



Huntington's  
Disease  
Association



Impact report  
2018



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## Our vision

A better life for anyone affected by Huntington's disease.

## Our mission

To enable everyone affected by Huntington's to live life to their full potential by:

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community and influencing decision makers

## Our values

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive



# Welcome

from the  
Chair and Chief Executive



2018 saw many achievements and developments at the Huntington's Disease Association. From our largest #TeamHDA running at the Virgin Money London Marathon to giving a voice to the Huntington's community in the fight for equal access to insurance; we have achieved a great deal throughout the year.

We have developed two new guides including one for GPs and primary care teams to help raise standards of care for people with Huntington's; we have also delivered bespoke training to over 2000 health and social care professionals.

Our advisory service continued to support families affected by Huntington's in their local communities, offering practical advice and information when needed. Our branch and support groups offered peer support and friendship through their networks.

In addition we are proud of our continued support of research with our funding of studies into physical therapy benefits, financial decision making and swallowing difficulties - three areas the Huntington's community have told us are important to them.

We joined forces with other organisations in the establishment of the All Party Parliamentary Group on rare genetic and undiagnosed conditions. This has led to discussions with MPs about the importance of equal access to medicines for people with rare conditions.

Our achievements this year have been made possible through our supporters, fundraisers, funders and volunteers. Thank you for helping us to bring Huntington's out of the shadows. We look forward to great things in 2019.

*Andrew Bickerdike*

*Cath Stanley*

# What is Huntington's disease?



Caused by a faulty gene and passed down through families



Affects both men and women



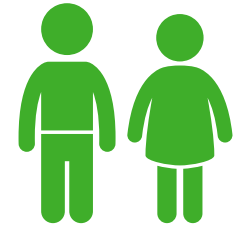
It changes the whole person - body, mind and behaviour



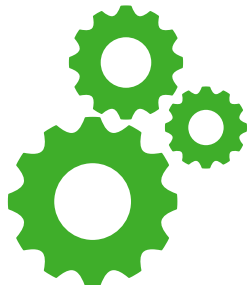
If a parent has the disease, their child has a 50% chance of inheriting it



Over 8000 people in the UK have Huntington's disease - that's 1 in 10000 people



Young people under 20 who show symptoms early have Juvenile Huntington's. This is a very rare form



It usually develops between the ages of 30 and 50 years old



Over 32000 people in the UK are at risk of developing Huntington's disease

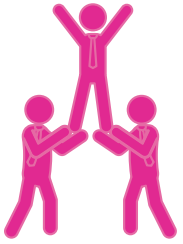


It is terminal. There is no cure. But, a recent breakthrough gives hope for potential treatment



# Huntington's Disease Association

## - Who are we?



Dedicated staff team of 38 people



Founded in 1971 when the charity began as a support group



An army of 700 loyal volunteers who help us raise awareness, funds and spirits



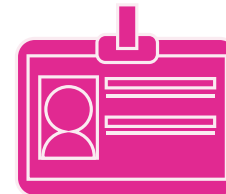
23 Specialist Huntington's disease Advisers across England and Wales



Around 50 committed branches and support groups across the country



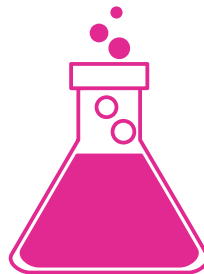
Two Specialist Huntington's Youth Workers



A membership of over 5000 - Huntington's families and professionals



The only dedicated Juvenile Huntington's Disease Adviser in the world



We fund selected studies and projects that aid people with Huntington's now and help people understand the disease better



Work closely with other organisations to give this rare disease a stronger voice

# How our advisory service helps families

## What can our advisers do for families?

Our advisers help people affected by Huntington's disease to live their lives to their full potential. The service is made up of 23 Specialist Huntington's Disease Advisers and two Specialist Youth Workers supporting people across England and Wales and a website full of useful tips and information.

## How can the advisory service help?

Living with Huntington's disease can be challenging, not just for those directly affected by the disease but also the people around them. Huntington's alters a person's mood and the way they behave as well as causing memory problems and involuntary movements. People affected by Huntington's can feel afraid, isolated and alone.

### We have five main strands to our service, these include:

- Face to face visits
- A dedicated telephone helpline
- Presence at specialist Huntington's disease clinics and multidisciplinary team meetings
- A website housing comprehensive explanations and guides to living with Huntington's
- The organisation of Huntington's disease events

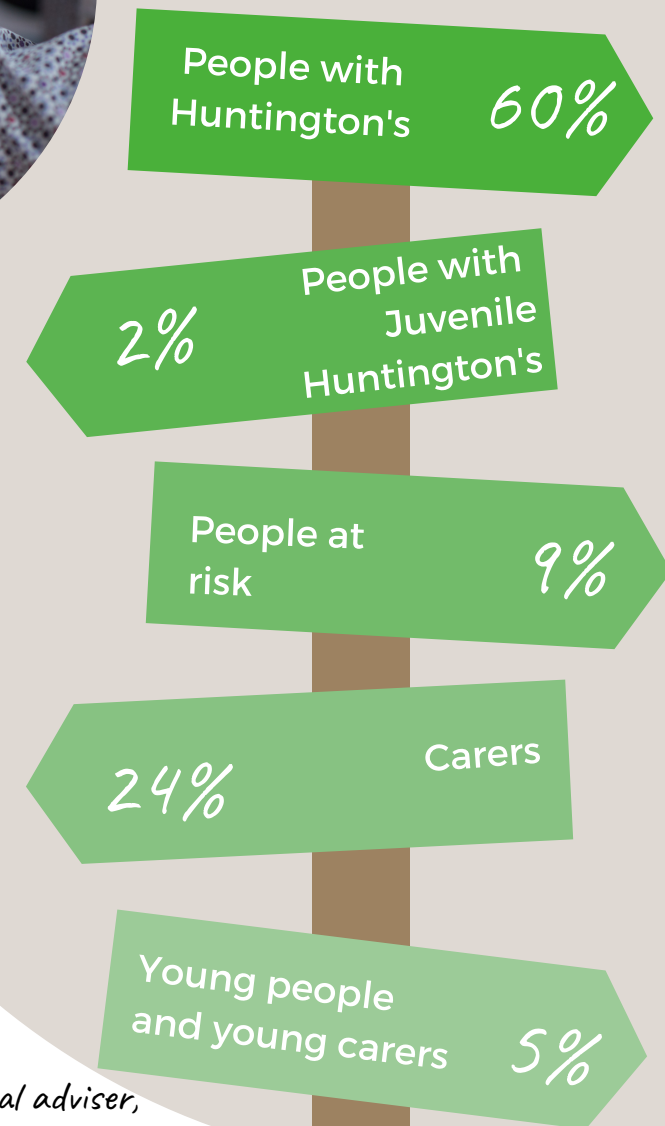
### When carrying out these services we focus on:

- Emotional support
- Guidance on how to live with Huntington's disease
- Financial advice
- Pointing people towards resources and organisations of support
- Educating professionals involved in Huntington's disease
- Preparing people for the future as the disease progresses
- Advocating for the person with Huntington's disease to get the best quality of care

*"It was our daughters who found the Huntington's Disease Association online and contacted our local adviser, who arrived within days, organised a quicker consultant appointment, filled in forms for us and pointed us towards useful information. She was so kind, knowledgeable, human and practical, and has continued to be an amazing, pro-active support ever since. She has also linked us with other local families affected by Huntington's for mutual support."*



## Who did we support in 2018?





## New guide for South Asian families

We have a suite of guides providing practical advice, tips and key information to help improve understanding of Huntington's and the quality of care people with the disease receive.

In 2018, we added to our publications, with a leaflet named 'A quick guide for South Asian families.' This was produced as part of a project called 'Breaking Down Barriers' funded by the Sylvia Adams Trust.

Consultation with family members showed that information about Huntington's when translated can often be misinterpreted leading to the possibility of it being hidden and misunderstood. This leaflet presents key facts and information in plain English in a way that is easy to understand for people whose first language is not English.



### How did our advisers help people in 2018?

**99%**  
Adviser helped them

**32%**  
Learnt about Huntington's research

**40%**  
Were helped in a crisis

**70%**  
Received emotional support

**38%**  
Were signposted onto other services

**71%**  
Felt less isolated

**17%**  
Received financial support

*"My adviser has been so helpful and supportive. Gave lots of really useful and helpful information. Reassured us about our situation and the support available to us. Helped us get back in touch with a research program. Made us feel we are not alone and we have her support for as long as we need it. Really changed our perspective on how we felt and how we feel about the future. Thank you, it was amazing meeting you and your help was invaluable. That's made such a difference in such a small but massive way."*

Caroline Hunter, family member, London

## Second youth worker joined the team

In 2018 new youth worker, Lilly, joined James O'Connor in our youth engagement service. Lilly has a background in theatre, caring for people with Huntington's disease and has a PGCE in primary teaching. Throughout 2018 Lilly has been a great asset to our charity, providing support and care to Young people in South England and South Wales.

*In 2018 there were 37 new referrals to our Youth Engagement Service*



# How our advisory service supports professionals

Understanding Huntington's and the complexities it brings can be challenging for health and social care professionals.

## Why do professionals need training?

Due to the rarity of Huntington's disease, medical professionals may not recognise symptoms or know how to manage them. Huntington's can sometimes be misdiagnosed due to the wide range of symptoms. Our training offers those who come into contact with people affected by Huntington's an essential understanding of this complex disease.

## How can our advisory service help?

Our team of advisers help health and social care professionals by providing expert training in many areas of Huntington's disease. They can deliver tailored training specific to the people with Huntington's in their care. They can also deliver more general training to teams, to give a better insight into Huntington's overall.

### We have five main strands to our service, these include:

- Bespoke in house training for teams
- Huntington's advice guides specifically for professionals
- Information pages on our website
- In depth national certificated training courses
- A dedicated telephone helpline

### When carrying out these services we focus on:

- General information about Huntington's
- Behaviour and cognitive changes in Huntington's
- Eating, swallowing and mobility issues
- Advances in Huntington's research
- How to talk to loved ones about the disease

*"As a registered nurse, I had a very basic knowledge of the disease. The course provided an excellent overview of the implications of Huntington's for the patient and family and useful, relevant information to manage symptoms both practically and emotionally. It demonstrated the usefulness and importance of each member of the multidisciplinary team in managing a person with Huntington's. Overall I feel much better equipped to start caring for people with Huntington's."*

**Peter Stokes, Registered Nurse, Newport, Wales**

**96%**

said after our training the quality of care that their team provides improved significantly

**100%**

said their knowledge and understanding of Huntington's improved as a result of our training

**99%**

said they knew where to go for advice and support about Huntington's as a result of our training







*"Huntington's affects people in very different ways. We pride ourselves on our ability to provide bespoke advice to professionals specific to the person they are caring for. Last year we gave 156 tailor made information sessions."*

Cath Stanley, Chief Executive, Huntington's Disease Association



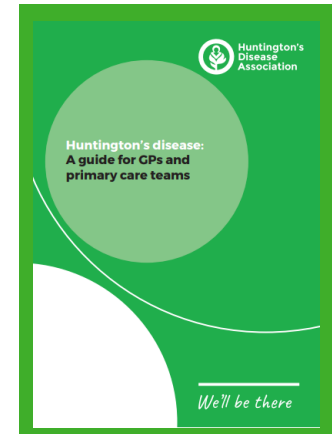
### Who did we deliver training to in the year?



## New guide for GPs and primary care teams

Our guide for GPs also underwent a complete revamp during the year. Content was updated to better reflect current professional practices. Due to the rarity of the disease, many GPs may have never come across Huntington's before or know very little about it. We hope this guide will be a valuable resource and reference for healthcare professionals around the country.

We have guides available to health and social care professionals covering various topics such as end of life care and mental health and mental capacity in Huntington's disease.



*"I admit to feeling a little overwhelmed when a family affected by Huntington's disease joined our practice. Although I had read about the illness, I had never cared for anyone with it before. The GP guide that the Huntington's Disease Association produce became a bit of a bible to me and I felt more confident in being able to give appropriate care and advice"*

Dr John Ashcroft, GP, Liverpool

# Mutual support

## Branches and Support Groups

We have around 50 dedicated branches and support groups across England and Wales. From Jersey to Newcastle, our branches and support groups are there for anyone affected by Huntington's. Groups meet for a mixture of social activities, information sessions and support.



## Other forms of Huntington's peer support

Alongside our branches and support groups, we provide other online and offline mutual support including:



### Social media channels

This includes Facebook, Twitter and Instagram. Relevant information is shared alongside engagement with users. Our social channels have an overall following of **16036** people.



### Our new website

Loaded full of helpful information, advice and downloadable guides with **116,197** people using the site in 2018.



### The message board

An online hub where people can discuss topics with others who may be affected by Huntington's. It has a total of **1715** active users with **325** new members in 2018.



## 2018 highlights

### Plymouth Support Group tried their hand at Boccia in 2018

Members of the Plymouth Support Group took part in a hand eye game named Boccia in 2018. Boccia is a game similar to boules, but is designed for people of all levels of physical and mental ability. The balls can be thrown, kicked, pushed off the lap or released with assistance from a ramp. Members now attend regular monthly sessions and find the game to be both enjoyable and helpful for hand eye co-ordination.



### New look message board

Our message board got a revamp in 2018. It is now much simpler to navigate and understand. The new board makes it easier to search for discussion topics and communicate with others. It is run and moderated by us but the Huntington's community have sole input into discussion and shared content. The forum enables people who may not be able to attend branch and support group meetings in person, to still find comfort, advice and friendship from people who understand their situation.



### North Staffordshire branch celebrate 25 years of support

In 2018, the North Staffordshire Branch celebrated the 25th anniversary of their first meeting. Branch members were joined by health professionals, both past and present, from the local neuropsychiatry service and Huntington's Disease Association staff. Branch Chair Sue Tams said that she was pleased that founding and longstanding members are still involved and that a warm welcome is always extended to new members who bring new ideas and enthusiasm.







## What it means to be part of a Huntington's Disease Association branch

*Chair of the Cumbria branch Dennis Whittaker tells his story*

### *What brought you in contact with the Huntington's Disease Association?*

"Prior to 2002 I was unaware of Huntington's disease until my wife's only sibling, her younger brother Jack, was diagnosed with Huntington's disease. He and his wife were told little about the disease other than there was no cure and were given a leaflet about the Huntington's Disease Association. Being an inquisitive type I took it upon myself to learn more about Huntington's and made contact with the local Specialist HD Adviser at the Huntington's Disease Association for the Cumbria area. Jack sadly died in 2017 but I now try to use what I learned during that time to help others on the same journey in my role as Chair of the Cumbria branch."

### *How did you first become involved with the Cumbria branch?*

"I had been aware of the Cumbria branch for many years before officially joining having donated money to them from the Keswick to Barrow Walk I was involved with. After a few years at the branch, I became both Chair and Treasurer in 2007 and gradually started to raise more awareness of Huntington's in the Cumbria area. I started giving informal talks on Huntington's, adding our branch details to local directories so we were better known and arranged an information day with Jimmy Pollard, a world respected Huntington's expert as guest speaker. Our local adviser regularly attended meetings giving advice and support about the issues families were dealing with, people were able to swap experiences and seek advice and we arranged local speakers to give talks on important areas such as benefits, wills and powers of attorney. I usually find that just having a chance to talk is beneficial as well as referring people to the Huntington's Disease Association who can signpost to local services."

### *What do you think your branch offers to your local Huntington's community?*

I think attending meetings and exchanging experiences is particularly beneficial during the early and mid-stages of the disease or during diagnosis. Especially if there is no experience in the family of Huntington's or dealing with the benefit system and social services. Attendees learn from each other's experiences. As people progress to late stages, they and their families have so much to contend with, attending meetings can sometimes become too much. Even if people are unable to meet face to face, a chat on the phone with someone who you do not have to explain what Huntington's is and its impact on you can reduce the feeling of isolation. Equally important to us as a branch is increasing awareness with professionals as this benefits families affected by Huntington's when they make contact with them as it saves them the repeated explaining of what Huntington's is.

Our branch, due to the money we fundraise locally, is in the favourable position to be able to award welfare grants to those that need financial support to purchase items or have experiences that will improve their quality of life. We award on average five a year up to a value of £300. These have been used in many ways over the years including, clothing, white goods replacement, respite breaks, funeral expenses and on one occasion, to clear rent arrears to allow someone to move to a more suitable apartment. In 2019 we are planning to run a family day for people affected by Huntington's in Cumbria featuring guest speakers and workshops and two carers events. The challenge to reach out to the wider Cumbria remains. We know there is a younger generation of people affected by Huntington's in the local area that we need to reach out to so they know support is out there."

*"I think attending meetings and exchanging experiences is particularly beneficial during the early and mid-stages of the disease or during diagnosis... Attendees learn from each other's experiences."*

# Influencing policy

## Insurance difficulties

### The challenge

People often tell us that they struggle to find insurance and sometimes feel discriminated against because of their illness. We embarked on a challenge to try to make getting insurance easier for people with Huntington's disease.

### What did we do?

In January MPs discussed insurance and genetic discrimination facing people with Huntington's disease at an adjournment debate in the House of Commons. We were able to collate and share the views of families in advance of this. It was the start of on-going work in this area. Throughout the year, alongside the Scottish Huntington's Disease Association, we met with the Department of Health and the Association of British Insurers, amongst others and were able to influence the update of the 'Code on Genetic Testing and Insurance'.



### What does this mean?

As a result of our conversations, the British Insurers Brokers' Association, which helps people to find insurance online or over the phone, have added Huntington's disease to the list of conditions on their 'Find A Broker' service. We hope that these steps will help people affected by Huntington's in securing fairer insurance policies in the future and that they will no longer have to face unfair treatment.

## CANH - Clinically assisted nutrition and hydration guide

In 2018, we represented the Huntington's community at a consultation event led by the British Medical Association looking at clinically assisted nutrition and hydration in adults who lack the capacity to consent. The consultation assessed situations where a person was not able to consent to being given artificial nutrition such as a feeding tube. And, where a person's quality of life was at risk leading to the feeding becoming no longer beneficial to the individual's quality of life.

From these discussions, a number of important changes were made. Now, in situations where doctors are not able to gain consent to stop treatment, they no longer have to apply to the court for the withdrawal. This will save many families from the heartache of going through court proceedings and dredging up painful memories.

We contributed to guidance on this subject to help facilitate the implementation of these important changes.

Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent

Guidance for decision-making in England and Wales



## Challenging recruitment policies

In 2018 we set out to influence unjust policies that are discriminatory to people affected by Huntington's disease.

Recruitment to the Police and Armed Forces in particular can be problematic for people affected by and at risk to Huntington's. We look to support those faced by this challenge by providing information and facts to recruitment centres.

We helped a young woman in Essex who was unjustly dismissed from a police recruitment program due to her being at risk of Huntington's disease and in their view 'unfit for service'. We made a case for Claire Atkins, writing to the police force recruiter and giving information about up to date genetic knowledge and potential future treatments. We also gave information on ways to manage someone who is at risk to ensure that if they were starting to display symptoms that may affect their ability to do their job, this could be identified.

After receiving this information, Claire was invited in for a second review and we hope that this additional information will help the Police Force reconsider their decision and accept Claire onto the Force.

*"Recruitment to the armed forces and police for people who at risk of Huntington's can prove problematic. We look to support those faced by this challenge by providing information and facts to recruitment centres."*

Cath Stanley, Chief Executive, Huntington's Disease Association

*"I recently went for a new job, was successful until my medical. The reason? I have the possibility of developing Huntington's. I was distraught and wasn't sure where to turn, and then I found the Huntington's Disease Association. They wrote many letters and emails and I am due to attend a second review. Whatever the outcome, I would never had got this far without the charity."*

Claire Atkins, Essex



# Working together

Together we can achieve great things. As Huntington's is a little known and rare disease we work to partner with other people and organisations to give Huntington's disease a louder voice.

## Together we are stronger



There are a number of health and social care professionals who have dedicated their careers to improving quality of life for people with Huntington's.

As a rare disease, the Huntington's community is small and tight knit meaning we are privileged to call these Huntington's experts Friends of the Huntington's Disease Association.

In 2018 we called on their expertise to help us to spread the word about Huntington's, give practical advice and share best practice as guest speakers at our certificated courses and flagship family and professional events.

Working together to increase knowledge and understanding of Huntington's means better standards of care for people affected by the disease.

## HD Voice

Who better to help us increase knowledge and understanding of the disease than the Huntington's community themselves.

Our patient and public involvement group (PPI), HD Voice, is made up of a number of representatives of the Huntington's community - people with or at risk of Huntington's, family carers and Health and Social Care professionals working with people affected by the disease.

The group review publications, online resources and give feedback to researchers on Huntington's projects making sure the voice of those affected are heard.

In 2018, HD Voice increased its membership to over 20 people and aligned with an international PPI group for Huntington's, HD COPE. This group was set up to provide Huntington's community experience to pharmaceutical companies, regulators, industry and Huntington's researchers on an international scale.

HD Voice member Steve Duckett has been appointed as the representative for England and Wales and attended the inaugural HD COPE meeting in London in January 2018. Steve is also a trustee for the Huntington's Disease Association and is a carer for his wife, Sandra who has Huntington's disease.

*"Patient-oriented input is vital to meet the needs of the Huntington's community, speed up recruitment and increase retention for clinical trials."*

Steve Duckett, HD Voice, Dorset



# HD VOICE

## Care home accreditation pilot

Work continued in 2018 on the design of a care home accreditation scheme. The need for such a scheme was identified due to the current lack of specific guidance on caring for people with Huntington's disease.

The Huntington's community told us that choosing a care home often feels like a battle and standards of care can vary significantly. Often a lack of understanding can result in a drop in standards, poor experiences of care and in extreme cases, people reported having been served notice because the care home simply could not cope. We want to change that.

Throughout the year we worked with the Huntington's community and care home providers, putting on consultation events and inviting comments to build a scheme that will benefit everyone. The proposed scheme requires participating care homes to adhere to a set of defined Huntington's Disease Association care standards, evidenced and monitored through a combination of self-assessment, practical evidence and onsite observations. We hope the scheme will make choosing a care home much easier, improve and standardise care, give reassurance to families and allow care providers to better highlight their specialist services.

The name 'Huntington's Disease Association Quality Assured' was voted on and agreed by the Huntington's community. Two care homes agreed to take part in a pilot and submitted evidence in 2018 for review against the accreditation criteria. If successful, both will be invited to become the first homes in England and Wales to be accredited. The full scheme is expected to launch in 2019.

*"This scheme is very important as from experience many care homes have never treated a Huntington's patient or have much knowledge of the disease. Being given the names of homes that know about Huntington's and not general nursing homes who cannot cope with their complex needs will be a great step forward."*

Paula James, Carer, Surrey



## Rare, Genetic and Undiagnosed Conditions APPG

The All Parliamentary Party Group (APPG) on Rare, Genetic and Undiagnosed Conditions was established in October 2017 by Rare Disease UK and we are proud to be one of its many members.

The APPG provides a mechanism for Parliamentarians to meet people affected by rare diseases, their families and the patient organisations and charities that represent them. It provides an opportunity for MPs to learn about the issues they face and gives people affected by rare, genetic and undiagnosed conditions a voice in parliament.

The group aims to increase awareness of rare, genetic and undiagnosed conditions in parliament and help ensure that people affected by rare diseases have access to the care and support they need. Joining together to represent rare diseases overall makes for a much stronger argument.

In December 2018 we took part in an APPG meeting to discuss 'Access to Medicines'; in particular how decisions are made in relation to rare disease medicine, and how this can be done in a fair, transparent and effective way improving access for people with rare conditions. This is very important to us at a time when huge advances are being made in drug development for Huntington's.

We were able to raise the important point that the 'cost of care' for people with Huntington's is in no way limited to medical care, but also to social care among many other services in complex cases.





# Media spotlight on Huntington's

## Call the Midwife

In 2018, Call The Midwife tackled Huntington's disease by shedding a light on the devastating consequences for a family affected by the disease in the 1960s.

We advised the show's script writers on the impact of living with someone affected by Huntington's and reviewed and commented on the script for the episode.



## Television

## Doctors

Last year the BBC show Doctors adopted an interesting Huntington's story line in which one of the hospitals employees, Dr Emma Reid, was confronted with a young patient who may have inherited Huntington's disease.

We supported the BBC in fact checking their scripts and information and advising on how best to tackle the subject of suspected Huntington's in a young person.

## Casualty

After an intense storyline in 2015 in which one of the characters with Huntington's, Emilie, passed away, Casualty revisited the storyline in 2018. This time featuring Emilie's son, Ethan, a doctor at the hospital, who inherited the disease.

We were once again asked to advise on scripts and help the BBC in the creation and execution of Ethan's storyline.



# Literature

Huntington's disease featured prominently in arts and media in 2018. One of the most notable achievements being Catherine Isaac's book, *You Me Everything*.

## You Me Everything

*You Me Everything* explores the challenges of a family living with Huntington's disease. The fictional tale follows the story of single mum Jess after learning about her mother's diagnosis of Huntington's disease. This life-changing news sets off a chain of events that encourage Jess to take chances, forgive, forget and be bold enough to live her life, for the sake of her son and herself.

Catherine Isaac reached out to the Huntington's Disease Association looking for advice on the medical aspects of her book. We worked with Catherine fact checking and making sure all medical language was correct. One of the key aspects we advised on was how the characters with Huntington's were referred to in the book so as to not cause offence to Huntington's readers.



*"Huntington's is a very misunderstood illness and there is very little awareness about the disease. You, Me, Everything raises many of the dilemmas faced by families affected by Huntington's. The importance of accurate information even in fiction cannot be underestimated, so having the opportunity to work with Catherine on this aspect of the book was invaluable."*

Cath Stanley, Chief Executive, Huntington's Disease Association

# Photography

Beauty of Rare is a national photography project organised by the non-profit Same But Different in 2018. Same but Different use the arts to give a greater voice to those affected by disability and rare diseases. They help people to see the person behind the condition and work with partners to bring communities closer together.

The Beauty of Rare project was created by photographer Ceridwen Hughes and includes a series of images designed to capture people's curiosity and interest. Each image is carefully designed to include elements that relate to the rare disease and its impact on the lives of those who have the condition.



We teamed up with Same But Different in 2018 to help find people who wanted to be involved in the Beauty of Rare project. The rare and neurological nature of Huntington's made it a perfect example of how a disease can impact everyone from the person with the disease to their family, friends, teachers, employers and so on. Lizzie (pictured above) and her family took part and shared their story. Beauty of Rare has helped raise awareness of Huntington's and Juvenile Huntington's disease to the general public by highlighting what it is like to live with the condition.

*"Lizzie is my youngest child, the baby. During her last year of secondary school she began suffering from depression and she started to disappear from the classroom and hide in the toilets. It was then that she also started to fall over a lot and became concerned that she too might have the disease. I didn't want to believe that she too could be affected."*

Kim, Lizzie's Mum, Beauty of Rare

# Events

In 2018 we held an array of events from in depth training events for medical professionals to activity weekends for children and young people; All unique in their format but alike in their goal of supporting people affected by Huntington's disease.

## Decisions, dilemmas and discussions

This weekend was held in March 2018 and was aimed at people aged 18-35 who are affected by Huntington's. There were a number of workshops available covering topics such as personality / cognitive changes and genetic testing.



*"The weekend made me feel in a good place with Huntington's and stronger to tackle it's difficulties in the future."*

## JHD weekend

The weekend was held in June 2018 and was jam packed full of activities for families living with Juvenile Huntington's disease. The weekend offered people with JHD and their families an opportunity to meet others in a similar situation, while also giving them a chance to find out more about JHD from our advisers.



*"A great opportunity to meet others in the same boat as yourself and help each other with coping strategies."*

## Inbetweeners day

The Inbetweeners day was held in February 2018 and was aimed at people affected by Huntington's between the ages of 35 and 45 years. During the day many important topics were discussed, ranging from how to talk to children about Huntington's to early symptoms and how to manage them.



*"I am very recently diagnosed, I'm also late 30's. The day helped me get things back in perspective and focus on positives."*

## Volunteer award ceremony

In July 2018 we celebrated the achievements of our fundraisers at the Volunteer Fundraiser Awards ceremony. A way for us to say thank you and celebrate their dedication and determination. Congratulations to the Most inspiring volunteer winners Linda Cullen-Moir and Helen Martin and Young Volunteer of the Year, Jessica Webb.



*"What an inspiring event. So many stories make you feel humble. Many thanks to all."*



## Family weekend (and AGM)

Our family weekend took place in October 2018, attendees had the chance to meet others affected by Huntington's, as well as finding out what's new in support, care, and research. There was lots of networking and time to browse the information/sponsor stands. The formal business section of the AGM included time for questions to be put to our board of trustees.



*"I have a new and better understanding of Huntington's. There is nothing not to enjoy. This annual event is unmissable."*

## Huntington's disease certificated course

We ran two in depth certificated courses on Huntington's disease in 2018. These events were an opportunity for people to meet with fellow professionals working with people affected by Huntington's, to develop a deeper understanding of the illness, to share ideas and discuss the management of complex situations. Attendees received a certificate stating that they have undertaken training approved by the Huntington's Disease Association.



*"The content of all of the lectures has opened my eyes as to the detail, research, and the degree of difficulties experienced by those with Huntington's."*

# Awareness week

## #LightItUp4HD

In 2018 the Huntington's community were shining bright for Huntington's disease. We joined forces with Huntington's charities and organisations across the world to light up buildings and landmarks as part of the #LightItUp4HD campaign.

Iconic locations such as the Spinnaker Tower in Portsmouth, Gateshead Millennium Bridge and the Mersey Gateway Bridge all lit up in pink and green to shine a light on Huntington's!



Not only did all these amazing building light up, but the community were also given the opportunity to light up their homes and workplaces with our light it up packs!

## Shining a light online

The Huntington's community took to the internet and raised awareness online by sharing their Huntington's stories using the hashtag #HDAwarenessWeek.



Supporters were also given the opportunity to upload an awareness ribbon to their social media profile picture to show support for us and raise awareness of Huntington's disease.

## Awareness events

Across the country the Huntington's community held events to raise money and awareness of the disease. Leaflets, balloons and stickers were shipped all over the country for bake sales, fundraising collections and information stalls.



# Investing in research

## Promoting physical activity in Huntington's

A research study by Cardiff University

We know that some people with Huntington's disease struggle to take part in physical activity, we also know that it's important for people with Huntington's to try and stay active.

In 2018 we continued to fund a three year study, led by Dr Una Jones of Cardiff University that aims to bring people together to develop a way for health professionals to guide and support people with Huntington's disease to keep physically active. From her research a workbook called PAT-HD was produced.

PAT-HD, and it's supplementary user guide, can support healthcare professionals to have a discussion with people with Huntington's and their families and carers to agree a personalised physical activity plan. It includes examples of activities and an overview of the benefits of physical activity. PAT-HD is currently being trialed in three Huntington's clinics in the United Kingdom.



Research in  
plain English

Research into Huntington's and breakthroughs which could bring potential future treatments a step closer are happening all the time. It is important that the Huntington's community know the work that is taking place bringing hope for future generations. However research can be hard to understand and written in scientific jargon that is difficult to decipher without prior knowledge.

We were thrilled to be able to continue our financial support in 2018 of HD Buzz; a Huntington's disease research website founded by Huntington's disease researchers Dr Ed Wild and Dr Jeff Carroll. Our support helped them continue to post impartial updates on complex research trial findings in a way that was easy to understand for the general public.

## How Huntington's affects financial decisions

A research study by the University of Cambridge

Huntington's disease is associated with a loss of connections in the brain, the breakdown of which can lead to problems with high level thinking and changes in behaviours. In Huntington's disease, these changes can often lead to patients acting impulsively, becoming more inflexible and having difficulty accurately evaluating the risks in situations.

In a world where internet and telephone banking, pin numbers and security codes have become commonplace, people with Huntington's are at increasing risk of financial abuse, such as theft, fraud and exploitation due to their reduced capacity to manage financial information and the complex changes to their thinking capabilities. Dr Roger Barker and his team at the University of Cambridge have set out to investigate further.

We continued to fund this important three year study in 2018. During the year, the team made contact with people with Huntington's, their families and those involved in their care and support to hear more about their experiences to see what factors influence financial decision making and what areas make people particularly vulnerable to financial abuse. Through this study, the team hope to find out how much a problem financial abuse is in Huntington's and also the factors that could help predict future financial vulnerability.

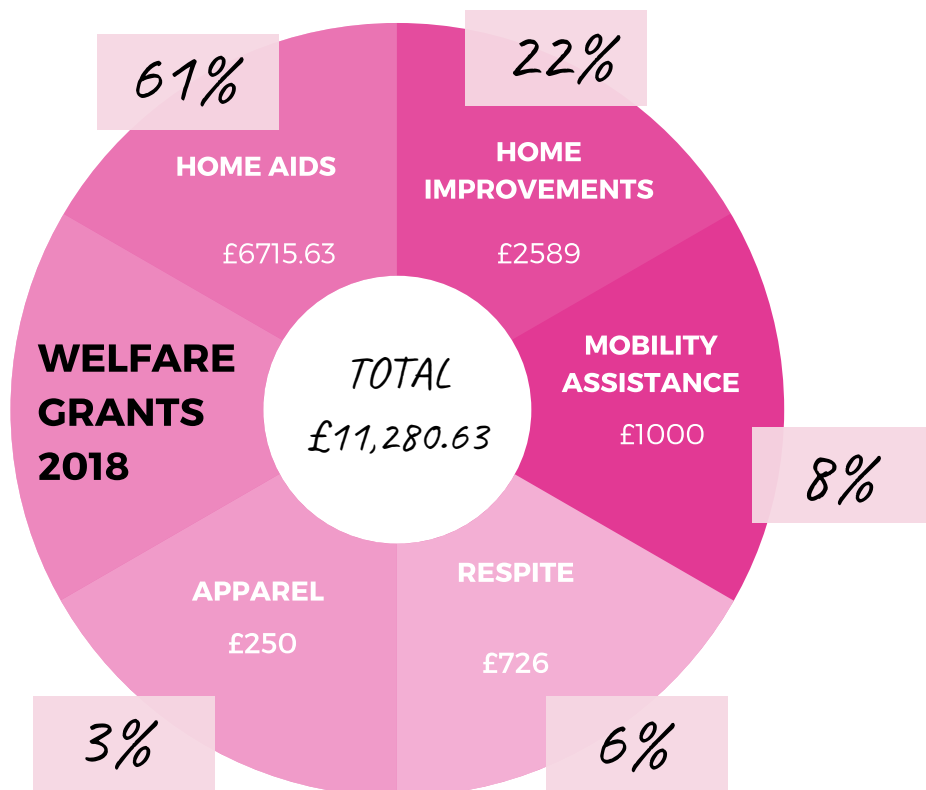




## Welfare grants

We continued to offer our welfare grant scheme in 2018, providing 36 grants, totaling over £11,000. Sometimes a small change or a particular piece of equipment is all that's needed to reduce the risk associated with a daily task for someone with Huntington's and allow them to maintain their independence for as long as possible.

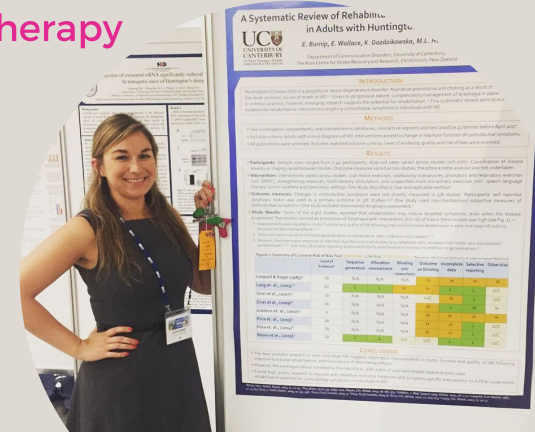
Some of the items we funded included hot water dispensers so people with Huntington's can make a cup of tea safely despite the involuntary movements they experience; laminate flooring so people's houses are easier to clean from spills caused by hands that shake; money toward mobility scooters to reduce isolation and short breaks to make memories with loved ones. We believe in the importance of providing financial assistance where funding is not easily attainable elsewhere. A small grant often means so much to someone's quality of life and independence.



# Investing in people

## A PhD study into dysphagia therapy

Swallowing difficulties are likely to affect everyone with Huntington's disease as the disease progresses. People with Huntington's often notice problems chewing, controlling food in their mouth, coughing or choking during mealtimes. There are also related problems with weight loss, malnutrition and food or drink going down the 'wrong way' which can cause chest infections or pneumonia. Currently there are no effective therapy techniques to treat or rehabilitate swallowing difficulties related to Huntington's and very limited research into the subject.



*"My ambition is to find an effective therapy to help people with swallowing difficulties secondary to this progressive neurological disease."*

When Emma Burnip, a Speech and Language Therapist specialising in adult neurology, approached us in 2016 with her PhD proposal to research and find an effective therapy to help people with Huntington's with swallowing difficulties (dysphagia) we were keen to financially support her study.

Coming from a family affected by Huntington's and having seen a lot of patients with the disease throughout her Speech and Language career, Emma is passionate about developing an effective swallowing therapy. One patient, a young person with JHD particularly inspired her. He asked "So Emma, what can I do when my swallow starts to go?", to which she had no response except trying to have safer diet and avoid harder foods which has made her determined to find a solution.

In 2018, Emma completed the second year of her three year study at the University of Canterbury, Christchurch, New Zealand where there is a world renowned swallowing research centre. Her research is currently the only clinical trial in the world investigating a new swallowing therapy for people with Huntington's disease.



# Our supporters

Here at the Huntington's Disease Association, we are immensely proud of our supporters, fundraisers and volunteers who are with us every step of the way as we continue to support people affected by Huntington's disease.

From our fantastic 'Do it for Dom' team who have raised over £73,000 through various activities including a Snowden Challenge, quiz nights and raffles to our friends Ellie and Issac who tinkled the ivories at a piano playing event raising £556 for our work. Not forgetting everyone else in between - from the army of bakers who took part in Cake That! HD and every other supporter who walked, ran, knitted, danced or gave up something for us - you are all hugely important to the Huntington's Disease Association. Thank you for supporting our work.



Record London Marathon  
year! 27 runners and  
£69,180.80 raised



£3,175.04 raised from  
bake sales as part of  
Cake that, HD!



£8,740.70 raised from  
overseas challenges

## Cake that, HD! Why I fundraise for the Huntington's Disease Association - Kelly Norton

In 2018, Kelly Norton and her family and friends took part in our fundraising campaign, Cake that, HD! The campaign encourages people to don their pinnies, channel their inner Mary Berry and get baking in aid of the Huntington's Disease Association. People held cake sales, afternoon teas and other cake filled events to support us year on year.



*"My connection to Huntington's started as a child, fundraising with a family close to me. As a teenager I saw this family's diagnosis as they struggled to cope with the effects of Huntington's and continued to fundraise alongside. I saw the family crumble, many took their own lives and others spent their lives living in the shadows of the diagnosis. I still see this now. As our generation took over fundraising as adults, we wanted to not only fundraise but raise awareness to help our town understand the effects of Huntington's and the help the Huntington's Disease Association can give."*

*Cake that, HD!*  
*5 September 2019*



*SAVE THE DATE!*

Kelly and her team of fundraisers hired a local Town Hall for a Cake that, HD! get together. They promoted their event on social media and put up posters in public places to encourage supporters to attend but also in the hope that it would attract anyone who may be struggling with Huntington's to come along and meet others facing similar situations.

*"We raised £289.40 and loads of people popped along for coffee, cake and a natter."*

*We had the next generation there too, as we always try to do, learning about fundraising as we did in case they choose to do the same one day."*

## Park Regis Birmingham made us their.....

We partnered with Park Regis Birmingham in 2018 who generously made us their charity of the year!



We were chosen, along with another charity benefiting children, after staff submitted suggestions close to their heart.



General Manager at the Park Regis Birmingham, Mark Payne (pictured left) said:

*"We usually have a single nominated charity but we made the unanimous decision to support two causes this year because both do incredible work, supporting individuals and their families."*

# thank you

to our sponsors!

For sponsoring our various events, publications and projects throughout the year.

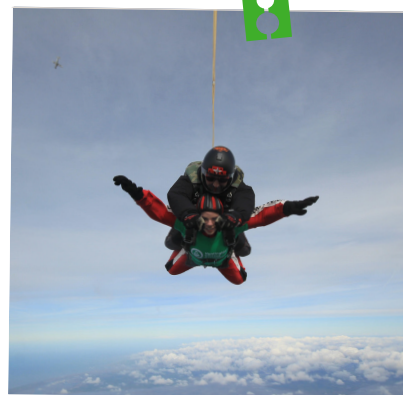
- Exemplar Healthcare
- PJ Care
- St Andrew's Healthcare
- Healthcare Matters
- Elysium Neurological



**£73,571.15 raised from corporate funding**



**£37,827.50 raised from bike rides**



**£29,677.95 raised from skydives**



## Ernest Kleinwort Trust

### Why the Trust supported us in 2018

We were delighted that the Ernest Kleinwort Trust chose to support our work in 2018. They provided a grant of £4000 to part-fund a vital specialist Huntington's disease Adviser role in the Sussex area.

The trust, founded by Ernest Kleinwort, has donated over £39.3 million since 1988 to many worthy causes in the Sussex area. We asked Sally Case, Director of the Trust, why they chose to support our work.



*"EKCT was pleased to support the HDA in 2018, as the leading charity supporting those with Huntington's disease in England and Wales. The Trustees were particularly drawn to the charity's specialist advisory service which aims to improve the care and support services for people with the disease, educate families and professionals, and provide advocacy for those that need it most. Trustees were pleased to provide a grant of £4,000 towards the cost of a specialist adviser for the 145 people in Sussex whose lives are impacted by the disease."*

Sally Case, Ernest Kleinwort, London



£450,875 raised in total  
from community  
fundraising



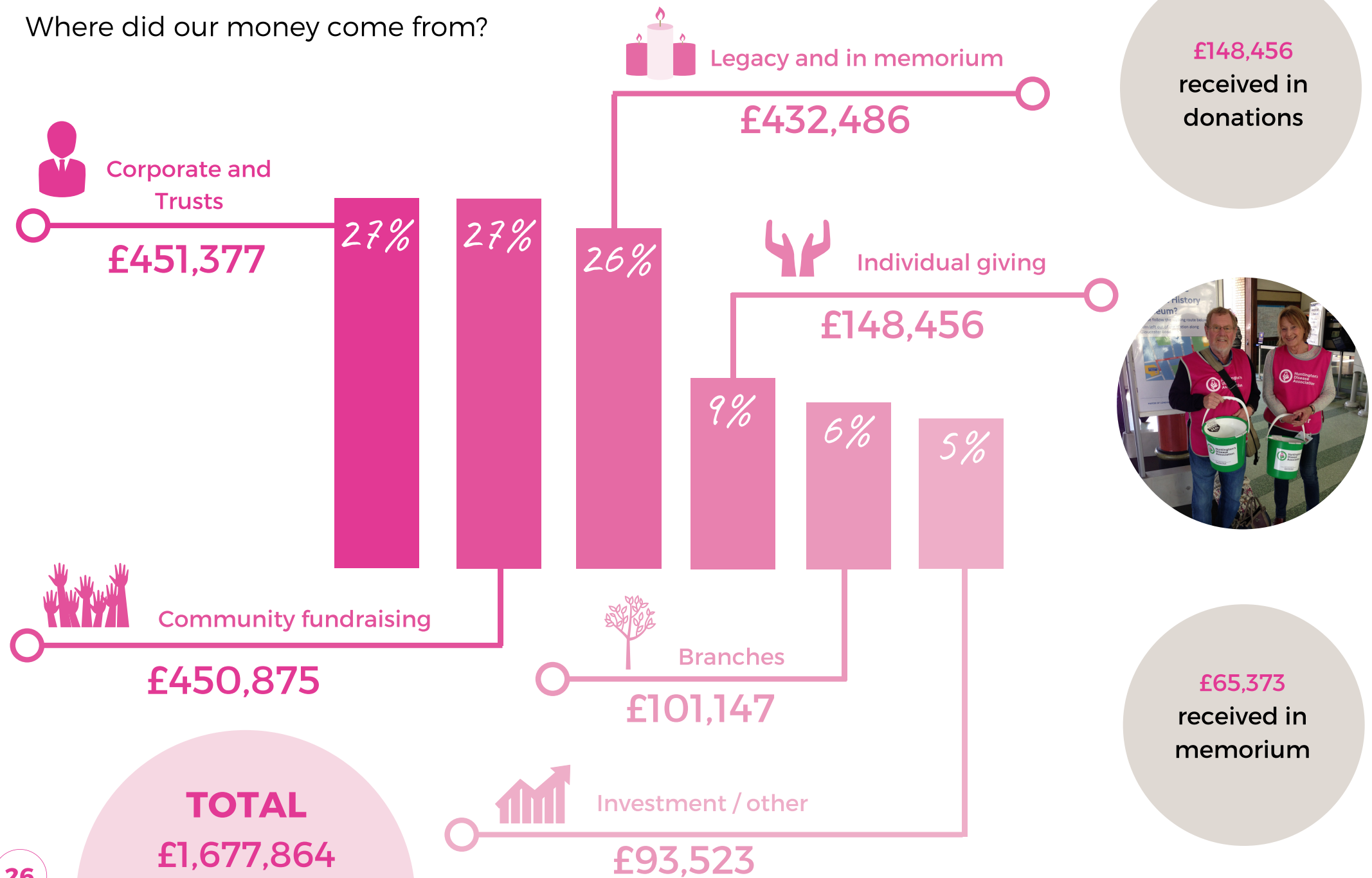
£377,805.85 raised from  
Trusts and Foundations



£367,113 raised from  
legacy gifts

# Finances

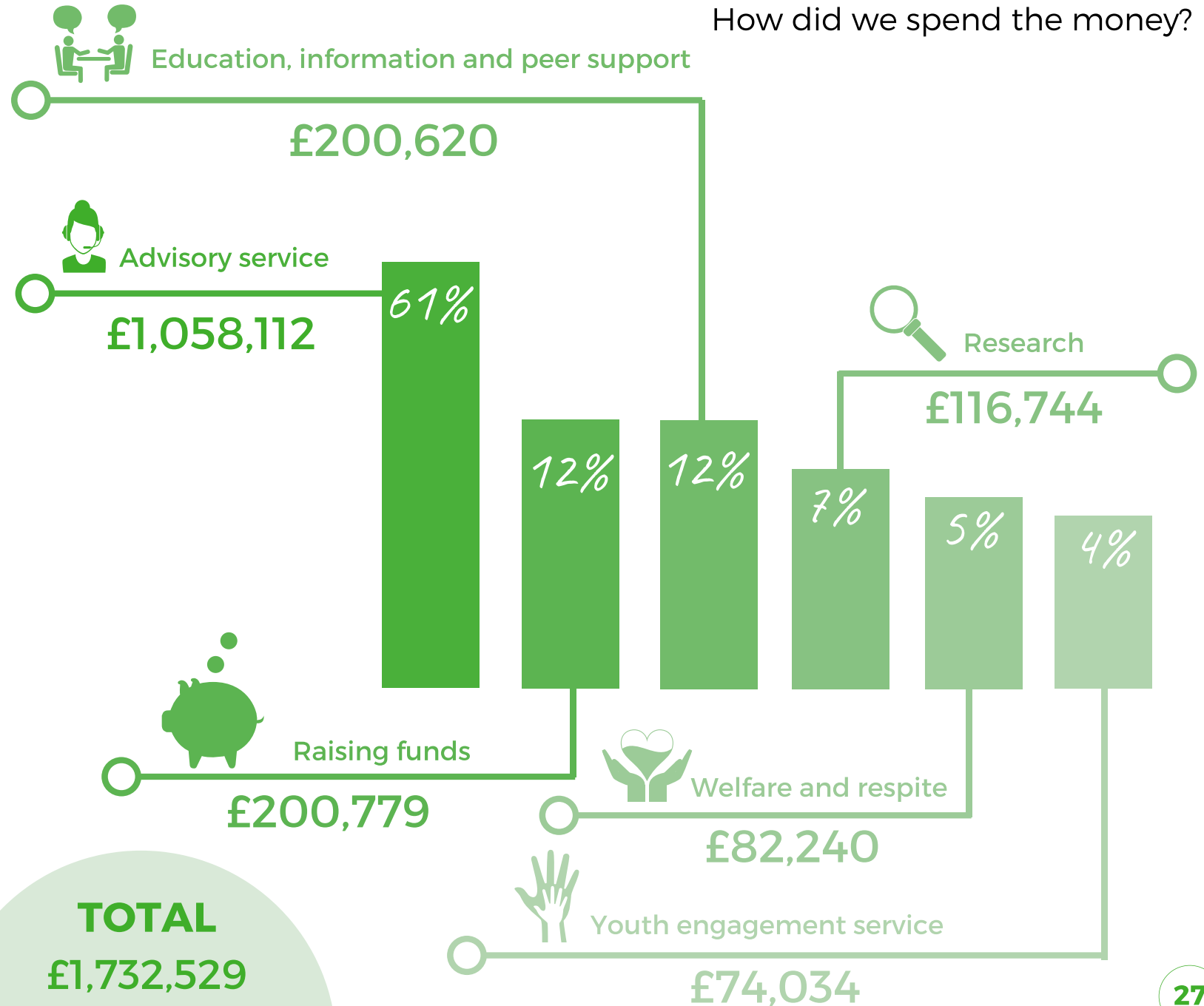
Where did our money come from?





# Finances

How did we spend the money?



For every **£1** spent on generating funds we raised an average of **£8.36**





# Our future plans

2018 saw the launch of the Association's new strategy. Our vision – a better life for everyone affected by Huntington's disease. After consultation with our supporters, staff and key partners and a review of the changing needs of the Huntington's community, we have identified the following strategic goals that will underpin our work over the next five years:



## Improved quality care and support

The quality of care and support available throughout England and Wales is inconsistent. We will do all we can to ensure those affected by Huntington's disease can access the care and support they need.



## Better knowledge and understanding of Huntington's

Huntington's disease is a rare illness which means many professionals have a lack of understanding of the impact of the disease and its symptoms. Education is vital.



## Greater opportunity for peer support and community involvement

The Huntington's community knows the complex nature and challenges of living under the shadow of Huntington's. They are best placed to support others facing similar situations. Likewise, their expert knowledge is invaluable in helping us to develop resources and inform our work.



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

A lack of awareness of Huntington's within the general public is one of the biggest frustrations our community has told us about. We want to change that.



## A strong charity to better champion the needs of our community

As a charity with a small staff team, we need to ensure we have the appropriate resources, strategies and processes in place to work as efficiently and effectively as we can, to best support people affected by Huntington's and the professionals involved in their care.



## Supporting Huntington's research

As a key organisation supporting people affected by the disease in England and Wales, we are best placed to gather evidence to help inform research priorities and provide pharmaceutical companies with family perspectives. We are a key link between the researchers and pharmaceutical companies and those affected by Huntington's. We can provide reliable and understandable guidance about advances and participation opportunities in research.

In line with the above goals,  
the following are some of  
the key areas we plan to  
focus on next year:

## Youth service provision

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

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

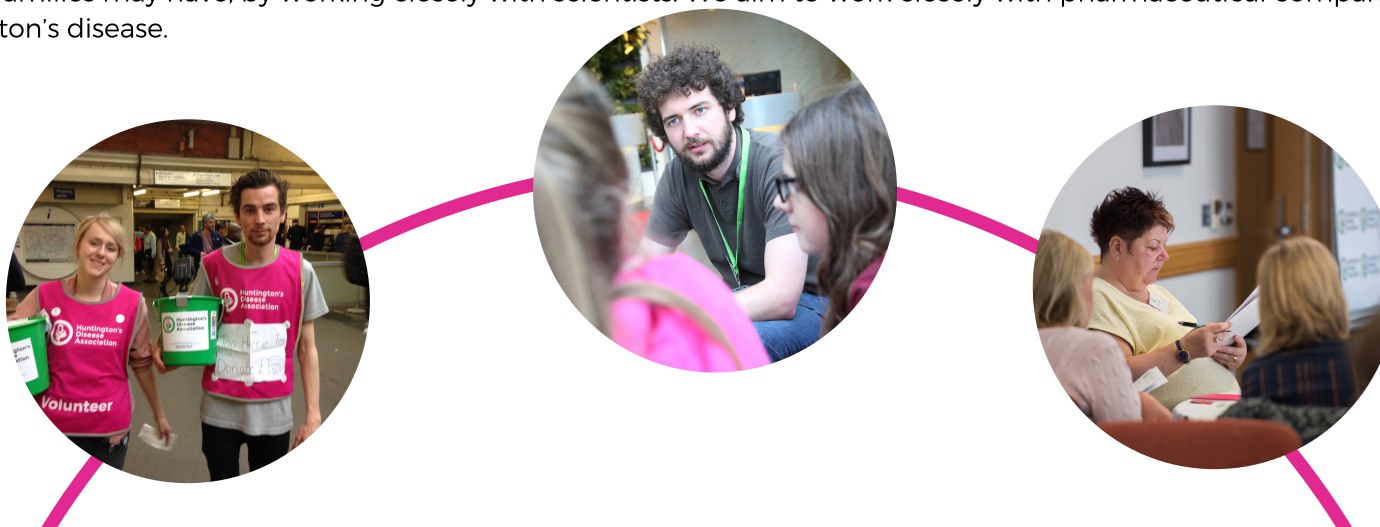
Sharing and disseminating accurate information about Huntington's remains a crucial to our mission. We plan to explore new ways to reach more people, at varying stages of the progression of Huntington's disease. We plan to embrace digital technology and to streamline the service we offer and invest in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

## Improving quality of care for people with Huntington's disease

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

## Influencing policy makers

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



# Our thanks

Austin and Hope Pilkington Trust  
Avast Foundation  
BBC Children in Need  
Birmingham and District Nursing Charitable Trust  
Birmingham City Council  
Blackburn with Darwen CCG  
Boshier-Hinton Charitable Foundation  
Brian Wilson Charitable Trust  
Bruce Wake Charitable Trust  
Chalk Cliff Trust  
Cheshire Community Foundation  
Chrysalis Trust  
Clara E Burgess Charity  
Clive & Sylvia Richards Charity  
Denman Charitable Trust  
DM Thomas Foundation for Young People  
Dorset CCG  
Douglas Arter Foundation (Good Neighbours Trust)  
Dowager Countess Eleanor Peel Trust  
Duchy of Lancaster Benevolent Fund  
Ernest Kleinwort Charitable Trust  
Essex Community Foundation  
George A Moore Foundation  
Goldcrest Charitable Trust  
Hull and East Riding Charitable Trust  
James Tudor Foundation  
John Avins Trust  
John James Bristol Foundation  
Joseph and Annie Cattle Trust  
Joseph and Lena Randall Charitable Trust  
LCVS - Community Impact Fund  
Leeds Genetic Laboratory  
London Catalyst  
Lord Cozens Hardy Charitable Trust  
Lord Leverhulme's Charitable Trust

Martin Laing Foundation  
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Milles Charitable Foundation Limited  
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NHS Cambridgeshire & Peterborough CCG  
Peter Stebbing's Memorial Charity  
PF Charitable Trust  
PH Holt Foundation  
RE Pilkington's No 4 Settlement  
Sheffield Town Trust  
Sir James Knott Trust  
Sir James Reckitt Charity  
Sir James Roll Charitable Trust  
Skelton Bounty  
Somerset Community Foundation  
Sovereign Health Care Charitable Trust  
Funding from Suffolk Community Foundation  
through Harris Family Fund  
Suffolk Giving Fund  
Sunrise Sidmouth Charitable Trust  
Sylvia Adams Charitable Trust  
The 29th May 1961 Charitable Trust  
The Alice Ellen Cooper Dean Charitable Foundation  
The Barbour Foundation  
The Bothwell Charitable Trust  
The Cardy Beaver Foundation  
The Chapman Charitable Trust  
The Charles Littlewood Hill Trust  
The Dyers' Company Charitable Trust  
The Edith Murphy Foundation  
The Eveson Charitable Trust  
The Florence Turner Charitable Trust  
The Fowler, Smith and Jones Charitable Trust  
The Frederick and Phyllis Cann Trust  
The Hadrian Trust  
The Hemby Trust  
The Hodge Foundation  
Zurich Community Trust for Dorset and Wiltshire

*Thank you to the following grant funders, foundations, sponsors and corporate supporters who have helped make our work possible, including those who wish to remain anonymous.*

*Without your generosity, we couldn't be there for people with Huntington's disease.*

The Hospital Saturday Fund  
The J G Graves Charitable Trust  
The Maud Elkington Charitable Trust  
The Paul Bassham Charitable Trust  
The Rayne Foundation  
The Roger De Haan Charitable Trust  
The Sir Jules Thorn Charitable Trust  
The Sobell Foundation  
The Souter Charitable Trust  
The Steel Charitable Trust  
The Strangward Trust  
The Talbot Trust  
The Tanner Trust  
The Valentine Charitable Trust  
The Walter Farthing Trust  
Virgin Care  
Wixamtree Trust



# Our people

Special thanks to those that have given their time and expertise in kind.

Cuthbert's Bakehouse  
Morrison's Belle Vale  
Ian Preedy  
Alex Reid  
Everyman and Playhouse Theatres  
Elephant Digital



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Shane Richie

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## Partnerships and affiliations

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HD Buzz  
HDYO  
International and European Huntington's Associations  
National Council for Palliative Care  
Neurological Alliance  
The United Kingdom and Ireland Huntington's Alliance

*"The Huntington's Disease Association support the people affected by Huntington's today whilst working to improve the lives of future generations."*

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*We'll be there*

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## Get in touch

For advice and support or to speak to a Specialist Huntington's Disease Adviser

email [info@hda.org.uk](mailto:info@hda.org.uk)

phone **0151 331 5444**

[www.hda.org.uk](http://www.hda.org.uk)



@hda\_tweeting



@hdauk



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Huntington's Disease Association

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## Get involved

Contact our fundraising team

email [fundraising@hda.org.uk](mailto:fundraising@hda.org.uk)

phone **0151 331 5445**

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