

**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 2017**

# HUNTINGTON'S DISEASE ASSOCIATION

## LEGAL AND ADMINISTRATIVE INFORMATION

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**Patrons**                      The Dowager Countess of Harewood  
Tony Hadley  
Shane Richie

**Trustees**                      Mr A Bickerdike  
Ms S M Abbott  
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

**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

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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 2017**

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The Trustees present their report and accounts for the year ended 31 March 2017.

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**

##### **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 are around 7,120 people living with HD in England and Wales.

##### **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 2017**

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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 14,000 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 5,600 people.

#### **Branches & Support Groups**

We are linked to 28 local HDA branches and 28 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**

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 of 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.

#### **Aims and objectives in 2016/17**

In 2016/17 the main activity of the charity was to support families affected by Huntington's disease with the following clearly defined strategic goals at the forefront of everything we do:

- 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

These strategic goals form part of the Association's Strategic plan for 2014-2017.

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# **HUNTINGTON'S DISEASE ASSOCIATION**

## **TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2017**

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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 2016/17**

##### **Improving quality of care**

Huntington's disease is a complex illness that affects each person differently and the professionals involved in their care often have very limited or no knowledge of the disease at all. Additionally whilst family members may have experienced caring for loved ones with Huntington's previously as a result of its hereditary nature, the diseases' complexities and the UK's ever changing care provision, mean that they regularly face new challenges. Improving people's knowledge about Huntington's and the quality and standard of care needed continued to be the key focus of our charity throughout the last year.

Our advisory service, delivered by 23 skilled advisers, each with a wealth of experience from previous employment in the medical, social and care fields, provided practical support to over 14,000 people affected by Huntington's disease in 2016/17.

Our advisers actively engaged with family members through a variety of mediums, including face to face support in familiar surroundings and advice over the phone, by email or by video chat through our specialist helpline. 98% of people who had contact with an adviser in 2016/17 felt that it helped them and 90% felt they had a much more in depth knowledge of HD after receiving guidance from the Huntington's Disease Association.

Accessing the right level of care and services is an issue faced by many HD families and one that the HDA has worked hard to improve throughout 2016/17. Our advisers worked closely with over 1,355 other healthcare professionals throughout the year carrying out joint home visits together, attending over 331 multi-disciplinary team meetings and either co-ordinating or assisting in the management of over 351 dedicated HD clinics. By bringing all those involved in the care of an individual with HD together and encouraging a collaborative approach, the standard and quality of care for many individuals was significantly improved.

Having secured funding for a care home accreditation scheme in early 2016 to provide families with greater assurances of a care home's suitability for their loved ones, we took a step further in 2016/17 towards the development of the project by advertising and recruiting a project co-ordinator who will start in 2017/18.

We continued to provide advice and guidance on our website and via a suite of guides throughout the year so that family members and professionals alike could easily access in depth information to improve their knowledge and subsequently improve care standards.

Throughout the year our advisers worked hard to build relationships with professionals involved in the care of people with HD across England and Wales, providing advice via the helpline, in person in the workplace and at various networking events to better improve their knowledge of the disease and how to best support those with HD in their care.

In 2016/17 the National Institute for Health and Care Excellence (NICE) updated their guidelines on end of life care for people with life limiting illnesses and we submitted evidence from a Huntington's disease perspective. We hope these guidelines will help to improve end of life care services for people with HD.

Our specialist youth worker supported 265 children living in HD families and 47 young carers looking after a relative with the disease in 2016/17. Children often face discrimination due to the stigma and misconceptions surrounding Huntington's disease. They also face difficulties at home due to their caring responsibilities or due to the changes HD brings to family relationships. For this reason, we see the importance of making sure young people are listened to, supported and represented. Through face to face visits at their schools and at home, our youth worker made sure children and young people in the Huntington's community had somewhere to turn.

# **HUNTINGTON'S DISEASE ASSOCIATION**

## **TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2017**

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### **Reducing risk**

By actively engaging with people affected by HD, being readily accessible via the telephone helpline, seeing people in their home environments and working collaboratively with other professionals involved in their care, our advisers were able to take proactive steps to support people and prevent crisis situations. In 2016/17 76% of those who had contact with their local adviser informed us that felt much more able to cope with their situation.

Throughout the year our advisers were involved in a number of adult and child safeguarding cases from direct referrals to protection services to provide support and advocacy at welfare and best interest meetings with statutory services, care homes and schools. Protecting the welfare of people with HD and their families was an important part of our work in 2016/17.

Living with HD and getting the appropriate resources, equipment and support can sometimes be difficult; especially as the disease progresses and people's ability to work and earn money is compromised. To help with this, in 2016/17 we provided 39 welfare grants to the value of over £11,000 for items ranging from a specialist chair to aromatherapy sessions. The grants provided recipients with items or experiences that significantly enhanced their quality of life without which they would have struggled.

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

In 2016/17 we supported 28 HDA branches and 28 local HD support groups who met regularly throughout England and Wales to provide peer support to each other, obtain practical advice from our advisers, fundraise and raise awareness of Huntington's disease in their local communities.

We provided further ways for those facing similar situations to meet, support each other and share knowledge, especially those in more remote areas who were unable to get to a branch or support group meeting. Both face to face opportunities in the form of carer's events and pop up support cafes were organised as well as virtual opportunities in the form of our message board and Facebook page. As at the end of March 2017, the message board reached 810 new members and had a total membership of 5,503 and our Facebook page achieved 10,000 likes in the year.

Through regular visits to hospitals, care homes and contact with care agency staff whilst visiting family homes throughout 2016/17, our advisers were able to give one on one information and advice about Huntington's tailored to suit the needs of the individual clients thus enabling health and care professionals to provide quality care and share best practice with their colleagues.

### **Reducing isolation**

69% of people informed that they felt less isolated after having made contact with the HDA.

Our confidential telephone helpline, operated by our advisers responded to 30,198 calls in 2016/17. This service was a lifeline for many people who needed advice, were struggling to cope or were facing crisis situations.

Throughout 2016/17 our advisers carried out 2,433 visits to people in their homes and care homes, providing advice and support to 5,347 family members. Our specialist youth worker visited 164 young people in schools or at home, and attended 10 statutory 'looked after child reviews.' They provided emotional support and information and acted as the link between HD families, services and local peer support networks to make sure that no-one affected by HD feels alone. 99% informed they had a much better understanding about the support available to them after contact with the HDA.

Key events in the HDA's social calendar throughout the year provided opportunities for families to meet others facing similar situations. Our annual family conference provided families with an occasion to socialise together and learn about developments in HD care, treatment and research. Our Juvenile HD activity weekend allowed young children with JHD and their siblings to participate in fun activities they wouldn't get the chance to do anywhere else and also provided their parents with the chance to meet other families and children affected by the illness, often for the first time. Our young adult's weekend aimed at those aged 18-35 with HD in their family provided advice and peer support for those people who have tested positive, tested negative or who are unsure whether they want to undergo predictive testing.

# **HUNTINGTON'S DISEASE ASSOCIATION**

## **TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2017**

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A new closed Facebook support group was launched in 2016/17 called 'Kim's Friends' aimed specifically at those who have gone through the predictive testing process and know that they will not go on to develop Huntington's disease. Research into the needs of our different client groups revealed that this group had very little existing support in place but the Facebook group now provides the opportunity for them to share their stories and seek advice from our advisers and others.

Another new initiative launched in 2016/17 was 'breaking down barriers,' a project which was set up to better explain Huntington's disease and support families from the South Asian Community whose first language is not English. Work progressed throughout the year to develop resources that can be easily translated so that this community can better access support and services and not feel isolated.

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

In 2016/17 our specialist HD advisers provided 397 specialist training and information sessions to approximately 3,635 healthcare professionals in hospitals, community and social services and care homes throughout England and Wales as part of our ongoing commitment to increasing knowledge and understanding of Huntington's disease. Training was tailored to meet the specific needs of professional groups and covered all aspects of the disease including symptoms, behaviour management and palliative care.

A three day in depth course for professionals working with and supporting clients with HD was also held in 2016. Professionals were able to learn from world renowned experts in the field of HD during the course. We also hosted a series of seminars led by acclaimed American HD expert Jimmy Pollard who toured the North of England educating healthcare professionals.

One to one advice during family visits, advice in our members' newsletters and on our website throughout the year provided family carers with an improved understanding of Huntington's and its complexities. We also worked closely with other organisations including St Andrew's Healthcare and Nutricia UK to develop information about the disease.

We continued to provide funding to Huntington's Disease Youth Organization (HDYO) to help make sure the needs and issues facing young people impacted by Huntington's disease are represented.

We know that increasing knowledge and understanding of Huntington's will mean better diagnosis and care for people with HD and as such training, whether formally in the workplace or on a one to one basis with a family carer, remained a core focus of our charity. 99% of those who received specialist training from the HDA in 2016/17 reported they felt better equipped to care for their clients with HD.

We challenged national policy and decision makers about unfair and outdated policies concerning people affected by Huntington's disease. One notable example in 2016/17 was our attempts to encourage the Ministry of Defence to review their recruitment policies that unnecessarily exclude those at risk of developing Huntington's and do not take into account current researched evidence. We are committed to championing the needs of the HD community and educating people about the disease to help bring about change.

We launched a patient public involvement group, HD Voice, in 2016/17 comprised of people who have HD in their family. The aim of the group is to assist in the selection of research projects, work with researchers to plan research and review HDA information and publications to make sure the current needs of the HD community are met, understood and represented. We also worked closely with international Huntington's Disease Associations with the aim of setting up an international PPI group to be involved in international trials as advances in research of Huntington's disease treatment take place.

We continued to promote participation in Enroll-HD, the world's largest observational study for Huntington's disease families and wrote many letters of support for medical institutions keen to obtain funding for HD research so that a better understanding of the disease can be achieved.

We continued to support and fund HD Buzz, a website providing reliable and easy to understand information about HD research written by Scientists to ensure people affected by the disease can gain insight into the development of potential treatments.



# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2017

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### **Raising awareness**

Our ongoing commitment to raising awareness of Huntington's disease continued in 2016/17.

We advised the BBC on a number of Huntington's disease storylines that appeared or are soon set to appear on primetime TV shows including a plotline on Doctors which will have certainly increased the public knowledge and understanding of the disease.

Our Chief Executive and Specialist HD Advisers spoke on numerous national and local BBC radio shows throughout the year covering key topical subjects such as the implications for HD families following changes to the benefits system and assessment criteria for Personal Independence Payments (PIP).

Our awareness week campaign in May 2016 aimed to raise the profile of the disease and make people more aware of what our charity offers to those people who need support. A series of specialist training sessions were delivered throughout the week, alongside a great many volunteer led awareness events such as cake sales and charity runs. We also launched a new project in which we asked our supporters to encourage local buildings and landmarks in their area to light up in our charity colours, pink and green, to help shine a light on the disease. Notable buildings such as Blackpool Tower, Spinnaker tower in Portsmouth and Liverpool Engineering building took part.

Our army of over 700 dedicated volunteers spent the year raising awareness and funds for us in a variety of different ways from jumping out of planes and scaling mountains to cake sales and raffles. We had some well-known faces showing us support throughout the year too including 90s Comedy duo Trevor and Simon who appeared on Pointless in aid of our charity and Juan Pablo Yopez, an actor on Hollyoaks, who ran the London Marathon on our behalf.

Our Patron, Tony Hadley, helped us celebrate some of our volunteers by attending a pre-London Marathon meet and greet event to help show out thanks and appreciation for their huge efforts in raising awareness of HD and fundraising to help us increase our reach.

### **Financial review**

The results for the year show an overall surplus of £74,805 after recognising net investment gains of £63,721. Income fell to £1,531,987. The decrease of 9% on the previous year resulted from a fall in both legacy income and exceptional donations which was only partially offset by increases in fundraising locally and nationally.

Expenditure was carefully controlled and the overall positive outcome helps the Association to maintain sufficient resources 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 2017. 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 £508,358 (2016: £423,689). The designated project reserve remained at £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.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2017

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### Future plans

We are due to reach the end of our current strategy at the end of 2017 so a key focus for the charity over the coming year will be to reflect on the changing needs of the Huntington's community as advances are made in HD research and changes are made to the way that people engage and access information. We will liaise with our supporters, staff and key partners to ensure the strategic direction of the charity over the next 5 years will lead to a better life for anyone affected by Huntington's disease.

After extensive preliminary work and planning, a rebrand of our charity website, information and image will launch in 2017/18. We feel we have listened to the opinions and ideas of our supporters and the information and way we will communicate moving forward will better meet the needs of the Huntington's disease community and make information about the disease much more accessible.

We will develop a detailed communications strategy to improve knowledge about Huntington's disease and will explore ways in which relations with the media can be improved to further raise public understanding.

With an increasing need for support by the young people living in HD families and greater pressure on our specialist youth worker as his client base and reach expands, We have secured funding to recruit a second youth worker for 3 years from BBC Children in Need.

Ensuring that the HD Advisory service is fully funded will be a key priority throughout the year. We have refreshed our case for support, so our need is clearly expressed; we have clearly defined outcomes for people with HD and clear cost base. Our approach to Trusts and Foundations continues with multiyear funding bids, we are building on current relationships and looking for new larger Trusts to be able to expand the support that we offer.

Community fundraising is a priority and we will continue to provide the best level of care and attention for volunteer fundraisers. We will thank and support them and follow them on their different donor journeys. We will provide free incentives (fundraising merchandise) in their supporter packs and improve literature and an information fundraising pack via rebrand and make getting involve online easier with new website.

We will look to purchase new rebranded stock with practical items people use every day such as mugs and plastic running bottles. There will be a fresh new feel to our merchandise making it more appealing to purchase. The new website will provide a better way to view the products on sale.

We will develop our legacy strategy. The success of this initiative will be linked to the rebrand and investment in legacy marketing since this is a significant part of our income and is largely unsupported and we believe it can make a greater contribution to our work. The new website will make leaving a legacy easier. Using this strategy we can grow this income stream.

Having successfully recruited a project co-ordinator for the care home accreditation project, work will begin in 2017/18 on the implementation of this scheme. Focus groups are planned with family members, care homes and key bodies such as the Care Quality Commission.

The need to improve the standards and quality of care for people living with HD and fair and equal access to opportunities will be paramount to our future activity. Work to help commissioners and stakeholders recognise the need for NICE guidelines for HD will continue. We will also further liaise with national bodies, such as the Ministry of Defence, to encourage equal access to opportunities for those with HD or living at risk of developing it in the future, in line with current evidence about HD and its manifestation.

Following the Charities Act 2016, it's our responsibility to provide an outline of our fundraising practices and approach to raising income for the HDA.

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2017

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### Approach to working

- Put donors and supporters first in our management of activities and resources to maximise net income
- Be early adopters of new technologies and fundraising initiatives
- Work in an open collaborative style sharing information and experience with colleagues
- Continue to consider return on investment as one indicator of success seeking to keep costs down, while acknowledging the need to invest for the longer term
- Support and recognise the achievements of our hugely committed fundraising volunteers alongside our staff
- Work with colleagues' volunteers and people affected by HD to ensure that we maximise income potential
- Meet or exceed all statutory and regulatory obligations

The Funding landscape for the sector in 2017 has changed beyond all recognition. The decline of statutory sources has hit all charities and there has been a move towards relationship fundraising for Trusts and Foundations. In order to be considered for the larger gifts, charities need to develop strong relationships built on connections and good reporting and monitoring. The HDA has been working towards this goal. Community Fundraising remains a priority for the HDA and we provide structured professional support to all those undertaking fundraising for the HDA and acknowledge this contribution by the annual Fundraising Volunteer Award Ceremony and the London Marathon Meet and Greet.

Fundraising staff can never work in isolation; we receive high levels of support from staff across the organisation in a variety of ways. For example fronting appeals supporting events and introducing useful contacts. To continue the growth of income that our strategy necessitates we will require this level of co-operation and more. We must acknowledge that other department's activities and decisions taken throughout the organisation impact on our ability to fundraise. The next level of integration requires that we are fully aware of the impact of organisational decisions on our fundraising potential. This is particularly true when dealing with communications, service delivery, external stakeholder's messages and relationships.

There is an obvious dependency with branding/membership and a new communications strategy. These changes will maximise value and will underpin our fundraising messages.

The HDA is a member of the Fundraising Regulator and we follow the Institute of Fundraising best practice guide and Charity Commissions guidance for Charity Trustees (CC20) We comply to PECR the Privacy and Electronic Communications regulations that sit alongside the current 1998 Data Protection Act and are undertaking all the relevant compliance preparations to ensure we are ready for GDPR (General Data Protection Act) new law coming into effect on the 25 May 2018.

For the year 2016/17 we did not receive any complaints about our fundraising practices or 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."

### 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

Mr P Morse

(Resigned 12 July 2016)

Ms S M Abbott

Dr G El-Nimr

Mr M Ellison

Mr N M Heath (Hon Treasurer)

Dr E M Howard

Professor H Rickards

# HUNTINGTON'S DISEASE ASSOCIATION

## TRUSTEES REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2017

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Ms A C Clarke  
Mr A Fryer

(Appointed 5 November 2016)

### **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 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

### **Auditor**

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

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

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

The Trustees report was approved by the Board of Trustees.

*N. M. Heath*

Mr N M Heath (Hon Treasurer)

Dated: 18 August 2017

# **HUNTINGTON'S DISEASE ASSOCIATION**

## **STATEMENT OF TRUSTEES RESPONSIBILITIES**

***FOR THE YEAR ENDED 31 MARCH 2017***

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

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

In preparing these accounts, the Trustees are required to:

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## INDEPENDENT AUDITOR'S REPORT

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

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We have audited the accounts of Huntington's Disease Association for the year ended 31 March 2017 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 and regulations made under that Act. 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 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 2017 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 DSG

18 August 2017

**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 2017

	Notes	Unrestricted funds £	Restricted funds £	Total 2017 £	Total 2016 £
<b><u>Income and endowments from:</u></b>					
Donations and legacies	2	881,320	27,908	909,228	1,155,900
Charitable activities	3	101,721	478,931	580,652	488,954
Other trading activities	4	25,323	-	25,323	11,422
Investments	5	16,219	-	16,219	14,652
Other income	6	565	-	565	7,012
<b>Total income</b>		<b>1,025,148</b>	<b>506,839</b>	<b>1,531,987</b>	<b>1,677,940</b>
<b><u>Expenditure on:</u></b>					
Raising funds	7	179,646	-	179,646	173,079
Charitable activities	8	843,687	497,570	1,341,257	1,418,574
<b>Total resources expended</b>		<b>1,023,333</b>	<b>497,570</b>	<b>1,520,903</b>	<b>1,591,653</b>
Net income/(expenditure) before net gains/(losses) on investments		1,815	9,269	11,084	86,287
Net gains on investments	12	63,721	-	63,721	(24,055)
<b>Net movement in funds</b>		<b>65,536</b>	<b>9,269</b>	<b>74,805</b>	<b>62,232</b>
Fund balances at 1 April 2016		810,384	124,178	934,562	872,330
<b>Fund balances at 31 March 2017</b>		<b>875,920</b>	<b>133,447</b>	<b>1,009,367</b>	<b>934,562</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 2017

	Notes	2017 £	£	2016 £	£
<b>Fixed assets</b>					
Tangible assets	13		7,240		6,429
Investments	14		507,489		444,049
			<u>514,729</u>		<u>450,478</u>
<b>Current assets</b>					
Stocks	15	5,281		9,809	
Debtors	16	146,436		197,162	
Cash at bank and in hand		437,442		385,341	
		<u>589,159</u>		<u>592,312</u>	
<b>Creditors: amounts falling due within one year</b>	17	(94,521)		(108,228)	
Net current assets			<u>494,638</u>		<u>484,084</u>
<b>Total assets less current liabilities</b>			<u>1,009,367</u>		<u>934,562</u>
<b>Income funds</b>					
Restricted funds	19		133,447		124,178
<u>Unrestricted funds</u>					
Designated funds	20	367,562		386,695	
General unrestricted funds		<u>508,358</u>		<u>423,689</u>	
			<u>875,920</u>		<u>810,384</u>
			<u>1,009,367</u>		<u>934,562</u>

The accounts were approved by the Trustees on 18 August 2017



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 2017

	Notes	2017 £	£	2016 £	£
<b>Cash flows from operating activities</b>					
Cash generated from/(absorbed by) operations	25		41,028		(46,171)
<b>Investing activities</b>					
Purchase of tangible fixed assets		(5,775)		(2,794)	
Purchase of investments		(7,362)		(10,607)	
Proceeds on disposal of investments		7,991		85,514	
Interest received		16,219		14,652	
<b>Net cash generated from investing activities</b>			11,073		86,765
<b>Net cash used in financing activities</b>					
<b>Net increase in cash and cash equivalents</b>			52,101		40,594
Cash and cash equivalents at beginning of year			385,341		344,747
<b>Cash and cash equivalents at end of year</b>			437,442		385,341

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2017

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### **1 Accounting policies**

#### **Charity information**

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

#### **1.1 Accounting convention**

The accounts have been prepared in accordance with the Charity's [governing document], 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 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.

#### **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.

#### **1.5 Resources expended**

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2017

---

### 1 Accounting policies

(Continued)

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

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

#### 1.6 Tangible fixed assets

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

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

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

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

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. During the period the timeshare was disposed for £nil.

#### 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 2017

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### 1 Accounting policies

(Continued)

#### 1.11 Financial instruments

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

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

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

##### **Basic financial assets**

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

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

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

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

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

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

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

##### **Basic financial liabilities**

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

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

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

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

### 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 2017	Total 2016
	£	£	£	£
Donations and gifts	589,179	14,275	603,454	767,359
Legacies receivable	217,163	2,633	219,796	263,400
Branch income	74,978	11,000	85,978	125,141
	<u>881,320</u>	<u>27,908</u>	<u>909,228</u>	<u>1,155,900</u>
<b>For the year ended 31 March 2016</b>	<u>1,079,169</u>	<u>76,731</u>		<u>1,155,900</u>
<b>Donations and gifts</b>				
Community fundraising	452,077	-	452,077	426,625
Other donations	137,102	14,275	151,377	340,734
	<u>589,179</u>	<u>14,275</u>	<u>603,454</u>	<u>767,359</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

### 3 Charitable activities

	2016 £	2016 £
Grants received	541,181	444,662
Merchandise income	12,238	11,952
Training and conferences income	27,233	32,340
	<u>580,652</u>	<u>488,954</u>
Analysis by fund		
Unrestricted funds	101,721	
Restricted funds	478,931	
	<u>580,652</u>	
<b>For the year ended 31 March 2016</b>		
Unrestricted funds		46,509
Restricted funds		442,445
		<u>488,954</u>

### 4 Other trading activities

	2017 £	2016 £
Raffle and sponsorship	5,973	6,072
Company sponsorships	19,350	5,350
Other trading activities	<u>25,323</u>	<u>11,422</u>

### 5 Investments

	2017 £	2016 £
Income from listed investments	15,556	14,412
Interest receivable	663	240
	<u>16,219</u>	<u>14,652</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

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### 6 Other income

	2017	2016
	£	£
Miscellaneous income	565	7,012

### 7 Raising funds

	2017	2016
	£	£
<u>Fundraising and publicity</u>		
Fundraising events	18,491	16,478
Fundraiser's costs	20,762	16,008
Staff costs	139,920	139,109
	<hr/>	<hr/>
Fundraising and publicity	179,173	171,595
	<hr/>	<hr/>
<u>Investment management</u>	473	1,484
	<hr/>	<hr/>
	179,646	173,079
	<hr/>	<hr/>



# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

### 8 Charitable activities

	Specialist Welfare and HD Advisory Service	Research Welfare and Respite Care	Research Education, Branch Liaison	Youth Worker	Total 2017	Total 2016
	£	£	£	£	£	£
Staff costs	746,997	1,891	945	30,263	796,959	846,113
Welfare grants	-	34,540	-	-	34,540	40,420
Research	-	-	11,619	-	11,619	15,089
Juvenile	15,686	-	-	6,248	21,934	19,601
Branch costs	-	-	-	-	44,384	55,061
Travel and training	79,566	-	-	6,835	86,806	102,344
Camps, conferences and AGM	21,886	-	-	-	21,886	35,228
Telephone and internet	24,196	-	-	393	24,614	23,540
Other costs	12,521	-	-	345	13,347	14,292
Newsletter	-	-	-	-	18,298	26,655
Publications and merchandise	-	-	-	-	23,156	13,442
	900,852	36,431	12,564	44,084	1,097,543	1,191,785
Share of support costs (see note 9)	140,958	11,746	2,349	9,397	234,927	218,282
Share of governance costs (see note 9)	8,787	-	-	-	8,787	8,507
	1,050,597	48,177	14,913	53,481	1,341,257	1,418,574
Analysis by fund						
Unrestricted funds	553,027	48,177	14,913	53,481	843,687	
Restricted funds	497,570	-	-	-	497,570	
	1,050,597	48,177	14,913	53,481	1,341,257	
For the year ended 31 March 2016						
Unrestricted funds	711,591	53,191	18,200	52,188		1,005,653
Restricted funds	412,921	-	-	-		412,921
	1,124,512	53,191	18,200	52,188		1,418,574

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

### 9 Support costs

	Support costs £	Governance costs £	2017 £	2016 £	Basis of allocation
Staff costs	93,205	-	93,205	92,861	
Depreciation	4,964	-	4,964	5,047	
Head office costs	136,758	-	136,758	120,374	
Audit fees	-	6,714	6,714	6,840	Governance
EC meeting costs	-	2,073	2,073	1,667	Governance
	<u>234,927</u>	<u>8,787</u>	<u>243,714</u>	<u>226,789</u>	
Analysed between Charitable activities	<u>234,927</u>	<u>8,787</u>	<u>243,714</u>	<u>226,789</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:

	2017 Number	2016 Number
Specialist HD Advisors	23	23
Management	3	3
Fundraising	4	4
Youth Worker	1	1
Administration	4	4
Branch Liaison	-	1
	<u>35</u>	<u>36</u>

#### Employment costs

	2017 £	2016 £
Wages and salaries	921,111	966,589
Social security costs	85,211	89,368
Other pension costs	23,762	22,126
	<u>1,030,084</u>	<u>1,078,083</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 2017

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

	2017	2016
	£	£
Revaluation of investments	62,605	(19,726)
Gain/(loss) on sale of investments	1,116	(4,329)
	<u>63,721</u>	<u>(24,055)</u>

### 13 Tangible fixed assets

	Timeshare	Fixtures and fittings	Total
	£	£	£
<b>Cost</b>			
At 1 April 2016	750	54,663	55,413
Additions	-	5,775	5,775
Disposals	(750)	-	(750)
At 31 March 2017	<u>-</u>	<u>60,438</u>	<u>60,438</u>
<b>Depreciation and impairment</b>			
At 1 April 2016	750	48,234	48,984
Depreciation charged in the year	-	4,964	4,964
Eliminated in respect of disposals	(750)	-	(750)
At 31 March 2017	<u>-</u>	<u>53,198</u>	<u>53,198</u>
<b>Carrying amount</b>			
At 31 March 2017	<u>-</u>	<u>7,240</u>	<u>7,240</u>
At 31 March 2016	<u>-</u>	<u>6,429</u>	<u>6,429</u>

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

### 14 Fixed asset investments

	Listed investments £
<b>Cost or valuation</b>	
At 31 March 2017	444,049
Additions	7,362
Valuation changes	62,953
Disposals	(6,875)
At 31 March 2017	507,489
<b>Carrying amount</b>	
At 31 March 2017	507,489
At 31 March 2016	444,049

### 15 Stocks

	2017 £	2016 £
Goods and goods for resale	5,281	9,809

### 16 Debtors

	2017 £	2016 £
<b>Amounts falling due within one year:</b>		
Trade debtors	9,022	7,306
Other debtors	101,969	157,317
Prepayments and accrued income	35,445	32,539
	146,436	197,162

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

	2017 £	2016 £
Other taxation and social security	22,476	23,169
Trade creditors	28,260	29,819
Accruals and deferred income	43,785	55,240
	94,521	108,228

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

### 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 or loss in respect of defined contribution schemes was £18,491 (2016 - £16,478).

### 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 2016 £	Movement in funds		Balance at 31 March 2017 £
		Incoming resources £	Resources expended £	
Research	67,085	14,503	(14,900)	66,688
Big Lottery Fund (Merseyside and South & West Yorkshire)	6,298	38,454	(44,752)	-
Specialist HD Advisory Service (SHDA)	19,000	314,882	(333,882)	-
Big Lottery Fund (Surrey)	7,040	41,109	(39,899)	8,250
Welsh Lottery	4,755	34,698	(39,453)	-
Breaking Down Barriers	-	5,000	(1,491)	3,509
Welfare Grants	-	2,000	(2,000)	-
Lord Cozens-Hardy Trust	20,000	-	(20,000)	-
Juvenile Huntingtons Disease	-	1,193	(1,193)	-
Exemplar Health Care	-	45,000	-	45,000
JHD Weekend	-	10,000	-	10,000
	<u>124,178</u>	<u>506,839</u>	<u>(497,570)</u>	<u>133,447</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 2017

### 19 Restricted funds

(Continued)

#### Breaking Down Barriers

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

#### Welfare Grants

A Grant was received from Sheffield Town Trust to be spent on Welfare Grants in the area.

#### Lord Cozens-Hardy Trust

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

#### 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 are to be spent on the JHD weekend in May 2017 including £1,000 from Skleton Bounty Trust, £2,500 from Jane Hodge Foundation.

### 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 2016 £	Movement in funds		Balance at 31 March 2017 £
		Incoming resources £	Resources expended £	
Special projects fund	270,000	-	-	270,000
Branch funds	116,695	85,977	(105,110)	97,562
	<u>386,695</u>	<u>85,977</u>	<u>(105,110)</u>	<u>367,562</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 leaving a balance of £270,000 carried forward. The fund will be 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 2017

### 21 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
	£	£	£
Fund balances at 31 March 2017 are represented by:			
Tangible assets	7,240	-	7,240
Investments	507,489	-	507,489
Current assets/(liabilities)	361,191	133,447	494,638
	<u>875,920</u>	<u>133,447</u>	<u>1,009,367</u>

### 22 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.

	2017 £	2016 £
Aggregate compensation	<u>182,514</u>	<u>205,246</u>

#### Transactions with related parties

Mr NM Heath is a partner in the firm RPG Crouch Chapman LLP, Chartered Accountants, RPG Crouch Chapman LLP, Chartered Accountants received fees for payroll services of £3,300 (2016: £3,500).

### 23 Contingent asset

The charity is a residuary beneficiary of an estate subject to a life tenancy. The value of the entitlement as at 12/06/2017 was £53,356 (16/06/2016 : £46,693).

# HUNTINGTON'S DISEASE ASSOCIATION

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2017

### 24 Branch funds

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

	2017 £	2016 £
Cash balances at 1 April 2016	116,695	103,838
Receipts in year	85,978	125,141
Less :		
Local welfare grants	(19,439)	(20,989)
Sent to head office	(41,287)	(36,234)
Branch activities, local newsletters, equipment, research etc	(44,384)	(55,061)
Cash balances at 31 March 2017	97,563	116,695

### 25 Cash generated from operations

	2017 £	2016 £
Surplus for the year	74,805	62,232
Adjustments for:		
Investment income recognised in statement of financial activities	(16,219)	(14,652)
(Gain)/loss on disposal of investments	(1,116)	4,329
Fair value gains and losses on investments	(62,605)	19,726
Depreciation and impairment of tangible fixed assets	4,964	5,047
Movements in working capital:		
Decrease/(increase) in stocks	4,528	(852)
Decrease/(increase) in debtors	50,726	(124,001)
(Decrease)/increase in creditors	(14,055)	2,000
Cash generated from/(absorbed by) operations	41,028	(46,171)