



**Huntington's
Disease
Association**

ANNUAL REPORT AND FINANCIAL STATEMENTS

For the year ended 31 March 2018

Charity Registration No. 296453

Company Registration No. 2021975 (England and Wales)

HUNTINGTON'S DISEASE ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Patrons	Tony Hadley Shane Richie
Trustees	Mr A Bickerdike Dr G El-Nimr Mr M Ellison Mr N M Heath (Hon Treasurer) Dr E M Howard Professor H Rickards Ms A C Clarke Mr A Fryer Ms C Lyon Ms S Barker
Chief executive	Mrs C Stanley RGN,BSc (Hons)
Charity number	296453
Company number	2021975
Registered office	Suite 24 Liverpool Science Park Innovation Centre 131 Mount Pleasant Liverpool L3 5TF
Auditor	DSG Castle Chambers 43 Castle Street Liverpool L2 9TL
Bankers	National Westminster Bank Plc 66/68 St John's Road Battersea London SW11 1PB

HUNTINGTON'S DISEASE ASSOCIATION

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HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2018

The Trustees present their report and financial statements for the year ended 31 March 2018.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts 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 2015)"

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.

Who we are and what we do

Huntington's disease, a brief overview

Huntington's disease (HD) is a degenerative neurological disorder that causes progressive mental deterioration, significant behavioural changes and severe physical incapacity. It is a hereditary condition that affects generations of families. Each child of a parent with Huntington's has a 50% chance of inheriting the faulty gene. It is estimated that there are around 8,000 people living with Huntington's in the United Kingdom.

Mission

Pioneers in the field of specialist care in all aspects of Huntington's disease, the HDA is a national charity committed to supporting people affected directly or indirectly by Huntington's disease. It pursues the best possible care; provides training, information and advice to families and professionals; raises awareness; and promotes research towards better treatment and care with the ultimate aim of a cure for Huntington's.

Who we are

The Association was founded in 1971, as a result of a family being given a diagnosis of Huntington's. They were told they were one of a few families in the country. They put an advert in the local paper asking if anyone knew of any other families in a similar situation and as a result the Association was formed. It was initially a self-help group with 76 members it was then known as the Association to Combat Huntington's Chorea.

In 1993, as a result of consultation with the HDA membership, a project known as the CASE (Care, Advice, Support and Education) was implemented. This was as a result of feedback that suggested families would benefit from professionals with knowledge and understanding of the illness supporting them in accessing information, care and support. This project is now known as the Specialist HD Advisory Service and continues to be a valued resource and focus for expansion and development.

The HDA covers England and Wales and supports anyone affected by or working with people with Huntington's. In addition we work closely with other organisations with similar interests.

We employ 38 staff members from a wide range of backgrounds from nursing and social care to fundraising and administration; all united in their dedication to supporting those impacted by Huntington's.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

What we do

Specialist Advisory Service

The Specialist HD Advisory service is made up of 23 Specialist HD Advisers, each covering the 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 available to them. They also offer training, advice and support to professionals involved in the care of people with Huntington's to improve the quality of care given to Huntington's patients.

Juvenile HD support

We are the only Huntington's Disease Association with a dedicated Specialist Juvenile HD Adviser in the world. They support children affected by the juvenile form of the disease and their families across England and Wales.

Youth Services

We have a Youth Engagement service providing support to young people aged 11-22 living in families affected by Huntington's.

Membership

We have a membership of over 5,000 people, both family and professionals.

Branches and Support Groups

We are linked to 28 local HDA branches and 32 support groups, led by dedicated volunteers. These branches and support groups provide invaluable peer support on a local level. They work tirelessly to help in all aspects of the Association's work and enable Governance and Administration costs to be kept at a minimum.

Partnership working

We are a charity with limited resources supporting people with a rare illness we work closely with other organisations for maximum impact and influence.

Organisations we regularly work with include the Neurological Alliance, Genetic Alliance UK, The King's Fund and GSK (as a former Impact Award Winner).

We also work with other HD Associations, particularly those geographically closest in Scotland and Ireland.

Research projects

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

Volunteers

We have over 700 committed volunteers 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 2017/18

The following strategic goals were the focus of the charity's work in the last year.

- Improving quality of care
- Reducing risk
- Empowering individuals, carers and professionals
- Reducing isolation
- Increasing knowledge and understanding of Huntington's disease
- Raising awareness

The Trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the Charity should undertake.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

Achievements and performance

Our impact in 2017/18:

Improving quality of care

We believe a better understanding of Huntington's by people with the disease in their families, by the professionals involved in their care and by service commissioners will lead to significant improvements in the quality of Huntington's care and support services in England and Wales.

We know that people prefer to access information about Huntington's in different ways so throughout the year we used a number of different platforms to offer advice and support including a face to face visit service, a presence at specialist Huntington's disease clinics around the country, a telephone and email helpline, specialist publications and dedicated advice and support sections of our website.

The advice and support we gave was wide ranging and included practical tips on symptom management, emotional support, promotion of wellbeing and assistance with financial and legal matters. Surveys conducted during the year told us that 71% of people felt more able to cope with their situation after contact with the Association.

In 2017/18 our dedicated helpline responded to over 24,000 calls and 37,000 emails from family members and professionals and our Specialist Huntington's Disease Advisers carried out 2,467 home visits, providing advice and support to over 4,000 family members. According to a feedback survey undertaken, 99% of people felt that the visit from their local adviser helped them.

Caring for a family member with Huntington's disease can be challenging. Family carers face complex physical, cognitive and behavioural symptoms day in day out. They have to witness their loved one slowly decline and are often at risk of developing the disease themselves. In 2017/18, carers accounted for 37% of the Association's total client base. We recognise that better support and advice for family carers means better quality of care for people with Huntington's, and as such, our advisers pay particular attention to the welfare and wellbeing of both. Of those surveyed throughout 2017/18, 90% felt they gained a much more in depth knowledge of Huntington's from their adviser and 63% felt their adviser had provided them with emotional support.

Often our advisers are the main person involved in the care and support of someone with Huntington's. They have in depth knowledge and understanding of the disease. They are often the link that helps to bring different professionals together to provide an individual with the best possible support. Throughout 2017/18, our advisers attended 271 specialist HD clinics, 418 multi-disciplinary team (MDT) meetings and provided bespoke, client-focussed advice and guidance in 160 information sessions to health and care professionals to ensure the complexities of the disease and the needs of their clients were better understood.

We continually strive to promote our services as a charity to reach those who need us and build support networks specific to emerging needs. New referrals in 2017/18 accounted for 10% of our total client base. In July 2017 we spoke at the Huntington's Disease Predictive Testing Consortium, attended by genetics departments from all over the UK, about Kim's Friends, an online support group we set up to support people who undergo the genetic test but receive a negative result. Whilst they won't go on to develop Huntington's disease, they may still be significantly emotionally impacted having lived 'at risk' for so many years and seeing their loved ones with Huntington's deteriorate. Promoting the group at the consortium ensured that genetics departments are aware of the service so they can signpost people to us.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

In 2017/18, we submitted Huntington's specific information to the National Institute for Health and Care Excellence (NICE) for their consultations on three key subjects - tackling depression, adult and social care improving people's experiences and diagnosing neurological conditions to help shape their recommended guidelines for health and care in England.

Our Juvenile Huntington's Disease Adviser supported 101 young people with JHD in 2017/18 and was instrumental in helping to facilitate a project led by Dr Oliver Quarrell, from Sheffield Children's NHS Foundation Trust, to improve the support model for patients and families living with Juvenile Huntington's disease (JHD) based on family feedback.

During the year, our advisers were involved in over 40 development meetings with local care providers to discuss how care and support services for people with Huntington's can be improved and expanded.

A key focus for the Association in 2017/18 was the launch of our care home accreditation scheme pilot in England and Wales. We were inspired to develop the scheme as the Huntington's community told us choosing a care home often feels like a battle and standards of care can vary significantly. After extensive consultation with the community and care home providers, we have developed a scheme which will require participating care homes to adhere to a set of defined care standards, evidenced and monitored through a combination of self-assessment, practical evidence and on site observations. We hope the scheme will make choosing a care home much easier, improve and standardise care, give reassurance to families and allow care providers to better highlight their specialist services. The full scheme is expected to launch in Autumn 2018 following the completion of the pilot.

Through partnership working we were able to gain a greater voice. We attended a patient empowerment group meeting run by Rare Disease UK, a dysphagia round table event run by Nestle Health Science, an event hosted by the Neurological Alliance to mark the launch of the parity of esteem for people affected by neurological conditions and a meeting with the Royal College of Speech and Language Therapists on a project to help launch a communication access symbol. Aligning ourselves with larger organisations gave us the opportunity to attend these important events and make sure the Huntington's community was represented and their needs taken into consideration.

Reducing risk

Protecting the welfare and well-being of people affected by Huntington's was a significant part of our work over the last year. Our advisers made 37 safeguarding referrals and were involved in a number of ongoing cases with over 200 calls made and best interest meetings attended to advocate and support Huntington's families.

Via our helpline and visit services, our advisers were able to help people find the services they needed in times of crisis. Joint working with other professionals, regular contact with families and prompt intervention by our advisers resulted in crisis prevention in many cases in 2017/18. In feedback received from family members about our service, 33% highlighted that their adviser had helped them in a crisis during the year.

We believe in the importance of providing our staff with the skills to best support families affected by Huntington's. In 2017/18 our advisory team received safeguarding training by the Social Care Institute for Excellence (SCIE) to ensure they were all up to date with changes to safeguarding practice in line with the Care Act. Another key area of continuing personal development offered during the year was breakaway training. As lone workers and with aggression a common symptom of Huntington's, our advisers are at risk of physical assault so safe self-defence training was paramount to their protection.

Throughout 2017/18 we continued to offer our welfare grant scheme, providing 30 grants, totalling over £8,000. Sometimes a small change or a particular piece of equipment is all that's needed to reduce the risk associated with a daily task for someone with Huntington's and allow them to maintain their independence for as long as possible. Some of the items we funded included laptops so people could order food online and keep in touch with friends and specialist equipment such as no spill cups, rocker knives and elastic shoe laces.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

Empowering individuals, carers and professionals

We know from speaking with the Huntington's community that they find immense comfort in talking to others facing similar situations. Those directly affected know the complexities and difficulties of the disease better than anyone. Continuing to provide effective peer support platforms and empowering people to support each other was a significant focus in 2017/18.

Throughout the year, we supported 28 HDA branches, 32 support groups and a number of local carer groups to provide peer support. We helped groups gain advice direct from their local adviser and supported with fundraising and raising awareness.

Our patient and public involvement group, HD Voice increased its membership to 16 members by year end. The aim of the group is to give the Huntington's community a voice. In 2017/18 the group reviewed various HDA publications, online resources and gave feedback to a number of Huntington's disease researchers on different projects. The group is now aligned and actively working with an international HD PPI group, HD Cope, providing a family perspective to pharmaceutical companies and researchers linked to national and international research trials.

We have a dedicated community fundraising team who supported our army of volunteer fundraisers throughout the year. From 63 marathons in 63 days to hair shaves and bake sales, our community worked tirelessly to raise over £436,880. We were thrilled to host a volunteer awards night during the year to thank our volunteers for their amazing efforts,

Reducing isolation

Huntington's disease can be an isolating experience. As physical and cognitive symptoms take hold, people with Huntington's find their independence is restricted as their mobility becomes limited. Similarly, carers looking after their loved ones with the disease are often unable to leave the house due to responsibilities at home. Our advisers are a lifeline to many, someone to chat to and a link to others that will understand. Feedback received during the year told us that 66% of people felt less isolated after contact with their SHDA.

For people living in remote areas, where there are no local branches or support groups, a number of our advisers held pop-up cafes throughout the year to help bring people together for peer support in hard to reach areas.

Our message board and Facebook page provided opportunity for peer support that people could access without having to leave home. At year end there were 8,101 message board members, 2,021 of whom had joined during 2017/18 and the Facebook page had 11,997 likes and followers.

A number of events in our annual calendar provided people with the opportunity to come together and meet others facing similar situations. Events included our Juvenile Huntington's Disease Weekend (an activity weekend for families affected by JHD), the Young Adults Weekend (a series of workshops relevant to young people directly or indirectly affected by Huntington's), family days organised locally by our advisers and the HDA's flagship Family Weekend (a national conference featuring key note speakers, workshops and social activities).

For young people living in families affected by Huntington's, childhood and adolescence can be particularly challenging. Often they witness a loved one steadily decline. They can be the main carer for a relative and may be at risk themselves – all whilst tackling the day to day challenges faced by all young people. In 2017/18 we recruited a second Specialist Youth Worker, a post funded by Children in Need to further support young people in England and Wales. Two post holders, one covering the North and the other the South, means we were able to support more young people and make our youth engagement service more accessible. Our youth workers supported 252 young people in 2017/18 and received 30 new referrals to the service.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

Increasing knowledge and understanding of Huntington's

Huntington's disease is often a little known disease, with many health and social care professionals never having encountered it before. To better improve understanding of the disease and to improve the quality of care and support available, we continued in our mission to educate health and social care professionals.

Around 3,000 professionals attended training events run by our specialist advisers or events at which our advisers were guest speakers. 95% of those who provided us with feedback told us that they felt better able to care for people affected by Huntington's after the training.

We ran two in depth Huntington's disease certificated courses during 2017/18, covering topics such as genetic testing, managing behaviour, physiotherapy and diet. In addition to education as the courses were attended by professionals from a range of disciplines, they were excellent networking opportunities for those involved in Huntington's care.

2017/18 witnessed the news about a promising breakthrough in the gene silencing Huntington's disease research trial, which found that the drug had been proven to successfully lower levels of the harmful protein called Huntingtin, which causes Huntington's disease. In support of this ground breaking research we have been instrumental in explaining to the Huntington's community what this trial means and the next steps as the trial progresses.

Throughout the year we continued to promote participation in Enroll-HD, the world's largest observational study for Huntington's disease families. It is only through continued research into the disease and participation in trials that a better understanding of Huntington's and a treatment can be achieved.

We continued to support and fund Huntington's disease research website HD Buzz in 2017/18. Our support helps them continue to post updates on complex research trial findings in a way that is easy to understand for non-scientists.

Following a robust application process, we awarded research grants to the University of Cambridge for a study into Huntington's disease economics and to Cardiff University for a study on physiotherapy at Huntington's clinics. We hope both projects will further increase knowledge and understanding of Huntington's and improve quality of care and services available.

Our Association underwent a rebrand in 2017/18, during which we reviewed our image and the way we communicate with families and professionals. We made improvements to ensure information about Huntington's disease is easy to understand and access including a new and much improved website. Since the relaunch of the website in October 2017 there were over 100,000 visitors, including over 87,000 who were new to the site and an increase of over 70% in the number of pages viewed and average session duration.

A number of our advisers were involved in a project called Breaking Down Barriers in 2017/18, funded by the Sylvia Adams Trust, which aimed to make information about Huntington's more accessible to people from South Asian communities living in the UK whose first language is not English. A leaflet was produced explaining the disease in terms that are easier to understand. Additional funding has been received for next year and it is hoped further resources can be developed for this and other communities.

A number of families reported difficulties with recruitment into the armed forces, with people wanting to join up left with little alternative than to undergo a predictive test that they may not have taken otherwise. The issue was raised by the HDA at the Huntington's Predictive Testing Consortium in July so that we can work in partnership with key geneticists and medical professionals in the field of Huntington's disease to encourage the Ministry of Defence to review its recruitment criteria

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

Raising awareness

'Out of the shadows' was the theme of our annual awareness week in May 2017. The focus was on going back to basics to inform people about the signs and symptoms of the disease, as lack of awareness is still a major obstacle. The HDA received pro bono support to create a fresh educational infographic that detailed the symptoms of Huntington's in an easy to understand format which led to an increase in shares and comments on social media.

The 'Out of the shadows' theme complemented the international 'Light it up for HD' awareness initiative and we encouraged the community to light up local landmarks and their own homes in pink and green. 14 notable buildings lit up across England and Wales including Blackpool Tower and Spinnaker Tower, Portsmouth.

On May 18, at Aula Paolo VI in Vatican City, Rome, Pope Francis became the first world leader to recognise the devastating plight of those living with and affected by Huntington's. The global gathering was inspired by families from South America living with Huntington's. An audience of thousands from all over the world joined together at the Vatican to raise awareness of Huntington's and lift the stigma around the disease. The event was organised by the HDdenmore organisation and we were invited to represent patient organisations in England and Wales, alongside some family representatives.

Merchandise has played a key part in increasing brand awareness. As part of the rebrand we invested in new stock which was on message and in the new brand. The new products have been received well by the community and are selling well.

A member of our community helped to raise awareness by facilitating an advert in the Financial Times asking for support by text donation. This was the third time the advert was included, undoubtedly adding to the general public's growing knowledge of Huntington's.

We have encouraged people in the Huntington's community to share their personal stories on our website and social media channels, and also with local and national media outlets. We have found that personal stories shared throughout the year had far greater impact and were shared more widely than those without a personal perspective. We have included case studies from different perspectives on our website so people can find information and stories most relevant to whatever stage they are at on their Huntington's journey.

Exemplar Health Care generously sponsored a photographic exhibition titled "Inherent", which was launched in October 2017. The exhibition explored the resilience of families living with Huntington's. It is an extremely powerful piece of art and is now being toured across England and Wales to raise awareness of the disease.

Fundraising

We continue to rely heavily on donations, legacies, and grant income to enable us to carry out our charitable activities. Our fundraising ratios are favourable compared to other charities that undertake similar methods of fundraising

We will continue to ensure our donors and supporters are fully stewarded and aware of all the options available to support the HDA to maximise income. We will work collaboratively with staff and volunteers to share stories and powerful messages.

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

Funding in 2018 has refocused on 'grass roots' fundraising with the Big Lottery Fund leading this change. Fundraising should be regionally based and use volunteers as a resource to maximise reach and enable partnership working. The continued decline in statutory funding remains problematic and means charities should work hard to steward relationships and provide robust update reports for remaining CCG and Local Authority funders. Trusts and foundations should be encouraged to provide multi-year funding and the charity needs to foster relationships with their trustees.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

Community fundraising is one area of fundraising that is increasing across the sector whilst other sources remain steady. This is something the HDA is keen to embed as we know great fundraising isn't about a one off gift or participating in one event, it's about growing opportunities for people to do more. We are committed to our annual stewardship events, and recognise the importance of celebrating our volunteer fundraisers through our Volunteer Fundraiser Awards.

We enlisted the support of consultants, Impact Fundraising - for the period February 2017 – December 2017 as an interim measure to support the fundraising team with Trusts and Foundations whilst our Trusts and Foundations Manager was on secondment.

The HDA is 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) that sit alongside the current Data Protection Act and have undertaken all the relevant compliance preparations to ensure we are ready for the new GDPR legislation from May 2018 onwards.

For the year 2017/18 we did not receive any complaints about our fundraising practices/approaches.

Protection of vulnerable people is something the HDA takes seriously. We adhere to the Institute of Fundraising's guidance – 'Treating Donors Fairly - Fundraising with people in vulnerable circumstances'.

Financial review

The results for the year show an overall deficit of £69,198 (2017: surplus £74,805) with a surplus on the general fund of £71,357 (2017: £65,536) and a deficit on the restricted funds of £140,555 (2017: surplus £9,269). The deficit on the restricted funds, as detailed in Note 20, resulted from the recognition of the full costs of the three year research grant awarded in the year. This policy is in accordance with the Statement of Recommended Practice and the deficit will be covered by fundraising in the remaining 2.5 years of the grant or by transfer from general funds.

Income streams were stable and the fundraising team must be congratulated in their achievements in a difficult year in which Lottery funding needed to be replaced. Legacy income increased substantially and is seen as an area which needs to be supported.

Expenditure continued to be carefully controlled with budgeted increases in staff costs relating to service delivery and in the research costs detailed above.

The Trustees are pleased with overall performance and are confident that the funding arrangements to support the charity are robust.

Reserves

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 2018. It is intended that general reserves should be built to cover six months' salary and running costs. As at the year end, free reserves available, excluding the designated project reserve, and funds held by branches, stood at £613,143 (2017: £508,358) against a target of £775,000. The designated project reserve stood at £230,000 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.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

Future plans 2018/19

2018/19 will see the launch of the Association's new strategy. Our vision – a better life for everyone affected by Huntington's disease.

After consultation with our supporters, staff and key partners and a review of the changing needs of the Huntington's community, we have identified the following strategic goals that will underpin the work of the Association over the next five years:

- 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 HDA's role with the general public
- A strong charity to better champion the needs of our community
- Supporting Huntington's research

In line with the above goals, the following are some of the key areas we plan to focus on in 2018/19:

Youth service provision

We plan to develop and expand the provision of care and support for children and young people living in families affected by Huntington's disease. With a second youth worker (funded by Children in Need) now in post, the youth service now has the capacity to reach more children across England and Wales. The youth workers will explore strategies and activities to help children in these families, focusing on bringing children of Huntington's families together for peer support, which is critical for their wellbeing.

Improving the quality range and means of providing advice and support to the Huntington's community

Sharing and disseminating accurate information about Huntington's remains a crucial to our mission. The HDA plans to explore new ways to reach more people, at varying stages of the progression of Huntington's disease. We plan to embrace digital technology and to streamline the service we offer and invest in the telephone helpline to ensure people who need to speak to an adviser when in need are able to do this. We will also review and revamp our professional guides and fact sheets for families, so they are easier to read and understand.

Improving quality of care for people with Huntington's disease

Improving the quality of care provided by the private and social care sector is an important future goal. The pilot care home accreditation scheme has demonstrated the gap in the market for this type of quality approved care home rating. The HDA is committed to helping shape how care homes can operate to support and care for clients with Huntington's disease. We are keen to respond to the needs of our community and this is an issue that they would like to see embraced.

Influencing policy makers

The Huntington's research landscape changed fundamentally in December 2017 when it was announced that the IONIS –HTTRx clinical trial showed promising results. The HDA will continue to act as a voice for the community. We will explain what the research means in clear language and be on hand to answer any questions families may have, by working closely with scientists. We aim to work closely with pharmaceutical companies to lobby for NICE guidelines for Huntington's disease.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

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

Ms S M Abbott (Resigned 14 October 2017)

Dr G El-Nimr

Mr M Ellison

Mr N M Heath (Hon Treasurer)

Dr E M Howard

Professor H Rickards

Ms A C Clarke

Mr A Fryer

Ms C Lyon (Appointed 14 October 2017)

Ms S Barker (Appointed 14 October 2017)

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 Association and devolve operational running to the management team..

The Chief Executive and senior managers oversee the operational management of the 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 Association 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, business plan, latest published annual report and accounts, financial projections and budgets, and project and programme plans and publications;
- Trustee details and staff structure;
- 'The Essential Trustee: what you need to know' (Charity Commission);
- Minutes and reports submitted to the previous three meetings of the board of trustees.

HUNTINGTON'S DISEASE ASSOCIATION

TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

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.

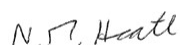
Auditor

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: 13 August 2018

HUNTINGTON'S DISEASE ASSOCIATION

STATEMENT OF TRUSTEES RESPONSIBILITIES

FOR THE YEAR ENDED 31 MARCH 2018

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 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 2018 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 2018 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 accounts section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the accounts 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.

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 MEMBERS OF HUNTINGTON'S DISEASE ASSOCIATION

Matters on which we are required to report by exception

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

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

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

Responsibilities of Trustees

As explained more fully in the statement of Trustees responsibilities, the Trustees, who are also the directors of the Charity for the purpose of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

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

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.

Use of 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
Chartered Accountants
Statutory Auditor

13 August 2018

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 2018

	Notes	Unrestricted funds £	Restricted funds £	Total 2018 £	Total 2017 £
<u>Income and endowments from:</u>					
Donations and legacies	2	1,104,797	28,167	1,132,964	909,228
Charitable activities	3	132,041	371,727	503,768	580,652
Other trading activities	4	22,486	-	22,486	25,323
Investments	5	17,654	-	17,654	16,219
Other income	6	992	-	992	565
Total income		1,277,970	399,894	1,677,864	1,531,987
<u>Expenditure on:</u>					
Raising funds	7	200,779	-	200,779	179,646
Charitable activities	8	991,301	540,449	1,531,750	1,341,257
Total resources expended		1,192,080	540,449	1,732,529	1,520,903
Net gains/(losses) on investments	12	(14,533)	-	(14,533)	63,721
Net movement in funds		71,357	(140,555)	(69,198)	74,805
Fund balances at 1 April 2017		875,920	133,447	1,009,367	934,562
Fund balances at 31 March 2018		947,277	(7,108)	940,169	1,009,367

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

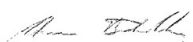
HUNTINGTON'S DISEASE ASSOCIATION

BALANCE SHEET

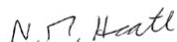
AS AT 31 MARCH 2018

	Notes	2018 £	£	2017 £	£
Fixed assets					
Tangible assets	13		11,160		7,240
Investments	14		500,588		507,489
			<u>511,748</u>		<u>514,729</u>
Current assets					
Stocks	15	4,504		5,281	
Debtors	16	337,021		146,436	
Cash at bank and in hand		287,161		437,442	
		<u>628,686</u>		<u>589,159</u>	
Creditors: amounts falling due within one year	17	(146,108)		(94,521)	
Net current assets			<u>482,578</u>		<u>494,638</u>
Total assets less current liabilities			<u>994,326</u>		<u>1,009,367</u>
Creditors: amounts falling due after more than one year	18	(54,157)			-
Net assets			<u><u>940,169</u></u>		<u><u>1,009,367</u></u>
Income funds					
Restricted funds	20		(7,108)		133,447
<u>Unrestricted funds</u>					
Designated funds	21	334,134		367,562	
General unrestricted funds		<u>613,143</u>		<u>508,358</u>	
			<u>947,277</u>		<u>875,920</u>
			<u><u>940,169</u></u>		<u><u>1,009,367</u></u>

The financial statements were approved by the Trustees on 13 August 2018



Mr A Bickerdike
Trustee



Mr N M Heath (Hon Treasurer)
Trustee

Company Registration No. 2021975

HUNTINGTON'S DISEASE ASSOCIATION

STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2018

	Notes	2018 £	£	2017 £	£
Cash flows from operating activities					
Cash (absorbed by)/generated from operations	26		(155,076)		41,028
Investing activities					
Purchase of tangible fixed assets		(5,227)		(5,775)	
Purchase of investments		(10,120)		(7,362)	
Proceeds on disposal of investments		2,488		7,991	
Interest received		17,654		16,219	
Net cash generated from investing activities			4,795		11,073
Net cash used in financing activities			-		-
Net (decrease)/increase in cash and cash equivalents			(150,281)		52,101
Cash and cash equivalents at beginning of year			437,442		385,341
Cash and cash equivalents at end of year			287,161		437,442
Short term deposits included in current asset investments			-		-
Bank overdrafts included in creditors payable within one year			-		-

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2018

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)" (as amended for accounting periods commencing from 1 January 2016). 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

At the time of approving the accounts, the Trustees consider that the charity has adequate reserves and divers revenue streams to continue in operational existence for the foreseeable future. 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 Incoming resources

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.

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

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

1 Accounting policies

(Continued)

1.5 Resources expended

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 2018

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 2018

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 to income 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 2018	Total 2017
	£	£	£	£
Donations and gifts	582,161	17,170	599,331	603,454
Legacies receivable	429,510	2,976	432,486	219,796
Branch income	93,126	8,021	101,147	85,978
	<u>1,104,797</u>	<u>28,167</u>	<u>1,132,964</u>	<u>909,228</u>
For the year ended 31 March 2017	<u>881,320</u>	<u>27,908</u>		<u>909,228</u>
Donations and gifts				
Community fundraising	440,415	10,460	450,875	452,077
Other donations	141,746	6,710	148,456	151,377
	<u>582,161</u>	<u>17,170</u>	<u>599,331</u>	<u>603,454</u>

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

3 Charitable activities

	2018 £	2017 £
Grants received	451,377	541,181
Merchandise income	14,694	12,238
Training and conferences income	37,697	27,233
	<u>503,768</u>	<u>580,652</u>
Analysis by fund		
Unrestricted funds	132,041	
Restricted funds	<u>371,727</u>	
	<u>503,768</u>	
For the year ended 31 March 2017		
Unrestricted funds		101,721
Restricted funds		<u>478,931</u>
		<u>580,652</u>

4 Other trading activities

	2018 £	2017 £
Raffle and sponsorship	4,596	5,973
Company sponsorships	17,890	19,350
	<u>22,486</u>	<u>25,323</u>
Other trading activities	<u>22,486</u>	<u>25,323</u>

5 Investments

	2018 £	2017 £
Income from listed investments	17,246	15,556
Interest receivable	408	663
	<u>17,654</u>	<u>16,219</u>

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

6 Other income

	2018	2017
	£	£
Miscellaneous income	992	565

7 Raising funds

	2018	2017
	£	£
<u>Fundraising and publicity</u>		
Fundraising events	20,792	18,491
Fundraising consultancy costs	46,070	8,500
Fundraiser's costs	12,137	12,262
Staff costs	121,210	139,920
Fundraising and publicity	200,209	179,173
<u>Investment management</u>	570	473
	200,779	179,646

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

8 Charitable activities

	Specialist Welfare and HD Respite Advisory Care Service	Research	Newsletter, Education, Branch Liaison	Youth Worker	Juvenile Accreditation	Nursing Home	Total 2018	Total 2017
Staff costs	£ 775,657	£ 930	£ 930	£ 31,970	£ 4,733	£ 25,986	£ 880,389	£ 796,959
Welfare grants	-	35,888	-	-	-	-	35,888	34,540
Research	-	-	115,814	-	-	-	115,814	11,619
Juvenile	17,858	-	-	9,481	-	-	27,339	21,934
Branch costs	-	-	-	-	-	-	34,790	44,384
Travel and training	75,633	-	34,790	-	-	-	88,336	86,806
Camps, conferences and AGM	23,565	-	1,110	6,966	-	4,627	23,565	21,886
Telephone and internet	26,784	-	-	712	-	369	28,219	24,614
Other costs	14,113	-	354	2,224	90	3,496	39,702	13,347
Newsletter	-	-	11,026	-	-	-	11,026	18,298
Publications and merchandise	-	-	16,775	-	-	-	16,775	23,156
Share of support costs (see note 9)	933,610	36,818	116,744	51,353	4,823	34,478	1,301,843	1,097,543
Share of governance costs (see note 9)	131,322	10,944	-	-	-	-	218,869	234,927
	11,038	-	-	-	-	-	11,038	8,787
	1,075,970	47,762	116,744	51,353	4,823	34,478	1,531,750	1,341,257

Expenditure on charitable activities was £1,531,750 (2017: £1,341,257) of which £991,301 was unrestricted (2017: £843,687) and £540,449 was restricted (2017: £497,570).

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

9 Support costs

	Support costs £	Governance costs £	2018 £	2017 £	Basis of allocation
Staff costs	95,651	-	95,651	93,205	Allocated on time
Depreciation	1,307	-	1,307	4,964	Head office assets
Head office costs	121,911	-	121,911	136,758	Actual/invoiced costs
Audit fees	-	7,194	7,194	6,714	Governance
EC meeting costs	-	3,844	3,844	2,073	Governance
	<u>218,869</u>	<u>11,038</u>	<u>229,907</u>	<u>243,714</u>	
Analysed between Charitable activities	<u>218,869</u>	<u>11,038</u>	<u>229,907</u>	<u>243,714</u>	

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 employees during the year was:

	2018 Number	2017 Number
Specialist HD Advisors	23	23
Management	3	3
Fundraising	3	4
Youth Worker	2	1
Administration	4	4
Communications	1	-
	<u>36</u>	<u>35</u>

Employment costs

	2018 £	2017 £
Wages and salaries	1,000,889	921,111
Social security costs	75,562	85,211
Other pension costs	20,799	23,762
	<u>1,097,250</u>	<u>1,030,084</u>

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

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

12 Net gains/(losses) on investments

	2018	2017
	£	£
Revaluation of investments	(12,997)	62,605
Gain/(loss) on sale of investments	(1,536)	1,116
	<u>(14,533)</u>	<u>63,721</u>

13 Tangible fixed assets

	Fixtures and fittings £
Cost	
At 1 April 2017	60,438
Additions	5,227
	<u>65,665</u>
At 31 March 2018	
Depreciation and impairment	
At 1 April 2017	53,198
Depreciation charged in the year	1,307
	<u>54,505</u>
Carrying amount	
At 31 March 2018	11,160
	<u>7,240</u>
At 31 March 2017	

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

14 Fixed asset investments

	Listed investments £
Cost or valuation	
At 1 April 2017	507,489
Additions	10,120
Valuation changes	(12,997)
Disposals	(4,024)
	<hr/>
At 31 March 2018	500,588
	<hr/>
Carrying amount	
At 31 March 2018	500,588
	<hr/>
At 31 March 2017	507,489
	<hr/>

15 Stocks	2018 £	2017 £
Merchandise	4,504	5,281
	<hr/>	<hr/>

16 Debtors	2018 £	2017 £
Amounts falling due within one year:		
Trade debtors	11,778	9,022
Other debtors	278,241	101,969
Prepayments and accrued income	47,002	35,445
	<hr/>	<hr/>
	337,021	146,436
	<hr/>	<hr/>

17 Creditors: amounts falling due within one year	2018 £	2017 £
Other taxation and social security	25,789	22,476
Trade creditors	33,290	28,260
Accruals and deferred income	87,029	43,785
	<hr/>	<hr/>
	146,108	94,521
	<hr/>	<hr/>

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

18 Creditors: amounts falling due after more than one year

	2018 £	2017 £
Accruals and deferred income	54,157	-

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 £20,799 (2017 - £23,762).

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:

	Balance at 1 April 2017 £	Movement in funds		Balance at 31 March 2018 £
		Incoming resources £	Resources expended £	
Research	66,688	10,446	(116,752)	(39,618)
Big Lottery Fund (Merseyside and South & West Yorkshire)	-	320,069	(320,069)	-
Specialist HD Advisory Service (SHDA)	-	17,721	(17,721)	-
Big Lottery Fund (Surrey)	8,250	21,085	(29,335)	-
Children in Need	-	11,678	(5,864)	5,814
Breaking Down Barriers	3,509	5,000	(5,317)	3,192
Juvenile Huntingtons Disease	-	895	(895)	-
Exemplar Health Care	45,000	-	(34,496)	10,504
JHD Weekend	10,000	13,000	(10,000)	13,000
	133,447	399,894	(540,449)	(7,108)

Research

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

The deficit on the research funds resulted from the recognition of the full costs of the three year research grant awarded in the year. This policy is in accordance with the Statement of Recommended Practice and the deficit will be covered by fundraising in the remaining 2.5 years of the grant or by transfer from general funds.

Big Lottery Fund (Merseyside and South & West Yorkshire)

This grant was awarded by the Big Lottery Fund to cover a full time Specialist HD Adviser post in Yorkshire and a part time post in Merseyside.

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

20 Restricted funds

(Continued)

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.

Big Lottery Fund (Surrey)

The funding for this post covers a Specialist HD Adviser in the Surrey area.

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.

Juvenile Huntingtons Disease

Funds were received from Sheffield Childrens NHS Foundation and individuals to fund this area of work.

Exemplar Health Care

Money was received in the year 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.

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:

	Balance at 1 April 2017	Movement in funds		Balance at 31 March 2018
	£	Incoming resources	Resources expended	£
Special projects fund	270,000	-	(40,000)	230,000
Branch funds	97,562	100,989	(94,417)	104,134
	<u>367,562</u>	<u>100,989</u>	<u>(134,417)</u>	<u>334,134</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, £60,000 of the fund was allocated to cover new fundraising initiatives and infrastructure support and a further £70,000 allocated in 2016 leaving a balance of £270,000 carried forward. £40,000 of the fund was used to support the new communication initiative in 2017/18.

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

22 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
	£	£	£
Fund balances at 31 March 2018 are represented by:			
Tangible assets	11,160	-	11,160
Investments	500,588	-	500,588
Current assets/(liabilities)	489,686	(7,108)	482,578
Long term liabilities	(54,157)	-	(54,157)
	<u>947,277</u>	<u>(7,108)</u>	<u>940,169</u>

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.

	2018 £	2017 £
Aggregate compensation	<u>207,813</u>	<u>182,514</u>

Transactions with related parties

Mr NM Heath was a partner in the firm RPG Crouch Chapman LLP, Chartered Accountants until 31 December 2017, RPG Crouch Chapman LLP, Chartered Accountants received fees for payroll services of £3,600 (2017: £3,300).

24 Contingent asset

The charity is a residuary beneficiary of an estate subject to a life tenancy. The value of the entitlement as at 12/06/2018 was £53,173 (2/06/2017 : £53,356).

HUNTINGTON'S DISEASE ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2018

25 Branch funds

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

	2018 £	2017 £
Cash balances at 1 April 2017	97,562	116,694
Receipts in year	100,989	85,978
Less :		
Local welfare grants	(23,188)	(19,439)
Sent to head office	(36,439)	(41,287)
Branch activities,local newsletters,equipment,research etc	(34,790)	(44,384)
Cash balances at 31 March 2018	104,134	97,562

26 Cash generated from operations

	2018 £	2017 £
(Deficit)/surplus for the year	(69,198)	74,805
Adjustments for:		
Investment income recognised in statement of financial activities	(17,654)	(16,219)
Loss/(gain) on disposal of investments	1,536	(1,116)
Fair value gains and losses on investments	12,997	(62,605)
Depreciation and impairment of tangible fixed assets	1,307	4,964
Movements in working capital:		
Decrease in stocks	777	4,528
(Increase)/decrease in debtors	(190,585)	50,726
Increase/(decrease) in creditors	105,744	(14,055)
Cash (absorbed by)/generated from operations	(155,076)	41,028

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