

Huntington's Disease Association

We'll be there

Annual Report

2015-2016



Contents

3	Our year 2015-2016
4	What is HD?
5	Our year in numbers
6-7	Specialist HD Advisory Service
8-9	Supporting young people
10-11	Training and education for healthcare professionals
12	Telephone helpline
13	Welfare programme
14-15	Facilitating peer support
16-17	Raising awareness
18-19	Our fundraising
20-21	Our finances
22	Acknowledgements
23	Our people

About the Huntington's Disease Association

Our 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.

Our objectives

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

Bankers

NatWest Bank Plc, 66-68 St John's Road, Clapham Junction, London SW11 1PB

Auditors

Duncan Sheard Glass, Castle Chambers, 43 Castle Street Liverpool L2 9TL

Policy

The Huntington's Disease Association is governed by an Executive Council; a management body elected by democratic vote at the annual general meeting. Overall policy is made at the annual general meeting, managed by the Executive Council and implemented by the Association's staff. Priorities set at the annual general meeting are reflected in the work of the Association.

Huntington's Disease Association

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Our year 2015-2016

Every family's version of the Huntington's disease story is different. But the devastating impact the disease has is the same.

The Huntington's Disease Association works to support families and individuals affected by HD. This is practical, hard, caring work, in the real world, with real families, and it is absolutely vital. We know that many people can find it incredibly hard to access appropriate care and the services they need, while juggling care commitments, and everything else which people have to think about, so we want to be able to help.

As a volunteer (as all of the trustees are), and a HD family member myself, I am consistently impressed by how much impact a relatively small (but brilliant!) team can have. The numbers in this report really highlight that. But of course behind every one of the numbers is a real life story, and we want to be able to do much more.

Advances in medicine certainly provide real hope in the future, but the HDA needs to be able to help

people right now, in communities across England and Wales.

I would like to pay tribute to the hard work of everyone who makes it possible for the HDA to do this vital work.

From the 23 specialist HD advisers, the Specialist Youth Worker, the small team in head office, and the fundraising team who support them, and to every individual around the country who has fundraised, donated, volunteered, helped at support groups, or pointed someone in the direction of the HDA for help. You are amazing. Thank you.

I hope you find this report as valuable as I have.

Andrew Bickerdike Chair of the Executive Council



2015-2016 was a really exciting and challenging year. The main focus of our work continued to be improving the quality of life for families affected by HD. Our Specialist HD Advisory Service, along with our youth worker, supported individuals and families in a variety of settings. We had almost a complete change of personnel in the fundraising team which brought a wealth of new ideas to enhance income with the aim of further developing the service.

Raising awareness of HD and increasing understanding of the disease was a prominent feature of our work. We continued to deliver specialist training to help improve knowledge and understanding of the complexities of HD and improve standards of care. We advised on scripts and on set during the filming of BBC1's Casualty HD storyline which helped bring an understanding and awareness of HD to millions who had not heard of it before. During our annual awareness week in May we paid particular attention to raising awareness of end of life care for people with Huntington's disease.

We remained committed to supporting research to develop care and medication for people with HD with the hope of one day finding an effective treatment.

Our branches and support groups did a fabulous job supporting others in a similar situation to themselves and offering peer support.

Looking ahead to next year, improving standards of care for people impacted by HD will be a prominent feature. We will continue to raise awareness of HD with new campaigns planned, including a HD photo documentary. We also plan to improve our website, information and publications to present information about HD and our services in a clearer way that is accessible by all.

Working with families affected by HD and watching their courage and resilience remains the inspiration and motivation for our charity. This annual report showcases the real difference that the HDA's work has made to the families living with Huntington's disease throughout England and Wales.

Cath Stanley Chief Executive



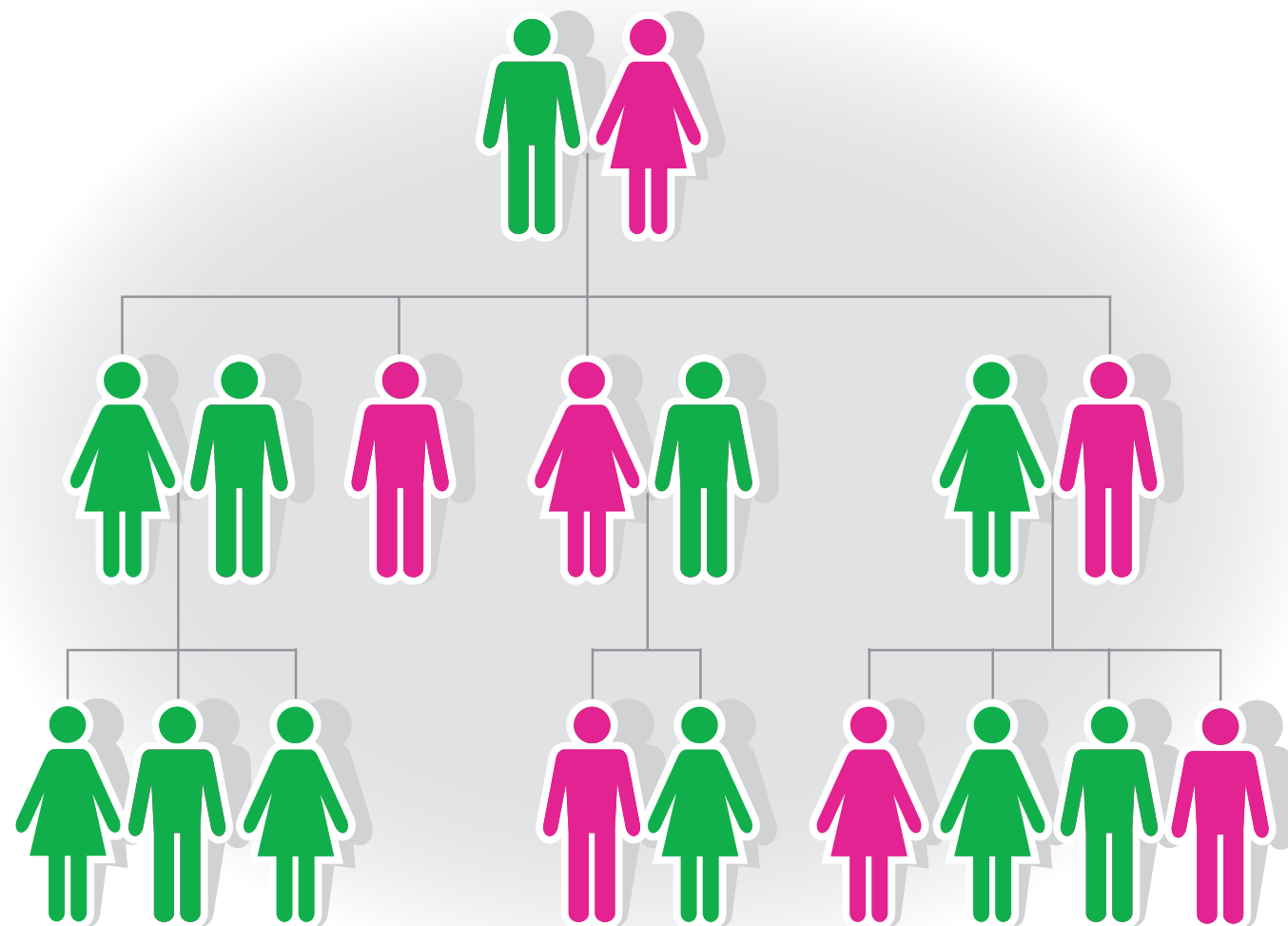
What is Huntington's disease?

Huntington's disease (HD) is a degenerative genetic disorder of the central nervous system that affects people's physical, behavioural and cognitive abilities.

Each child of a parent with Huntington's disease has a 50% chance of inheriting the faulty gene; it doesn't skip a generation, so if a person tests positive they will, at some stage, develop HD. Symptoms of the disease typically start between the ages of 30 and 50 and the duration of the disease varies between 10 and 25 years, though HD can affect either sex at any age.

HD has been described as like having Motor Neurone disease, Schizophrenia, Parkinson's and Alzheimer's disease all at the same time. It is an extremely challenging and complex terminal illness that needs expert care and round the clock support in the later stages.

Doesn't have the HD Gene Has the HD Gene



It's easy to see how HD can spread from generation to generation.

With a 50% chance of inheriting the disease from a parent with HD, **it's like tossing a coin.**

Our year in numbers...



Specialist Huntington's Disease Advisory Service

A Huntington's disease diagnosis can be truly devastating and its implications can have a ripple effect across entire families. Our aim is to ensure no-one has to face HD alone.

Our team of 23 Specialist Huntington's Disease Advisers (SHDAs) provide dedicated support, advice and information across the length and breadth of England and Wales, to make sure anyone facing a HD diagnosis or living with the condition has the knowledge and skills to tackle life with HD.

The key aims of our service are to:

- improve quality of care for people with HD
- reduce isolation and improve quality of life
- empower individuals, carers and professionals through support, advice and training
- increase knowledge and understanding of HD while raising awareness of the disease

13,809 people across England and Wales benefitted from our Specialist HD Advisory Service in 2015-2016

Home visits

As Huntington's disease symptoms can cause paranoia, apathy and denial, this, coupled with mobility problems, can make it difficult for people with HD to get to medical appointments. Our Specialist HD Advisers arrange to meet families at home, where they feel more comfortable, and where our advisers can get a better understanding of their needs. Through these visits, over the last year our advisers have provided practical information about the day to day management of HD, identified and advised on services available to improve quality of life, and provided emotional support to help families through a tough time.

95% of people we visited said their home visit helped

Support for carers

Life can be incredibly difficult for people caring for a loved one with HD. Our advisers use a holistic approach to help the husbands, wives, siblings, parents and other family members who have the hard and often thankless task of being a HD carer. To help reduce the stress and anxiety this can cause, we held informal carers groups, provided practical and emotional support, and put people in touch with other carers in a similar situation who could relate to each other's experiences.

“(As a full time carer to a wife with HD, our adviser spent time with me to check that I'm coping with the situation and enquired about my wellbeing. This was very good as a lot of professionals concentrate on the sufferer only.)”

Specialist HD clinics

Finding a specialist with clinical knowledge can be a real challenge for families new to HD, as many healthcare professionals, such as GPs, aren't aware of services available for this rare condition. To help combat this, many of our advisers have co-ordinated or assisted in the management of dedicated HD clinics, attended by experienced and knowledgeable professionals including consultant neurologists, psychiatrists, physiotherapists, speech and language therapists, dietitians and occupational therapists.

With limited specialists in the field of HD, clinics are mainly held in larger cities in across the country, meaning that families can have to travel significant distances to attend. Throughout the year, our advisers helped to synchronise the care required at home with the complex clinical health needs of each HD patient.

Our Specialist HD Advisers co-ordinated and attended over **263** HD clinic sessions, accessed by over **2,000** families and attended by HD healthcare experts

Co-ordinating multi-disciplinary teams in the community

The vast majority of people experiencing symptoms of HD need care and attention in the community. By increasing the number of multidisciplinary health and social care teams involved in patient care, including district nurses, community mental health teams and social services, our advisers gave families living with Huntington's disease the support network needed to improve their quality of life and cope better with HD symptoms. Through this we helped to keep families together for longer and avoid unnecessary hospital stays.



Vulnerable adult and child protection

We are committed to protecting the welfare of people with HD and their families. In 2015-2016 our advisers were involved in 58 adult and 37 child safeguarding cases, including representation and advocacy at statutory meetings and referrals to protection services.

As a result of support from our Specialist HD Advisory Service:

94% gained a better understanding of the support available to them

77% felt more able to cope with their situation

64% felt less isolated

“(I have much more of an understanding of HD following the adviser's visit. From the leaflets he gave to me to read I am learning things every day. Remembering all the things the adviser spoke to me about is helping.)”

Care worker

“(Our Specialist HD Adviser's visit is very important to us. She always provides emotional support and good advice and makes us feel we are more able to deal with our situation.)”

Family

“(The advisory service has helped me a great deal. A year ago I was homeless and suicidal and my adviser helped me put my life back together again.)”

Person with HD

“(Our adviser always puts things into perspective, especially at times when things seem pretty low. Her advice is always very professional and positive for both myself and family members. She is helping us get over the first hurdles following a positive test result and is proactively recommending small steps forward to help cope with the situation.)”

Family

“(Our adviser was truly wonderful towards us and we learnt far more in the time she spent talking with us than we had gleaned from any other professional. She explained and advised on so many aspects of the disease and we both felt reassured that now someone was on our side.)”

Family carer

Supporting young people

Youth engagement service



Our Youth Engagement Service, delivered by our Specialist Youth Worker Adam Cho, continued to be an invaluable support for young people aged 8-25 living in a family affected by HD.

In 2015-2016 Adam visited a total of 153 young people either in their schools or homes across the whole of England and Wales, to provide additional support. The service is confidential allowing the young people the opportunity to talk about the effects HD has on their family.

Because of the nature of HD, families and children face discrimination due to fear, stigma and misunderstanding of the disease.

The person is often thought to be drunk because of the difficulties in walking, slurring of speech, apathy and problems with mental health and cognitive thought process. This is sometimes overwhelming for young people. Add this to the fact children are 50% at risk of inheriting the disease, they have to care for a parent knowing that potentially they could end up the same way. Adam is fully aware of this pressure on children as carers and ensures the right support is in place for the family as well as the individual and signposts and refers to the appropriate agencies.

Youth engagement continues to be a priority for the HDA as it allows us to influence future generations of individuals, so they approach the disease in a fully informed way and are able to talk with confidence about the future and how this disease can be managed.

“Adam Cho has been indispensable for me. The kids like him and open up to him because they know he understands and is fun. I feel better knowing they have him.”

203 young people and 40 young carers were supported across England and Wales by our Specialist Youth Worker

153 young people visited at home or in school by our Specialist Youth Worker



Summer camps Supported by Children in Need

In 2015-2016 we ran two weekend summer camps in Staffordshire and Kent for children aged 9-15 who have family members with HD. Having HD in the family often means that children have to grow up quickly with many caring for their loved ones as well as trying to fit in going to school and maintaining friendships.

These camps were an opportunity for the 26 young people that attended from all over England and Wales to have fun, let go and spend some time with their peers in a place where HD was not the focus.

Young adults weekend

In April 2015 we held an event for young adults between the ages of 18-35 who have HD in their family. This unique weekend welcomes people who are at risk of inheriting HD, who may or may not have decided to have the genetic test, as well as their partners.

This annual event is always popular, as it gives people the chance to discuss difficult topics such as genetic testing, caring responsibilities and family planning with HD experts and peers, away from any family pressure they might be experiencing.

“I really enjoyed hearing about other people's personal journeys because I can draw comparisons between what they have been through and compare it to my own life. I also appreciate talking to others in a similar situation to me – I am not alone!”

Specialist JHD Adviser

We are the only Huntington's Disease Association in the world to have a specialist dedicated Juvenile Huntington's Disease Adviser.

JHD is a rare and devastating form of a complex and predominantly adult onset disorder, meaning families with children who have the Juvenile form of HD can be even more isolated. In 2015-2016, our JHD Adviser, Helen Santini, supported 50 children affected by JHD and their families, providing specialist knowledge and guidance, and facilitating peer support.

We continued working with Dr Oliver Quarrell and Rachael Cann at Sheffield Children's Hospital to involve JHD families in a project to understand families' need and identify if there are better ways of delivering services and providing care. They are looking at options such as virtual clinics for JHD patients. Our adviser Helen played a crucial role in recruiting participants for the study and conducting interviews – we hope this will lead to improved services for families living with JHD across the country.

50 families affected by JHD received support from our Specialist JHD Adviser

JHD family weekend

We held our annual JHD Family Weekend at the Calvert Trust, a specialist disability centre where children affected by JHD can participate in activities they wouldn't get the chance to do elsewhere.

The weekend offers a unique opportunity for families to come together for a weekend of fun, learning, peer support and empowerment. It gives siblings the chance to meet others who are in a similar situation, as their friends at school are unlikely to be able to relate to the challenges they experience every day.

Most families with children affected by JHD will never have met another family or child with the illness. Most of the professionals involved in their child's care will never have cared for anyone with JHD so often the parent becomes the specialist teaching about their child's care. It's hard to describe the amount of stress and pressure these families experience. For parents, it offers much needed respite alongside specialist training from our advisers so they are better equipped to support their terminally ill child.

“Amazing weekend, thanks to all the staff who have made it a wonderful, fantastic, positive weekend which we all thoroughly enjoyed.”



Training and education for health care professionals

We made strides in increasing knowledge and understanding of Huntington's disease amongst healthcare professionals in 2015-2016.

Families regularly say that one of the biggest challenges they face is lack of awareness and understanding of HD when they are looking for diagnosis, treatment and ongoing care. Experience tells us that many professionals will have never met, cared for or treated anyone with HD before. This means often people with HD are not cared for appropriately because doctors, nurses and allied healthcare professionals have a lack of understanding of their symptoms, behaviour and needs. In many cases, roles can become reversed, with the patient teaching professionals about the disease rather than receiving the care and support they sought.

Throughout the year our Specialist HD Advisers delivered training and information sessions to address local needs, ranging from a general overview of the disease and its symptoms, to bespoke sessions on topics such as end of life care, understanding behaviour, eating, swallowing and diet, genetic implications and mental illness.

Our advisers also organised study days and conferences to give a more in depth understanding. The aim of each session was to improve understanding of HD symptoms and its progression to help professionals provide a better service and meet the needs of HD patients in their everyday practice.

As a result of the training and information sessions delivered by our Specialist HD Advisers:

100% reported an increased understanding of HD

99% felt more able to care for HD clients

98% positively rated the training and their trainer

What our delegates learned from their HD training:

- “ **I gained better knowledge and understanding of the disease.** I learned why my patients do or do not do certain things and the importance of being patient with them.”
- “ **I learned to take things one step at a time** with HD patients and I will definitely look to change the way I work with some of my clients now.”
- “ **I learned that recognition memory works better in HD than recall of information,** and that HD patients have involuntary movements rather than aggressive outbursts.”
- “ **It was good to be reminded of the person behind the disease** and the impact of the disease on the whole family.”

Our Specialist HD Advisers provided **414** training and information sessions to **4,303** healthcare professionals throughout the year.



“ I found the course extremely useful, informative and insightful. It has significantly increased my knowledge and understanding and provided me with some useful ideas to introduce into the care home I manage.”

HD Certificated Course

We ran two in-depth certificated courses in London and Liverpool, aimed at professionals working with and supporting clients with HD.

78 delegates attended across the two courses and benefitted from presentations from a number of world renowned experts in the field of HD. We provided comprehensive teaching and discussions on key subjects including genetics, research, psychiatry, neurology, occupational therapy, physiotherapy, diet, communication and swallowing.

In addition to improving their knowledge and skills, delegates were able to network with peers working in similar environments to share their own stories of working with HD patients and learn from each other's experiences.

97% felt their knowledge and understanding of HD had increased after attending the course

98% felt they were more able to carry out their work with people affected by HD after attending the course

Telephone helpline



Our telephone helpline is available to anyone affected by Huntington's disease, whether they have HD themselves, or are at risk, and need some emotional support, or are a concerned carer, friend or family member in need of advice on how to help their loved one. Our advisers help with a range of questions, helping to avoid a crisis situation or with an ongoing concern. Sometimes all our callers need is a supportive listening ear.

In 2015-2016 we received over 18,000 calls to our helpline, which has helped people struggling to cope, feel better informed and more in control. Callers have described it as "a lifeline", "cheerful and encouraging" and a "wonderful support."

Our helpline is also an essential resource for healthcare professionals, such as Occupational Therapists, Mental Health and Neurology Nurses, Physiotherapists and GPs, who work with patients with HD and need guidance on how to manage symptoms, behaviours and treatments.

“As Huntington's is rare, nice to talk to someone who understands.”

“I feel happier knowing that the HDA is just a phone call away.”

“At the moment, all this is very new and still somewhat 'raw' to us. It is truly fantastic that I know that our adviser is available on the phone if I or my husband need advice. I genuinely do not know how we would cope emotionally in particular, if this service was not available to us.”

“The specialist help from the advisers on the phone on how to best deal with certain situations has been fantastic. It's great to have someone to contact in a crisis or just for a chat.”

Welfare programme

We know how challenging it can be to live with HD, but all the more so without the right resources, equipment and support. Through our welfare programme, people with HD can apply for household aids, specialist equipment and replacements for items damaged as a result of their HD symptoms that they would otherwise be unable to fund themselves or through their local authority.

Because of the progression of its symptoms, many people with HD and their carers have to give up work, meaning their income can suffer and making it hard to afford the things that would improve their quality of life.

In 2015-2016 our welfare programme helped 51 families by funding the purchase of items such as a specialist wheelchair, an iPad with communication software and a rise and recline chair.

£14,465.19 provided to improve quality of life for HD families through our welfare programme

The HDA's welfare fund enabled Alan and Jenny to buy two single beds. Alan had worried constantly about his night time chorea disturbing Jenny. The grant meant Alan could now settle knowing he wouldn't disturb Jenny and Jenny was able to get a good night's sleep and was fully rested and ready to care full time for Alan.

The welfare fund recently enabled a young man to purchase a lego architecture studio - this has helped immensely with his mental wellbeing and is proving to be a positive distraction and something he and his children can focus on together.



“I would like to thank you, for grant that I have recently received. The Lego Architecture Studio will enable me to bring two leisure pursuits together as I would like to visit local architectural sites photograph them and then try to represent them in Lego.”

Facilitating peer support

Branches and support groups

In 2015-2016 we supported a total of 30 support groups and 29 HDA branches across England and Wales, with 4 new support groups being established in Doncaster, Lowestoft, North Yorkshire and Wirral.

Many people who are new to HD find peer support invaluable in helping them come to terms with the discovery of HD in their family. For others, it is a chance to share and gain tips and advice on how best to care for their loved ones with HD, and to share their experiences and socialise in an environment where everyone understands the challenges each other is facing.

Our Specialist HD Advisers attended 159 branch and support group meetings in 2015-2016 to offer advice and guidance about HD and to highlight the help and support available from the HDA for all the family.

Branches and support groups are run locally by volunteers and we are very grateful to everyone who gave up their time in 2015-2016 to organise the wide range of meetings, trips, activities and fundraisers that took place throughout the year.

Case study

"When HD first manifested itself in my family, I was SO lucky to find the North Kent HDA Support Group, which held monthly meetings only half an hour's drive away. This was a revelation to both myself and my sister, to know there were others facing the same dilemmas and decisions as us. To be able to chat to them in a relaxed atmosphere, was reassuring and we became regular attendees. The group showed us that we weren't the only ones to have HD looming large (we'd never heard of it before) and the feeling of isolation soon left us with the many friends we made supporting each other at the meetings.

We learned more about the illness through talks given by a genetic counsellor from Guy's Hospital and other professionals, gradually becoming better informed. Over the years we met others affected by the illness at coffee meets, cream teas and on boat trips. Without the support group, living with HD in the family would have been a whole lot different."

Sandra Abbott, Trustee and Chair of North Kent Support Group



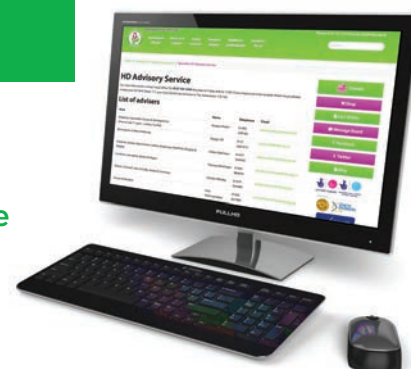
Peer support online

Our online message board is a unique resource for the HD community, which enables people to post questions about every aspect of HD imaginable and gain insights and practical tips from others in a similar position living with HD.

In 2015-2016, we had 751 new users join our online community with 421 new conversations about topics ranging from coping with denial of symptoms, to options for having a family and how to manage eating and swallowing problems.

4,997 members of our online message board community shared and received peer support

"Thank you to everyone who shares here and the wonderful members who respond with such wise and kind words of advice and support. Just visiting this page makes me feel better, if not a little sad too of course. I have the same problems such as worrying about little tics or twitches and to hear that I'm not alone in this is very comforting."



Family Conference and AGM

From 16 – 18 October, we held our annual Family Conference and AGM, which brought over 200 people affected by or involved with HD to Telford for an insightful weekend.

As well as hearing from HD experts, families were able to let their hair down and enjoy a quiz and dinner dance after a day of talks and exhibitions.

Discussions about major strides in HD research meant there was a real buzz at the event. Families felt hope for the first time of a future where the onset of HD could be delayed for their loved ones and future generations affected by the HD gene, if the trials are deemed a success.

"It is always a mix of happy and sad to come to the HDA Family Conference. It's good to be properly updated to be ready to spread the word. It's sad to watch folks struggle who used to stride. To have a weekend each year when we are wrapped up by the HDA advisers is extraordinary. You are knowledgeable, accepting, insightful, warm, thoughtful and skilled. Please know you are appreciated."

"Hearing Ed's update and learning from Dr Robertson. Whilst bright consultants are on the case, knowledge and care will continue to improve and families will gain confidence to ask and ask again if need be."

"Meeting up again with friends from different branches who I've enjoyed seeing each year plus all the presentations plus evening events."



"Letting my hair down and relaxing and meeting new people in the same situation."

"Lovely atmosphere - caring, accepting, friendly. Some great talks."

"Being with others who understand. The talks by Dr Dene Robertson and Dr Ed Wild and the party! Liked the way emotional videos interweaved research as topic so emotive for us as families."

Raising awareness



Primetime storyline for HD

We were delighted to work with the team behind BBC1's Casualty on a storyline featuring Huntington's disease, which ran during its primetime Saturday night slot from November 2015 to spring 2016.

The emotive plot saw adopted brothers and doctors at the hospital, Cal and Ethan, reunited with their biological mother Emilie, who was living with HD. We worked with the BBC researchers, writers and production staff to help them depict the disease and the challenges faced by HD families. We arranged for the cast and crew to meet people living with HD to get a better understanding of the disease and were invited on set to provide advice and guidance to the actors during filming.

This was an incredible opportunity to raise much needed awareness of Huntington's disease outside the HD community.

According to the Broadcasters' Audience Research Board, viewing figures for the Casualty episodes were in excess of 5 million. Whilst some of those watching will have a good understanding of the disease already, for millions, it will have been the first time they had heard of HD. It only takes a discussion about the episode the next day with family and friends for this understanding and awareness to spread much further.

“This storyline is brilliant! It's about time HD was spoken about and not hidden.”

Facebook follower

“It has been an extremely rewarding and important storyline for us. We really hope that Emilie's story and subsequently Cal and Ethan's story will help to highlight and raise awareness of HD and continue to help those affected by the disease.”

Ross Southard, Casualty researcher

VIEWING FIGURES

Episode 16	6.57 Million
Episode 17	5.35 Million
Episode 20	5.86 Million
Episode 22	5.97 Million
Episode 26	5.92 Million
Episode 27	5.82 Million
Episode 28	6.46 Million
Episode 29	5.68 Million

Information sourced from: <http://barb.co.uk/viewing-data>



750 new Facebook likes during the storyline

Improving understanding of end of life care

Our annual Awareness Week returned from 11 – 17 May 2015, with a focus on end of life care.

Late stage Huntington's disease can be extremely distressing for the person with HD, their family and their carers, so we wanted to highlight how care can be improved to help families at this difficult time.

We delivered 60 specialist training sessions to over 540 people to help improve the quality of care provided to people with end stage HD.

We also provided a specially created booklet on end of life care, covering issues such as communication, managing late-stage symptoms and coming to terms with loss, to over 500 health and social care professionals and carers.

Over **500** Care in Advanced HD booklets distributed
Over **60** specialist training sessions provided



Increasing awareness online



639 new followers on Twitter, taking our total to 2,021 followers



2,506 new likes on our Facebook page took our total Facebook followers to **9,400**



Our first video appeal 'Caring for Generations' reached **43,722** people on Facebook

Supporting HD research

We continued to support research studies into Huntington's disease, actively promoting involvement in studies and sharing research news with our members, who are keen to learn of any new developments.

We encouraged participation in Enroll-HD, an international observational study of Huntington's disease, which aims to learn more about HD in order to speed up the development of therapies.

We continued to maintain excellent links with the Huntington's Disease Centres across England and Wales, working with staff from the research teams to share research insights with HDA members and deliver presentations at our conferences for healthcare professionals and families.

We continued our partnership with HDBuzz, a website of reliable, impartial, easy-to-understand information about HD research written by scientists, which gives our members fantastic insight into the development of potential treatments, and ongoing work to ultimately find a cure for Huntington's disease.

Our Head of Advisory Service, Bill Crowder, demonstrated his dedication to supporting HD research by enrolling as a healthy control participant for the HTT lowering clinical trial.



Our fundraising

Caring for Generations video appeal

In January we launched our first online fundraising campaign to support our Specialist Huntington's Disease Advisory Service.

The video reached 43,722 people through our social media channels and raised over **£7,000**. Huge thanks to the Saunders family for sharing their story of Huntington's disease in the video and helping us to raise much needed funds and awareness.



#giveatoss4HD

At our Family Conference and AGM in October we launched #giveatoss4HD – an innovative idea from dedicated HDA volunteer Jackie Harrison whose family lives with Huntington's.

Thank you to Jackie for creating this fantastic awareness raising campaign.

The coin toss was embraced across the HD community and we received some fantastic videos to share on our social media channels.



Lady Harewood's Christmas Appeal

Our Patron the Dowager Countess of Harewood raised over £2,000 in her first Christmas appeal for the HDA.

With the help of her two miniature Dachshunds, Lulu and Minnie, who featured in the appeal, this fantastic support helped us to continue to support families affected by Huntington's disease so they do not have to face it alone.

Photo courtesy of living portraits.co.uk



Virgin Money London Marathon 2015



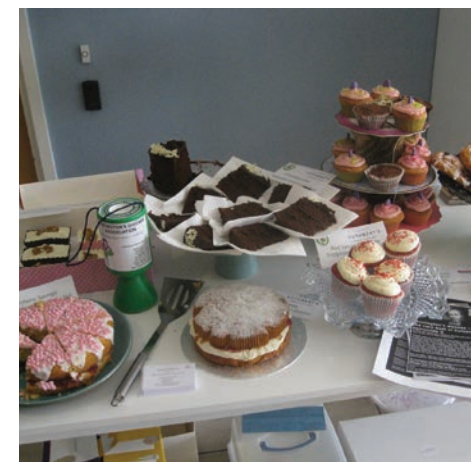
The Virgin Money London Marathon is a highlight in the HDA fundraising calendar with tough competition for places each year. 2015 saw 27 runners conquering 26.2 gruelling miles raising a fantastic **£51,158.92** to help families facing Huntington disease.

Cake That, HD!

In May 2015 we launched Cake That, HD!, a fundraising campaign encouraging people to host a cake sale during our Awareness Week to raise money for our advisory service.

We were delighted to hear from John, who cares for his wife Rose who has Huntington's disease. John was having a tough week when he decided to take part in Cake That, HD! but after initially raising £40 by selling cakes at his local pub, he rushed home to make another batch.

John told us he loved the challenge of baking and getting his community to support the HDA, and that it was the welcome distraction he needed. The initiative raised a brilliant **£3,792.83** and many of our star bakers told us they are already planning for next year!



Supporting the Huntington's Disease Association

There are lots of reasons why people choose to support the Huntington's Disease Association and we rely on the enormous generosity of individuals and organisations to make sure we can be there to support anyone affected by Huntington's disease.

Penelope began supporting the HDA seven years ago, following the death of her husband Oliver, who lived with Huntington's disease for many years. She has two children and five grandchildren at risk of HD.

Penelope said: "I wanted to help the HDA address the stigma of the disease, supporting an organisation that is an expert in all aspects of Huntington's disease. The HDA uses all funds raised for the benefit of families living with Huntington's. In a small way, I am making a difference to the stigma associated with the disease by enabling them to train more healthcare professionals on the disease progression and helping families live a full life with Huntington's. By donating regularly, it also keeps me connected with the organisation."



Penelope Worsley and her daughter Georgina

Thank you to everyone who donated in 2015-2016 – your support ensures no-one has to face Huntington's disease alone.

Our finances

We are very grateful to everyone who is supporting us financially. We have a broad range of income streams so we are not reliant on one source of funding. This is very important to us as it means we can be independent and are less vulnerable to changes in one area of income.

How we use our money

We spent **£1.6 million** in 2015-2016

We spent **£1.4 million** on delivering our charitable work

The cost of generating funds was **£173K**

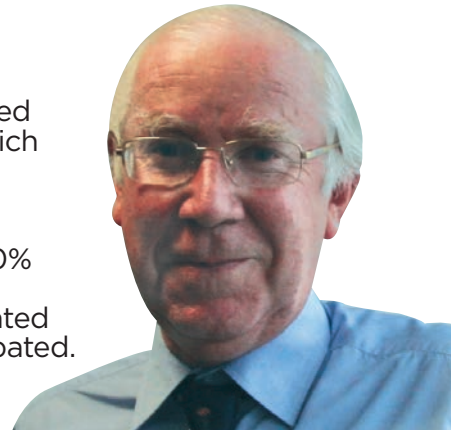
For every **£1** we received in donations we spent **97p** on our Specialist HD Advisory Service

For every **£1** we spent on generating funds we raised an average of **£9.25**

Treasurer's Report 2015-2016

The accounts for the year show a substantial improvement as compared with 2014-2015. The Charity achieved an overall surplus of £62,232 which compares with a deficit in excess of £140,000 in the previous year.

Income has grown substantially to £1,677,940 which amounted to a 20% increase on the previous year reflecting additional contributions from general fundraising, grant making bodies 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.

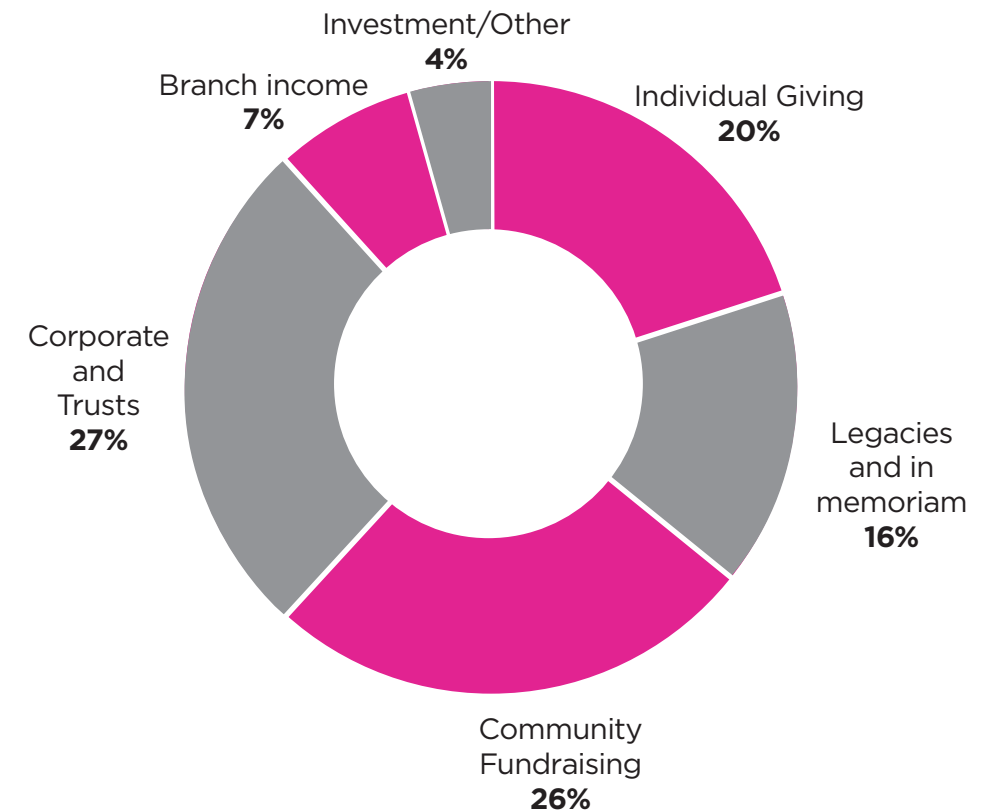


Expenditure stabilised in accordance with the strategic plan. Total costs amounted to £1,591,653 which included salaries and direct staff costs of almost £1.1m. The importance of social media and publicity has been recognised and we have acted to strengthen our fundraising team to ensure that we can take advantage of opportunities and maintain the highest ethical standards.

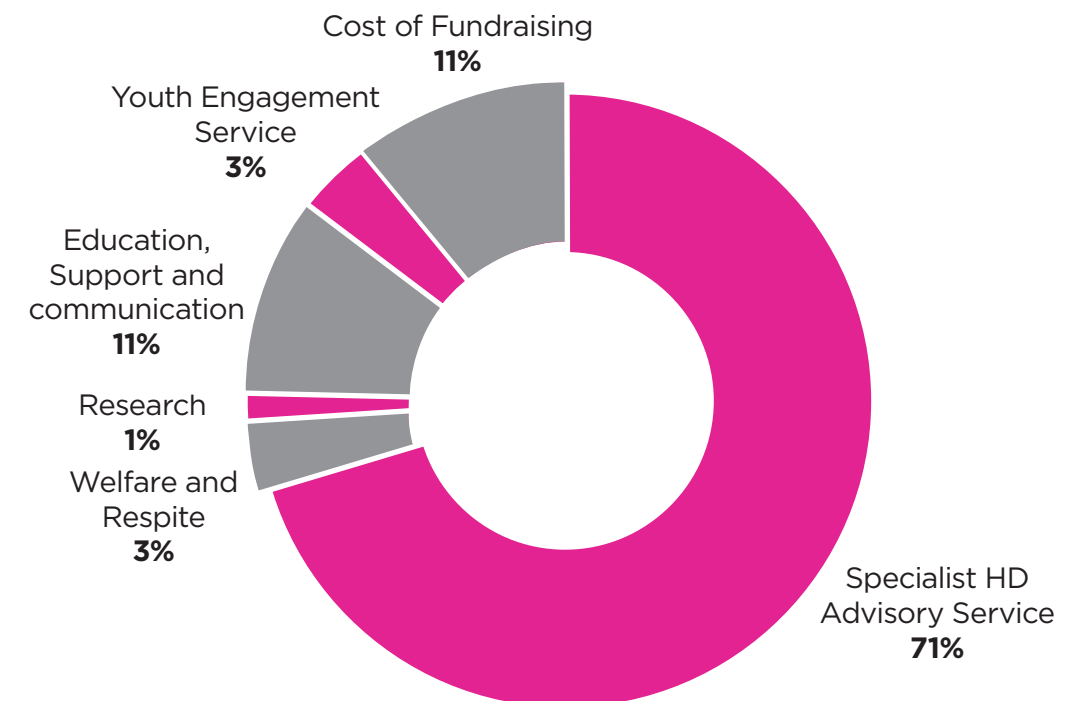
Looking forward from the balance sheet date, legacy income has boosted our cash reserves to a level that provides a buffer in the event of short term fluctuations in giving and grant funding. This gives the Trustees confidence that current activities can be sustained, improvements made and new initiatives considered.

Nick Heath
Treasurer

Our income



Our spending



Acknowledgements

We are incredibly grateful to all our supporters whose generous donations have a huge impact across all aspects of our work. We extend our sincere thanks to the following supporters, including those who have chosen to remain anonymous.

Grant funders, trusts, foundations and corporate support

- The Albert Hunt Trust

The Alice Ellen Cooper-Dean Foundation

The Barbour Foundation

The Benham Charitable Settlement

Bernard Lewis Family Charitable Trust

Birmingham City Council

BBC Children in Need

BG Group

Big Lottery Fund (Wales)

Big Lottery Fund - Reaching Communities

The Birmingham District Nursing Charitable Trust

Blackburn with Darwen CCG

The Building Forum for Devon and Cornwall

Community Foundation for Calderdale – Health Connections

Cambridgeshire and Peterborough CCG

Cathedral Lodge

The Clive and Sylvia Richards Charity Limited

Cotteswold Lodge

Dorset CCG

Dudley Metropolitan Borough Council

The Dyers’ Company Charitable Trust

Eastes Lodge

The Earmark Trust

East Staffordshire CCG

Essex Community Foundation – Yellow Car Charitable Fund

Exemplar Healthcare

The February Foundation

Fowler Smith and Jones Charitable Trust

The Hadrian Trust

Hampshire County Council

The Hospital of God at Greatham

The Hospital Saturday Fund
- John James Bristol Foundation

The Leach Fourteenth Trust

Lodge of Rectitude and Harmony

The Lord Cozens-Hardy Trust

The Miss Pannett Charitable Trust

The Norman Family Charitable Trust

North Derbyshire CCG

Northern, Eastern and Western Devon CCG

The Oakdale Trust

The Patricia and Donald Shepherd Charitable Trust

P F Charitable Trust

PJ Care

The RCN Foundation

The Roger Raymond Charitable Trust

The Sandford Trust

The Schuh Trust

Silverfleet Capital

The Simon and Philip Cohen Charitable Trust

Sir James Knott Trust

South Southern Central CCG

St Andrews Healthcare

Sunderland City Council

The Sunrise (Sidmouth) Charitable Trust

Susan Dennison and Jean Wilson Education Trust

The Sir James Reckitt Charity

Telford & Wrekin Council

Telford & Wrekin CCG

The Tempests of Broughton Charitable Trust

Walter Farthing (Trust) Limited

The Wixamtree Trust

Zurich Community Trust

Special thanks

To the following who have donated their time and expertise to support the HDA in fulfilling its mission of helping families and individuals impacted by HD.

- Alex Reid

Carol Royle

Cuthbert’s Bakehouse

The Saunders Family
- Les Shan

Costco

Travis Perkins Plc brand team

Our people

Patrons

- The Dowager Countess of Harewood

Tony Hadley

Shane Richie

Executive Council (Trustees)

- Heather Thomas, Chair (resigned October 2015)

Andrew Bickerdike, Chair (appointed December 2015)

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Peter Morse, Company Secretary

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Partnerships and affiliations

- The United Kingdom and Ireland Huntington’s Alliance

International Huntington Association

National Council for Palliative Care

Association of Medical Research Charities

Genetic Alliance UK

Neurological Alliance

Huntington's Disease Association

We'll be there



Get involved

Become a fundraising volunteer

Email: events@hda.org.uk or Tel: **0151 331 5445** for your fundraising pack

Get in touch

For advice and support or to speak to a Specialist HD Adviser

Email: info@hda.org.uk or Tel: **0151 331 5444**

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