,613)	87,579
Gross transfers between funds		(3,295)	3,295	-	(42,418)	42,418	-
Net movement in funds		54,943	6,440	61,383	57,774	29,805	87,579
Fund balances at 1 April 2019		1,005,052	22,697	1,027,749	947,278	(7,108)	940,170
Fund balances at 31 March 2020		1,059,995	29,137	1,089,132	1,005,052	22,697	1,027,749

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 2020

		2020		2019	
	Notes	**£**	**£**	**£**	**£**
Fixed assets					
Tangible assets	**13**		9,317		8,039
Investments	**14**		374,827		338,453
			384,144		346,492
Current assets					
Stocks	**15**	5,891		4,804	
Debtors	**16**	271,334		342,856	
Cash at bank and in hand		579,341		486,415	
		856,566		834,075	
Creditors: amounts falling due within one year	**17**	(136,060)		(100,718)	
Net current assets			720,506		733,357
Total assets less current liabilities			1,104,650		1,079,849
Creditors: amounts falling due after more than one year	**18**		(15,518)		(52,100)
Net assets			1,089,132		1,027,749
Income funds					
Restricted funds	**20**		29,137		22,697
Unrestricted funds					
Designated funds	**21**	308,081		325,215	
General unrestricted funds		751,914		679,837	
			1,059,995		1,005,052
			1,089,132		1,027,749

The financial statements were approved by the Trustees on 30 October 2020

N M Heath

Mr A Bickerdike (Chairperson)
Trustee

Mr N M Heath (Hon Treasurer)
Trustee

Company Registration No. 02021975

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2020

		2020		2019	
	Notes	**£**	**£**	**£**	**£**
Cash flows from operating activities					
Cash generated from operations	**27**		160,881		16,200
Investing activities					
Purchase of tangible fixed assets		(5,340)		(2,453)	
Purchase of investments		(75,000)		-	
Proceeds on disposal of investments		-		168,219	
Interest received		12,385		17,288	
Net cash (used in)/generated from investing activities			(67,955)		183,054
Net cash used in financing activities			-		-
Net increase in cash and cash equivalents			92,926		199,254
Cash and cash equivalents at beginning of year			486,415		287,161
Cash and cash equivalents at end of year			579,341		486,415

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 immediate 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.

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

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.

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.

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
	2020	**2020**	**2020**	2019	2019	2019
	£	**£**	**£**	£	£	£
Donations and gifts	804,671	26,272	830,943	731,183	19,826	751,009
Legacies receivable	254,495	3,305	257,800	400,212	-	400,212
Other	92,578	9,251	101,829	120,147	-	120,147
	1,151,744	38,828	1,190,572	1,251,542	19,826	1,271,368
Donations and gifts						
Community fundraising	554,853	6,222	561,075	583,836	11,095	594,931
Other	249,818	20,050	269,868	147,347	8,731	156,078
	804,671	26,272	830,943	731,183	19,826	751,009

3 Charitable activities

	2020	**2019**
	£	**£**
Grants received	423,438	427,522
Merchandise	10,901	10,301
Other income	31,529	30,925
	465,868	468,748
Analysis by fund		
Unrestricted funds	91,930	100,538
Restricted funds	373,938	368,210
	465,868	468,748

4 Other trading activities

	Unrestricted funds	Unrestricted funds
	2020	2019
	£	£
Raffle and sponsorship	308	111
Company sponsorships	9,950	6,950
Other trading activities	10,258	7,061

5 Investments

	Unrestricted funds	Unrestricted funds
	2020	2019
	£	£
Income from listed investments	10,896	16,826
Interest receivable	1,489	462
	12,385	17,288

6 Other income

	Unrestricted funds	Unrestricted funds
	2020	2019
	£	£
Miscellaneous income	2,035	798

7 Raising funds

	Unrestricted funds	Unrestricted funds
	2020	2019
	£	£
Fundraising and publicity		
Fundraising events	16,775	32,336
Fundraising consultancy costs	-	2,280
Other fundraising costs	20,050	16,483
Staff costs	141,125	135,320
Fundraising and publicity	177,950	186,419
Investment management	-	160
	177,950	186,579

8 Charitable activities

	Specialist HD Advisory Service	**Welfare and Respite Care**	**Research**	**Communication**	**Youth Worker & Juvenile**	**Branch**	**Total 2020**	**Total 2019**
	£	**£**	**£**	**£**	**£**	**£**	**£**	**£**
Staff costs	758,251	688	688	46,010	56,804	10,000	872,441	900,371
Welfare grants	-	38,608	-	-	-	-	38,608	38,206
Research	-	-	11,998	-	-	-	11,998	12,832
Juvenile	-	-	-	-	2,816	-	2,816	21,986
Branch activities	-	-	-	-	-	48,324	48,324	46,427
Travel and training	61,530	-	-	374	10,015	-	71,919	96,034
Camps, conferences and AGM	16,612	-	-	-	20,282	-	36,894	22,271
Telephone and internet	24,215	-	-	329	1,081	-	25,625	22,703
Other costs	29,126	60	60	3,948	1,041	1,437	35,672	29,579
Newsletter	-	-	-	9,453	-	-	9,453	7,777
Publications and merchandise	-	-	-	9,066	-	-	9,066	15,501
	889,734	39,356	12,746	69,180	92,039	59,761	1,162,816	1,213,687
Share of support costs (see note 9)	137,316	11,443	-	16,020	16,020	48,061	228,860	272,173
Share of governance costs (see note 9)	11,483	-	-	-	-	-	11,483	11,329
	1,038,533	50,799	12,746	85,200	108,059	107,822	1,403,159	1,497,189

Expenditure on charitable activities was £1,403,159 (2019: £1,497,189) of which £993,538 was unrestricted (2019: £1,096,540) and £409,621 was restricted (2019: £400,649).

8 Charitable activities (Continued)

For the year ended 31 March 2019

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Communication	Youth Worker & Juvenile	Branch	Nursing Home Accreditation	Total 2019
	£	£	£	£	£	£	£	£
Staff costs	785,488	688	688	34,101	58,792	-	20,614	900,371
Welfare grants	-	38,206	-	-	-	-	-	38,206
Research	-	-	12,832	-	-	-	-	12,832
Juvenile	18,120	-	-	-	3,866	-	-	21,986
Branch activities	-	-	-	-	-	46,427	-	46,427
Travel and training	79,824	-	-	762	14,813	-	635	96,034
Camps, conferences and AGM	22,271	-	-	-	-	-	-	22,271
Telephone and internet	21,350	-	-	324	780	-	249	22,703
Other costs	21,769	-	-	3,434	4,052	-	324	29,579
Newsletter	-	-	-	7,777	-	-	-	7,777
Publications and merchandise	-	-	-	15,501	-	-	-	15,501
	948,822	38,894	13,520	61,899	82,303	46,427	21,822	1,213,687
Share of support costs (see note 9)	163,304	13,608	-	-	-	95,261	-	272,173
Share of governance costs (see note 9)	11,329	-	-	-	-	-	-	11,329
	1,123,455	52,502	13,520	61,899	82,303	141,688	21,822	1,497,189

9 Support costs

	Support costs	**Governance costs**	**2020**	Support costs	Governance costs	2019
	£	**£**	**£**	£	£	£
Staff costs	89,352	-	89,352	121,239	-	121,239
Depreciation	4,062	-	4,062	5,574	-	5,574
Head office costs	135,446	-	135,446	145,360	-	145,360
Audit fees	-	7,608	7,608	-	7,710	7,710
EC meeting costs	-	3,875	3,875	-	3,619	3,619
	228,860	11,483	240,343	272,173	11,329	283,502
Analysed between						
Charitable activities	228,860	11,483	240,343	272,173	11,329	283,502

10 Trustees

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

11 Employees

Number of employees
The average monthly number of employees during the year was:

	2020 Number	**2019 Number**
Specialist HD Advisors	21	24
Management	2	2
Fundraising	3	4
Youth Worker	2	2
Administration	5	4
Communications	1	1
	34	37

Employment costs	**2020**	**2019**
	£	**£**
Wages and salaries	1,004,671	1,053,042
Social security costs	75,173	79,737
Other pension costs	23,074	24,151
	1,102,918	1,156,930

There were no employees whose annual remuneration was £60,000 or more.

12 Net gains/(losses) on investments

	Unrestricted funds	Unrestricted funds
	2020	2019
	£	£
Revaluation of investments	(38,626)	5,950
Gain/(loss) on sale of investments	-	134
	(38,626)	6,084

13 Tangible fixed assets

	Fixtures and fittings
	£
Cost	
At 1 April 2019	68,118
Additions	5,340
At 31 March 2020	73,458
Depreciation and impairment	
At 1 April 2019	60,079
Depreciation charged in the year	4,062
At 31 March 2020	64,141
Carrying amount	
At 31 March 2020	9,317
At 31 March 2019	8,039

14 Fixed asset investments

	Listed investments £
Cost or valuation	
At 1 April 2019	338,453
Additions	75,000
Valuation changes	(38,626)
At 31 March 2020	374,827
Carrying amount	
At 31 March 2020	374,827
At 31 March 2019	338,453

15 Stocks

	2020 £	2019 £
Merchandise	5,891	4,804

16 Debtors

Amounts falling due within one year:	2020 £	2019 £
Trade debtors	34,572	8,520
Other debtors	205,601	295,358
Prepayments and accrued income	31,161	38,978
	271,334	342,856

Other debtors include £154,000 (2019: £249,500) of legacies receivable.

17 Creditors: amounts falling due within one year

	2020 £	2019 £
Other taxation and social security	24,869	24,105
Trade creditors	26,080	33,840
Accruals and deferred income	85,111	42,773
	136,060	100,718

18 Creditors: amounts falling due after more than one year

	2020 £	2019 £
Accruals and deferred income	15,518	52,100

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 £23,074 (2019 - £24,151).

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 2018	Incoming resources	Resources expended	Transfers	Balance at 1 April 2019	Incoming resources	Resources expended	Transfers	Balance at 31 March 2020
	£	£	£	£	£	£	£	£	£
Research	(39,618)	10,719	(13,519)	42,418	-	8,703	(11,998)	3,295	-
Specialist HD Advisory Service (SHDA)	-	327,371	(327,371)	-	-	292,955	(292,955)	-	-
Children in Need	5,814	27,249	(33,063)	-	-	38,196	(37,351)	-	845
Breaking Down Barriers	3,192	-	(3,192)	-	-	-	-	-	-
Exemplar Health Care	10,504	-	(10,504)	-	-	-	-	-	-
JHD Weekend	13,000	22,697	(13,000)	-	22,697	19,482	(21,555)	-	20,624
Publications (Mazars)	-	-	-	-	-	12,000	(10,500)	-	1,500
Youth Services	-	-	-	-	-	20,000	(20,000)	-	-
BUPA Old Carers	-	-	-	-	-	20,930	(14,762)	-	6,168
Events	-	-	-	-	-	500	(500)	-	-
	(7,108)	388,036	(400,649)	42,418	22,697	412,766	(409,621)	3,295	29,137

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

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

20 Restricted funds (Continued)

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

Breaking Down Barriers
A grant was received from the Sylvia Adams Charitable Trust in relation to the working with Asian Communities.

Exemplar Health Care
Money received in relation to running a Care Home Accreditation project. A project co-ordinator was recruited and the implementation of this project began in April 2017.

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 3 separate grants from Trusts 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

21 Designated funds

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

		Movement in funds			Movement in funds		
	Balance at 1 April 2018	**Incoming resources**	**Resources expended**	**Balance at 1 April 2019**	**Incoming resources**	**Resources expended**	**Balance at 31 March 2020**
	£	**£**	**£**	**£**	**£**	**£**	**£**
Special projects fund	230,000	-	(16,000)	214,000	-	-	214,000
Branch funds	104,134	120,129	(113,048)	111,215	101,829	(118,963)	94,081
	334,134	120,129	(129,048)	325,215	101,829	(118,963)	308,081

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.

22 Analysis of net assets between funds

	Unrestricted funds	**Restricted funds**	**Total**	Unrestricted funds	Restricted funds	Total
	2020	**2020**	**2020**	2019	2019	2019
	£	**£**	**£**	£	£	£
Fund balances at 31 March 2020 are represented by:						
Tangible assets	9,317	-	9,317	8,039	-	8,039
Investments	374,827	-	374,827	338,453	-	338,453
Current assets/ (liabilities)	691,369	29,137	720,506	710,660	22,697	733,357
Long term liabilities	(15,518)	-	(15,518)	(52,100)	-	(52,100)
	1,059,995	29,137	1,089,132	1,005,052	22,697	1,027,749

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.

	2020 **£**	**2019** **£**
Aggregate compensation	151,259	175,183

Transactions with related parties

During the year a donation of £25,000 (2019: £nil) 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:

	2020 **£**	**2019** **£**
Within one year	48,129	39,433
Between two and five years	28,655	50,408
	76,784	89,841

25 Contingent asset

The charity is a residuary beneficiary of an estate subject to a life tenancy. The value of the entitlement as at 11/06/2020 is £51,247 (12/06/2019 : £52,018).

26 Branch funds

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

	2020 **£**	**2019** **£**
Cash balances at 1 April 2019	111,215	104,134
Receipts in year	101,829	120,129
Less :		
Local welfare grants	(27,293)	(24,384)
Sent to head office	(43,346)	(42,237)
Branch activities,local newsletters,equipment,research etc	(48,324)	(46,427)
Cash balances at 31 March 2020	94,081	111,215

27 Cash generated from operations

	2020 **£**	**2019** **£**
Surplus for the year	61,383	87,579
Adjustments for:		
Investment income recognised in statement of financial activities	(12,385)	(17,288)
Gain on disposal of investments	-	(134)
Fair value gains and losses on investments	38,626	(5,950)
Depreciation and impairment of tangible fixed assets	4,062	5,574
Movements in working capital:		
(Increase) in stocks	(1,087)	(300)
Decrease/(increase) in debtors	71,522	(5,834)
(Decrease) in creditors	(1,240)	(47,447)
Cash generated from operations	160,881	16,200

28 Analysis of changes in net funds

The Charity had no debt during the year.