

Charity Registration No. 296453

Company Registration No. 2021975 (England and Wales)

**HUNTINGTON'S DISEASE ASSOCIATION**  
**ANNUAL REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2016**

# HUNTINGTON'S DISEASE ASSOCIATION

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Patrons</b>	The Dowager Countess of Harewood Tony Hadley Shane Richie
<b>Trustees</b>	Mr A Bickerdike (Chair from Oct 2015) Ms S M Abbott Dr G El-Nimr Mr M Ellison Mr NM Heath (Hon Treasurer) Dr E M Howard Professor H Rickards Mrs C Clarke
<b>Chief executive</b>	Mrs C Stanley RGN,BSc (Hons)
<b>Charity number</b>	296453
<b>Company number</b>	2021975
<b>Registered office</b>	Suite 24 Liverpool Science Park Innovation Centre 131 Mount Pleasant Liverpool L3 5TF
<b>Auditor</b>	Duncan Sheard Glass Castle Chambers 43 Castle Street Liverpool L2 9TL
<b>Bankers</b>	National Westminster Bank Plc 66/68 St John's Road Battersea London SW11 1PB

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# HUNTINGTON'S DISEASE ASSOCIATION

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# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (INCLUDING DIRECTORS' REPORT)

**FOR THE YEAR ENDED 31 MARCH 2016**

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The Trustees present their report and accounts for the year ended 31 March 2016.

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.

### **Strategic aims and objectives**

#### **HD, a brief overview**

Huntington's disease (HD) is a devastating 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 HD has a 50% chance of inheriting the faulty gene. It is estimated that there is around 5,700 people living with HD 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 the ultimate aim of a cure for HD.

#### **Who we are**

The Association was founded in 1971, as a result of a family being given a diagnosis of HD. 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. This has remained the most valued resource of the HDA and is the focus of expansion and development.

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

We employ 35 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 HD.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2016

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### 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 HD and their families. They promote local services, assist with the organisation of care packages and answer crisis calls to ensure people with HD 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 HD to improve the quality of care given to HD patients.

We provide support to over 13,000 people with HD, their family members and carers.

#### Juvenile HD support

We are the only Huntington's Disease Association with a dedicated Specialist Juvenile HD Adviser who supports children affected by HD and their families across England and Wales.

#### Youth Services

We have a Youth Engagement service which is run by a dedicated Specialist Youth Worker who provides support to young people aged 11-22 living in a family affected by HD.

#### Membership

We have a membership of over 5,500 people.

#### Branches & Support Groups

We are linked to 29 local HDA branches and 30 support groups, led by dedicated volunteers. These branches and support groups provide invaluable peer support on a more 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

As a small charity 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 HD in their search for ways to improve care and treatment for people with HD 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 HD, supporting those impacted by the disease and fundraising to help ensure we can continue our support and advice service for those that need it.

# HUNTINGTON'S DISEASE ASSOCIATION

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

### FOR THE YEAR ENDED 31 MARCH 2016

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#### Aims and objectives in 2015/16

In 2015/16 the main activity of the charity was to support the Specialist HD Advisory Service which has the following clearly defined goals. These also form part of the HDA's Strategic plan for 2014-2017.

- i. Improving quality of care
- ii. Reducing risk
- iii. Empowering individuals, carers and professionals
- iv. Reducing isolation
- v. Increasing knowledge and understanding of Huntington's disease
- vi. Raising awareness

In order to achieve these goals coverage of the whole of England and Wales was maintained and developed during the year with additional / replacement posts and increased staff hours whenever possible.

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

#### Achievements and performance

##### Impact in 2015/16

##### Improving quality of care

In 2015/16 supporting individuals and families affected by HD remained the main focus of the Specialist HD Advisory Service. Our 23 dedicated advisers provided support throughout England and Wales, each covering areas that spanned up to 4 counties. We supported 13,809 individuals and family members impacted by the disease either through visits in person or email, telephone, skype and social media messaging. Our JHD Adviser supported around 50 children affected by JHD and their families.

95% of our clients reported that the home visit they received from the adviser had helped them; 94% said they gained a better understanding of the support available; and 90% felt they had a much more in depth knowledge of HD after contact with their local adviser.

Accessing the right level of care and services is imperative for HD sufferers. In 2015/16, our advisers co-ordinated and assisted in the management of dedicated HD clinics which were attended by healthcare professionals with expert knowledge and experience of HD. These clinics helped to synchronise and tailor the care and support HD patients received to best suit their complex health needs. Our SHDAs attended over 263 clinics which were accessed by over 2,000 families and attended by over 1,000 professionals.

Our Specialist Youth Worker visited 153 young people across the whole of England and Wales and was in contact with a total of 203 young people and 40 carers to listen, offer support and guidance to help them better cope with living in a family impacted by HD.

We provided 51 welfare grants to the value of £14,465.19 in 2015/16 to HD families in order to enhance their quality of life. Amongst others, the grants were used to purchase a specialist wheelchair and specialist communication software.

We worked with specialists in the field of HD to provide a complimentary booklet providing advice and guidance on end of life care. Over 500 were distributed to healthcare professionals.

In 2015/16 the National Institute for Health and Care Excellence (NICE) began working on guidelines on neurological problems and we registered as a stakeholder and submitted evidence. We hope these guidelines will help to create better services for HD patients.

# HUNTINGTON'S DISEASE ASSOCIATION

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

**FOR THE YEAR ENDED 31 MARCH 2016**

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### **Reducing risk**

Our telephone helpline, a lifeline for many callers struggling to cope, needing advice or help in a crisis, received in excess of 18,000 calls. Our helpline advisers provided specialist advice and signposted to services to help resolve and minimise crisis situations.

We are committed to protecting the welfare of HD sufferers and their families and in 2015/16, our SHDAs were involved in 58 adult and 37 child safeguarding cases. Their involvement ranged from making direct referrals to protection services due to safeguarding concerns to attending meetings with protection services, care homes and schools to discuss and ensure the ongoing welfare of their clients. Due to the degenerative nature of the disease and the cognitive changes that take place, people with HD can be vulnerable to exploitation. HD can also impact greatly on the wider family with children sometimes experiencing neglect or abuse due to the effects of HD on their parent or relative.

### **Empowering individuals, carers and professionals**

In 2015/16 we supported 30 support groups and 29 HDA branches across England and Wales. This support ranged from providing guidance to set up a group/branch to providing fundraising tools and offering advice and guidance about HD. Our advisers attended 159 branch and support group meetings to offer advice about HD and to highlight the support the HDA can offer.

In 2015/16 a number of our advisers ran carers groups and 'pop up' events to provide advice and support to those caring for loved ones with HD. These groups also allowed people living in more remote parts of the county, where there are no branch or support groups, to access support and meet peers facing similar journeys.

Our 2015/16 Family Weekend and AGM was one of the most inspirational events in our calendar. 208 family members, trustees, professionals and HDA staff took part. Specialist speakers provided advice and expertise on the management of HD symptoms, research developments and ways of improving quality of life.

### **Reducing isolation**

With HD in their family, children often have to grow up quickly with many caring for their loved ones as well as trying to fit in attending school and maintaining friendships. In 2015/16 we ran two activity camps aimed at children aged 9-15 living in HD families to allow them to have fun, let go and spend time and form friendships with peers who understand the challenges they face.

We also ran an activity weekend specifically for individuals and families impacted by Juvenile HD. JHD is even rarer than HD so can be a very isolating experience for those affected. Families had the opportunity to meet others in similar situations, gain advice and support from our advisers but most importantly have fun and make lasting memories that they can cherish.

In April 2015 we held an event for young adults between the ages 18-35 who have HD in their family. It was an invaluable opportunity for those at risk of developing HD to come together, some with their partners, to gain advice from the HD experts and for peer support.

### **Increasing knowledge and understanding of Huntington's disease**

Many healthcare professionals have very little knowledge of HD or how to care for and support someone with it. In 2015/16 our advisers provided 414 training and information sessions to 4,303 healthcare professionals about HD, its symptoms and progression to better equip them to meet the needs of their HD patients. 100% reported an increased understanding of HD and 99% informed they felt more able to care for clients with HD as a direct result of the training and contact with our advisers.

We also ran two in depth training courses for professionals supporting clients with HD. 78 delegates benefitted from presentations from world renowned experts in the field of HD. 97% reported an increase in their knowledge of HD as a result of the course.

# HUNTINGTON'S DISEASE ASSOCIATION

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

### FOR THE YEAR ENDED 31 MARCH 2016

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#### **Raising awareness**

In 2015/16 BBC1's Casualty ran a storyline on Huntington's disease over a number of weeks and involved two of the shows key protagonists. We were brought in to provide expert insight during research and story development and our advisers were invited on set during filming to provide guidance to the actors involved to ensure an accurate depiction. This was an incredible opportunity to raise awareness outside the HD community. Episode viewing figures were in excess of 5 million, bringing knowledge and understanding of HD to millions that knew nothing of it beforehand.

Our 2015/16 Awareness Week had an end of life care focus. Our advisers delivered 60 training sessions to over 540 professionals to improve their understanding of HD and the quality of care they need to provide to people at the end stage of the disease. In addition, we launched a campaign called 'Cake That, HD!' which encouraged people to hold cake sales to raise awareness and funds. An incredible £3,792.83 was raised and many learnt about HD as a result of the campaign.

We launched our first ever digital awareness and fundraising campaign, 'Caring for Generations,' a video appeal in which families and professionals donated their time to talk about their experiences of HD. The first post of the video on Facebook reached 43,722 people and raised £7,005.50.

A campaign led by dedicated supporter Jacqui Harrison also gained huge momentum. Jacqui produced a video which followed her family's emotional struggle with HD and invited people to hashtag "giveatoss" for HD which involved supporters flipping a coin on film to highlight the 50/50 chance of inheriting the disease. The video was viewed over 4,000 times on YouTube and many people created their own videos including our patron Tony Hadley and TV personalities Trevor and Simon.

Our presence on social media increased further during the year with 639 new followers on Twitter, taking our total to 2,021 followers, and a total of 9,400 likes on Facebook, 2,506 of which were new in 2015/16. The Casualty storyline had a significant impact and brought 750 new likes to our page.

We remained committed to supporting research studies led by HD professionals throughout the year. We assisted with the recruitment participants for a study by TEVA into how people with HD cope with everyday life and taking medication. We also supported university student research into Huntington's disease, advertising projects on social media for participants. One study from a Lancaster University student involved the collation of views on assisted dying and end of life care. Another student from the University of Sheffield focused on personal experience of suitable food products for dysphagia sufferers. Our Chief Executive wrote letters of support for Sussex University, for a project on the development of a cognition enhancing drug for the treatment of cognitive impairment associated with HD, and for Cardiff University to empower HD sufferers and carers to get the most out of their visits to clinicians.

We actively promoted participation in Enroll-HD, the world's largest observational study for Huntington's disease families. It aims to learn more about HD through the collection of information from participants, in order to accelerate the development of therapies for HD. The information collected will be available for use by HD researchers worldwide to help inform their investigations. In March 2016, our Head of Advisory Service, Bill Crowder, demonstrated his dedication and commitment to raising awareness about HD and supporting HD research by enrolling in Enroll-HD as a healthy control participant for the HTT lowering clinical trial.

We continued to support HD Buzz a website which presents news and information about Huntington's disease research in a way that is easy to understand and is accessible for all. It gives HD families a fantastic insight into the development of therapies and potential treatments of the disease.



# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2016

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### Financial review

The results for the year show an overall surplus of £62,232 after recognising net investment losses of £24,055. Income grew substantially to £1,677,940 which amounted to a 21% increase on the previous year. This was a result of growth in general donations from supporters, grant income and legacies. This compensated for a continuing fall in funding from statutory bodies which was anticipated. Volunteers were active in branch and other campaigns which resulted in continuing growth in their financial contribution.

Expenditure increased marginally to £1,591,653. Costs were carefully controlled in order to ensure that sufficient reserves are maintained to ensure continuing high quality services.

The Trustees are pleased that free reserves have been maintained in the year and are confident that they can be rebuilt to target levels in coming years.

### 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 fluctuations. This policy enabled the Charity to continue its work throughout the year ended 31 March 2016. It is intended that general reserves should be re-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 at branches stood at £423,689 (2015: £410,569). The designated project reserve amounted to £270,000.

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 the major risks.

### Future plans

In 2016/17 we aim to further develop our service in line with the strategic plan which outlines our priorities until 2017. Our objectives will continue to be:

- improving quality of care
- reducing risk
- empowering individuals, carers and professionals
- reducing isolation
- increasing knowledge and understanding of HD
- raising awareness.

All campaigns, projects and service developments will be undertaken with these objectives in mind. We hope to initiate, develop and focus on the following key priorities in the coming year:

### Specialist HD Advisory Service

With SHDAs currently stretched to capacity and a steady number of new referrals, we plan to review the specialist advisers' working model to help make best use of their time so that they can continue to provide families with a quality advice and support service. One avenue we will be considering is the use of facilities such as Facetime and Skype where appropriate to minimise the time SHDAs spend travelling and so increase the amount of time they can provide support.

### Youth Service

Another service expansion plan is to recruit a second youth worker to alleviate the time and travel pressure on our existing Specialist Youth Worker, who currently travels around the whole of England and Wales supporting children in HD families. Both post holders would then have scope to focus on additional projects such as youth activity camps to promote peer support.

# HUNTINGTON'S DISEASE ASSOCIATION

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

**FOR THE YEAR ENDED 31 MARCH 2016**

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### **Fundraising**

With a reduction in fundraising staff and an increase of workload, we hope to recruit an assistant fundraiser to support the team with the more administrative tasks associated with their roles to give them scope to accommodate further campaigns and projects.

Increasing income will be the main priority to ensure the advisory service is fully funded and to be able to recruit a second youth worker post. We are planning to increase multi-year bids to funders capable of committing support over a longer period and will be working hard to develop those relationships. A second direct mail campaign will be launched to encourage regular gifts from donors. We will also be growing our digital/social media fundraising, offering more ways to get involved with the HDA to raise money and using it to engage donors.

Stewardship will be a key priority, thanking and communicating with our donors in a meaningful way. We also hope to develop our corporate approaches to secure different types of corporate support.

### **Awareness and understanding**

In order to raise greater awareness, we aim to meet with the UK and Ireland HD associations to discuss the possibility of a common awareness week in 2017 with the same area of focus. We hope to build on the success of last year's 'Cake That, HD!' fundraising and awareness campaign and launch a new initiative, 'Shine a Light on HD', during which we will aim to get as many iconic buildings throughout England and Wales to light up in our corporate colours.

We have begun to work with notable photographer, Stephen King on a photo documentary project which we hope to officially launch with an exhibition in 2017.

Following the success of our online awareness campaigns in 2015/16, we plan to produce a new video campaign to bring much needed awareness to Juvenile Huntington's disease and the challenges the families affected face.

### **Improving standards of care**

We have been successful in obtaining funding from Exemplar Healthcare for a post holder who will implement and oversee a care home accreditation scheme. We hope this scheme, once it is established, will help to improve standards of care for people with HD living in care homes.

### **Research**

Subject to the appropriate funds being received, we hope to be able to offer selected research grants to researchers from academic clinical establishments for studies that will help improve standards of care and the development of medical advances for people with HD.

We will be working with the University of Chester on a project focusing on the burdens of illness and the health economics of Huntington's disease.

We are supporting theatre company, Highly Sprung Performance Co, in their search for funding for a theatre project using acting performances to increase awareness of HD and inspire children to become more interested in the sciences. Fostering such interest at an early age may lead to positive developments in the treatment of diseases such as HD in the future.

We want to give HD families a voice in HD research and also in the way we run the HDA so plan to set up a Patient and Public Participation group (PPI) to help researchers and the HDA seek service user opinion on projects and documents produced.

### **Rebrand**

We will be rolling out the restyle of the HDA brand which will include a complete update of our website, communication tools and information publications. We want our image to be more in keeping with the innovative, growing and professional organisation we are today.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2016

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### Structure, governance and management

#### Governing document

The company is a registered Charity founded in 1971 and incorporated on 21st 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 were:

Mr A Bickerdike (Chair from Oct 2015)

Mr P Morse (Resigned 12 July 2016)

Ms S M Abbott

Dr G El-Nimr

Mr M Ellison

Mr NM Heath (Hon Treasurer)

Dr E M Howard

Mr K C Taylor (Resigned 5 December 2015)

Mrs H Thomas (Chair to Oct 2015) (Resigned 1 October 2015)

Mr B J Tindell (Resigned 1 October 2015)

Professor H Rickards (Appointed 9 July 2015)

Mrs C Clarke (Appointed 1 October 2015)

#### 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 four 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 are closely involved in the running of the Association and are pleased that the appointment of a Chief Executive has enabled them to focus on the strategic decisions required for the overall governance of the Association.

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 (CONTINUED)(INCLUDING DIRECTORS' REPORT)

**FOR THE YEAR ENDED 31 MARCH 2016**

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### Statement of Trustees responsibilities

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.

### Auditor

In accordance with the company's articles, a resolution proposing that Duncan Sheard Glass 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 NM Heath**

Trustee

Dated: 10 September 2016

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT

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

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We have audited the financial statements of Huntington's Disease Association for the year ended 31 March 2016 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102.

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 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 its members as a body, for our audit work, for this report, or for the opinions we have formed.

#### **Respective responsibilities of Trustees and auditor**

As explained more fully in the statement of Trustees responsibilities, the Trustees, who are also the directors of Huntington's Disease Association for the purposes of company law are responsible for the preparation of the accounts and for being satisfied that they give a true and fair view.

Our responsibility is to audit and express an opinion on the accounts in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

#### **Scope of the audit of the accounts**

An audit involves obtaining evidence about the amounts and disclosures in the accounts sufficient to give reasonable assurance that the accounts are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the Trustees; and the overall presentation of the accounts. In addition, we read all the financial and non-financial information in the Trustees Annual Report to identify material inconsistencies with the audited accounts and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

#### **Opinion on accounts.**

In our opinion the accounts:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2016 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### **Opinion on other matter prescribed by the Companies Act 2006**

In our opinion the information given in the Trustees Report for the financial year for which the accounts are prepared is consistent with the accounts.

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT (CONTINUED)

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

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

We have nothing to report in respect of the following matters where 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 accounts 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.



**Andrew Moss BA FCA (Senior Statutory Auditor)**  
for and on behalf of Duncan Sheard Glass

10 September 2016

**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 2016

	Notes	Unrestricted funds £	Restricted funds £	Total 2016 £	Total 2015 £
<b><u>Income and endowments from:</u></b>					
Donations and legacies	2	1,079,169	76,731	1,155,900	843,337
Charitable activities	3	46,509	442,445	488,954	518,665
Other trading activities	4	11,422	-	11,422	9,479
Investments	5	14,652	-	14,652	16,987
Other income	6	7,012	-	7,012	1,665
<b>Total income and endowments</b>		<b>1,158,764</b>	<b>519,176</b>	<b>1,677,940</b>	<b>1,390,133</b>
<b><u>Expenditure on:</u></b>					
Raising funds	7	173,079	-	173,079	150,975
Charitable activities	8	1,005,653	412,921	1,418,574	1,422,914
<b>Total resources expended</b>		<b>1,178,732</b>	<b>412,921</b>	<b>1,591,653</b>	<b>1,573,889</b>
Net (losses)/gains on investments	12	(24,055)	-	(24,055)	41,074
<b>Net movement in funds</b>		<b>(44,023)</b>	<b>106,255</b>	<b>62,232</b>	<b>(142,682)</b>
Fund balances at 1 April 2015		854,407	17,923	872,330	1,015,012
<b>Fund balances at 31 March 2016</b>		<b>810,384</b>	<b>124,178</b>	<b>934,562</b>	<b>872,330</b>

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

# HUNTINGTON'S DISEASE ASSOCIATION

## BALANCE SHEET

AS AT 31 MARCH 2016

	Notes	2016		2015	
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	13		6,429		8,682
Investments	14		444,049		543,011
			<u>450,478</u>		<u>551,693</u>
<b>Current assets</b>					
Stocks	15	9,809		8,957	
Debtors	16	197,162		73,161	
Cash at bank and in hand		385,341		344,747	
		<u>592,312</u>		<u>426,865</u>	
<b>Creditors: amounts falling due within one year</b>	17	<u>(108,228)</u>		<u>(106,228)</u>	
Net current assets			484,084		320,637
<b>Total assets less current liabilities</b>			<u>934,562</u>		<u>872,330</u>
<b>Income funds</b>					
Restricted funds	19		124,178		17,923
<u>Unrestricted funds</u>					
Designated funds	20	386,695		443,838	
General unrestricted funds		423,689		410,569	
		<u>810,384</u>		<u>854,407</u>	
			<u>934,562</u>		<u>872,330</u>

The accounts were approved by the Trustees on 10 September 2016



Mr A Bickerdike  
Trustee



Mr NM Heath  
Trustee

Company Registration No. 2021975



# HUNTINGTON'S DISEASE ASSOCIATION

## STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 31 MARCH 2016

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	Notes	2016 £	£	2015 £	£
<b>Cash flows from operating activities</b>					
Cash absorbed by operations	26		(46,171)		(156,962)
<b>Investing activities</b>					
Purchase of tangible fixed assets		(2,794)		(6,186)	
Purchase of fixed asset investments		(10,607)		(12,166)	
Proceeds on disposal of fixed asset investments		85,514		76,532	
Interest received		14,652		16,987	
<b>Net cash generated from investing activities</b>			86,765		75,167
<b>Net cash used in financing activities</b>			-		-
<b>Net increase/(decrease) in cash and cash equivalents</b>			40,594		(81,795)
Cash and cash equivalents at beginning of year			344,747		426,542
<b>Cash and cash equivalents at end of year</b>			385,341		344,747

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# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS

**FOR THE YEAR ENDED 31 MARCH 2016**

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### 1 Accounting policies

#### Company 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

These accounts have been prepared in accordance with FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102"), "Accounting and Reporting by Charities" the Statement of Recommended Practice for charities applying FRS 102, the Companies Act 2006 and UK Generally Accepted Accounting Practice as it applies from 1 January 2015. The Charity is a Public Benefit Entity as defined by FRS 102.

The accounts 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.

These accounts for the year ended 31 March 2016 are the first accounts of Huntington's Disease Association prepared in accordance with FRS 102, The Financial Reporting Standard applicable in the UK and Republic of Ireland. The date of transition to FRS 102 was 1 April 2014. The reported financial position and financial performance for the previous period are not affected by the transition to FRS 102.

#### 1.2 Going concern

At the time of approving the accounts, the Trustees have a reasonable expectation that the Charity has adequate resources 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. Full accrual is made for interest income 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 treated as a contingent asset.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

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### 1 Accounting policies

(Continued)

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

#### 1.5 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.

Major Research grants are usually made once during 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:

Leasehold land and buildings	
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.

The timeshare donated to the Charity was valued according to the minimum price of timeshares at the development in Wales and this resulted in the net book value being reduced to nil.

#### 1.7 Impairment of fixed assets

At each reporting end date, the Charity reviews the carrying amounts of its tangible and intangible 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).

Recoverable amount is the higher of fair value less costs to sell and value in use. In assessing value in use, the estimated future cash flows are discounted to their present value using a pre-tax discount rate that reflects current market assessments of the time value of money and the risks specific to the asset for which the estimates of future cash flows have not been adjusted.

If the recoverable amount of an asset is estimated to be less than its carrying amount, the carrying amount of the asset is reduced to its recoverable amount. An impairment loss is recognised immediately in income/(expenditure) for the year, unless the relevant asset is carried at a revalued amount, in which case the impairment loss is treated as a revaluation decrease.

Recognised impairment losses are reversed if, and only if, the reasons for the impairment loss have ceased to apply. Where an impairment loss subsequently reverses, the carrying amount of the asset is increased to the revised estimate of its recoverable amount, but so that the increased carrying amount does not exceed the carrying amount that would have been determined had no impairment loss been recognised for the asset in prior years. A reversal of an impairment loss is recognised immediately, unless the relevant asset is carried in at a revalued amount, in which case the reversal of the impairment loss is treated as a revaluation increase.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

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### 1 Accounting policies

(Continued)

#### 1.8 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.

#### 1.9 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.

#### 1.10 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 end 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.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

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### 1 Accounting policies

(Continued)

#### ***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 receipts discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

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

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

#### ***Derecognition of financial liabilities***

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

#### **1.11 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.

#### **1.12 Retirement benefits**

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

#### **1.13 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.

#### **1.14 Branch Funds**

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

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

### 2 Donations and legacies

	Unrestricted funds	Restricted funds	Total 2016	Total 2015
	£	£	£	£
Donations and gifts	753,700	13,659	767,359	496,378
Legacies receivable	202,428	60,972	263,400	180,703
Branch income	123,041	2,100	125,141	166,256
	<u>1,079,169</u>	<u>76,731</u>	<u>1,155,900</u>	<u>843,337</u>
<b>For the year ended 31 March 2015</b>	<u>815,663</u>	<u>27,674</u>		<u>843,337</u>
<b>Donations and gifts</b>				
Community fundraising	426,625	-	426,625	383,082
Donations from support groups	-	-	-	1,532
Other donations	327,075	13,659	340,734	111,764
	<u>753,700</u>	<u>13,659</u>	<u>767,359</u>	<u>496,378</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2016

### 3 Charitable activities

	2016	2015
	£	£
Grants received	444,662	454,245
Merchandise income	11,952	15,470
Training and conferences income	32,340	48,950
	<u>488,954</u>	<u>518,665</u>
Analysis by fund		
Unrestricted funds	46,509	
Restricted funds	442,445	
	<u>488,954</u>	
<b>For the year ended 31 March 2015</b>		
Unrestricted funds		100,486
Restricted funds		418,179
		<u>518,665</u>

Included within grants received is an amount of £31,363 received from Birmingham City Council Adults and Communities.

### 4 Other trading activities

	2016	2015
	£	£
Raffle and sponsorship	6,072	5,843
Company sponsorships	5,350	3,636
	<u>11,422</u>	<u>9,479</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

### 5 Investments

	2016	2015
	£	£
Income from listed investments	14,412	16,127
Interest receivable	240	860
	<u>14,652</u>	<u>16,987</u>

### 6 Other income

	2016	2015
	£	£
Miscellaneous income	<u>7,012</u>	<u>1,665</u>

### 7 Raising funds

	2016	2015
	£	£
<u>Fundraising and publicity</u>		
Fundraising events	16,478	12,104
Fundraiser's costs	16,008	21,943
Staff costs	139,109	116,105
	<u>171,595</u>	<u>150,152</u>
<u>Investment management</u>	1,484	823
	<u>173,079</u>	<u>150,975</u>



# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2016

### 8 Charitable activities

	Specialist HD Advisory Service	Welfare and Respite Care	Research	Newsletter, Education, Branch Liaison	Youth Worker	Total 2016	Total 2015
	£	£	£	£	£	£	£
Staff costs	789,652	1,857	928	23,446	30,230	846,113	815,193
Welfare grants	-	40,420	-	-	-	40,420	51,476
Research	-	-	15,089	-	-	15,089	4,694
Juvenile	14,603	-	-	-	4,998	19,601	15,132
Branch costs	-	-	-	55,061	-	55,061	68,430
Travel and training	94,297	-	-	865	7,182	102,344	92,381
Camps, conferences and AGM	35,228	-	-	-	-	35,228	61,675
Telephone and internet	22,754	-	-	429	357	23,540	32,327
Other costs	12,944	-	-	658	690	14,292	15,788
Newsletter	-	-	-	26,655	-	26,655	27,094
Publications and merchandise	-	-	-	13,442	-	13,442	20,338
Share of support costs (see note 9)	969,478	42,277	16,017	120,556	43,457	1,191,785	1,204,528
Share of governance costs (see note 9)	146,527	10,914	2,183	49,927	8,731	218,282	208,889
	8,507	-	-	-	-	8,507	9,497
	1,124,512	53,191	18,200	170,483	52,188	1,418,574	1,422,914
Analysis by fund							
Unrestricted funds	711,591	53,191	18,200	170,483	52,188	1,005,653	
Restricted funds	412,921	-	-	-	-	412,921	
	1,124,512	53,191	18,200	170,483	52,188	1,418,574	
For the year ended 31 March 2015							
Unrestricted funds	640,056	68,074	8,528	206,310	47,324	970,292	
Restricted funds	452,622	-	-	-	-	452,622	
	1,092,678	68,074	8,528	206,310	47,324	1,422,914	

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

9 Support costs	Support costs	Governance costs	2016	2015	Basis of allocation
	£	£	£	£	
Staff costs	92,861	-	92,861	88,769	
Depreciation	5,047	-	5,047	10,139	
Head office costs	120,374	-	120,374	109,981	
Audit fees	-	6,840	6,840	5,670	Governance
EC meeting costs	-	1,667	1,667	3,827	Governance
	<u>218,282</u>	<u>8,507</u>	<u>226,789</u>	<u>218,386</u>	
Analysed between Charitable activities	<u>218,282</u>	<u>8,507</u>	<u>226,789</u>	<u>218,386</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:

	2016 Number	2015 Number
Specialist HD Advisors	23	23
Management	3	3
Fundraising	4	4
Youth Worker	1	1
Administration	4	3
Branch Liaison	1	1
	<u>36</u>	<u>35</u>
<b>Employment costs</b>	<b>2016</b> £	<b>2015</b> £
Wages and salaries	966,589	914,903
Social security costs	89,368	84,043
Other pension costs	22,126	21,121
	<u>1,078,083</u>	<u>1,020,067</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 2016

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

	2016	2015
	£	£
Revaluation of investments	(19,726)	37,593
Gain/loss on sale of investments	(4,329)	3,481
	<u>(24,055)</u>	<u>41,074</u>

#### 13 Tangible fixed assets

	Leasehold land and buildings	Fixtures and fittings	Total
	£	£	£
<b>Cost</b>			
At 1 April 2015	750	51,869	52,619
Additions	-	2,794	2,794
	<u>750</u>	<u>54,663</u>	<u>55,413</u>
At 31 March 2016	750	54,663	55,413
<b>Depreciation and impairment</b>			
At 1 April 2015	750	43,187	43,937
Depreciation charged in the year	-	5,047	5,047
	<u>750</u>	<u>48,234</u>	<u>48,984</u>
At 31 March 2016	750	48,234	48,984
<b>Carrying amount</b>			
At 31 March 2016	<u>-</u>	<u>6,429</u>	<u>6,429</u>
At 31 March 2015	<u>-</u>	<u>8,682</u>	<u>8,682</u>

#### 14 Fixed asset investments

	2016	2015
	£	£
Listed investments	444,049	543,011
	<u>444,049</u>	<u>543,011</u>
Listed investments included above:	<b>2016</b>	<b>2015</b>
	£	£
Listed investments carrying amount	444,049	543,011
	<u>444,049</u>	<u>543,011</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

<b>14</b>	<b>Fixed asset investments</b>	<b>(Continued)</b>	
	<b>Movements in fixed asset investments</b>		<b>Shares</b>
			<b>£</b>
	<b>Cost or valuation</b>		
	At 31 March 2016		543,011
	Additions		10,607
	Valuation changes		(24,055)
	Disposals		(85,514)
	At 31 March 2016		<u>444,049</u>
	<b>Carrying amount</b>		
	At 31 March 2016		<u>444,049</u>
	At 31 March 2015		<u>543,011</u>
<b>15</b>	<b>Stocks</b>	<b>2016</b>	<b>2015</b>
		<b>£</b>	<b>£</b>
	Finished goods and goods for resale	9,809	8,957
		<u>9,809</u>	<u>8,957</u>
<b>16</b>	<b>Debtors</b>	<b>2016</b>	<b>2015</b>
	<b>Amounts falling due within one year:</b>	<b>£</b>	<b>£</b>
	Trade debtors	7,306	4,361
	Other debtors	157,317	41,986
	Prepayments and accrued income	32,539	26,814
		<u>197,162</u>	<u>73,161</u>
<b>17</b>	<b>Creditors: amounts falling due within one year</b>	<b>2016</b>	<b>2015</b>
		<b>£</b>	<b>£</b>
	Other taxation and social security	23,169	24,485
	Trade creditors	29,819	19,736
	Accruals and deferred income	55,240	62,007
		<u>108,228</u>	<u>106,228</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

### 18 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 and loss in respect of defined contribution schemes was £16,478 (2015 - £12,104).

### 19 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 2015	Movement in funds		Balance at 31 March 2016
	£	Incoming resources £	Resources expended £	£
Research	14,034	71,251	(18,200)	67,085
Big Lottery Fund (Merseyside and Yorkshire)	3,889	75,963	(73,554)	6,298
Specialist Huntington Disease Advisory Service	-	252,728	(233,728)	19,000
Big Lottery (Surrey)	-	39,049	(32,009)	7,040
Welsh Lottery	-	45,271	(40,516)	4,755
RCN Foundation	-	4,783	(4,783)	-
BBC Children in Need	-	6,998	(6,998)	-
Lord Cozens-Hardy Trust	-	20,000	-	20,000
Juvenile Huntingtons Disease	-	3,133	(3,133)	-
	<u>17,923</u>	<u>519,176</u>	<u>(412,921)</u>	<u>124,178</u>

#### Research

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

#### 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.

#### 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.

#### Welsh Lottery

This grant was awarded to cover a Specialist HD Adviser post in North Wales.

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

### 19 Restricted funds

(Continued)

#### RCN Foundation

Funding was given for the SHDA's to receive specific training.

#### BBC Children in Need

Funding was received to fund the Summer camps that took place in the year.

#### Lord Cozens-Hardy Trust

Funding was received during the year and was allocated to be spent on the Youth Conference and JHD Weekend, both of which took place in April 2016.

#### Juvenile HD

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

### 20 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 2015	Movement in funds		Balance at 31 March 2016
	£	Incoming resources £	Resources expended £	£
Special projects fund	340,000	-	(70,000)	270,000
Branch funds	103,838	125,141	(112,284)	116,695
	<u>443,838</u>	<u>125,141</u>	<u>(182,284)</u>	<u>386,695</u>

A Designated 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.

### 21 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
	£	£	£
Fund balances at 31 March 2016 are represented by:			
Tangible assets	6,429	-	6,429
Current assets/(liabilities)	378,906	105,178	484,084
	<u>385,335</u>	<u>105,178</u>	<u>490,513</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

(Continued)

### 22 Operating lease commitments

#### Lessee

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:

	2016 £	2015 £
Within one year	40,048	40,048
Between two and five years	157,599	159,579
In over five years	12,340	50,408
	<u>209,987</u>	<u>250,035</u>

During the year operating lease payments have been recognised as an expense in the Statement of Financial Activities to the value of £40,048 (2015: £40,048).

### 23 Related party transactions

#### Remuneration of key management personnel

The remuneration of key management personnel is as shown below.

	2016 £	2015 £
Aggregate compensation	<u>184,225</u>	<u>177,113</u>

#### Transactions with related parties

Mr NM Heath is a partner in the firm RPG Crouch Chapman LLP, Chartered Accountants, who derived benefit from fees for payroll services of £3,500 (2015: £3,708).

### 24 Contingent asset

The charity is a residuary beneficiary of an estate subject to a life tenancy. The value of the entitlement as at 16 June 2016 was £46,693 (11 June 2015 : £49,136).

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2016

### 25 Branch funds

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

	2016 £	2015 £
Cash balances at 1 April 2015	103,838	90,292
Receipts in year	125,141	166,256
Less :		
Local welfare grants	(20,989)	(29,615)
Sent to head office	(36,234)	(54,665)
Branch activities,local newsletters,equipment,research etc	(55,061)	(68,430)
Cash balances at 31 March 2016	<u>116,695</u>	<u>103,838</u>

### 26 Cash generated from operations

	2016 £	2015 £
Surplus/(deficit) for the year	62,232	(142,682)
Adjustments for:		
Investment income recognised in profit or loss	(14,652)	(16,987)
Loss/(gain) on disposal of investments	4,329	(3,481)
Fair value gains and losses on investments	19,726	(37,593)
Depreciation and impairment of tangible fixed assets	5,047	10,139
Movements in working capital:		
(Increase) in stocks	(852)	(2,800)
(Increase)/decrease in debtors	(124,001)	36,067
Increase in creditors	2,000	375
<b>Cash absorbed by operations</b>	<u>(46,171)</u>	<u>(156,962)</u>