Huntington's Disease Association

Magazine

Summer 2018

Football legends: how one woman and her supporters keep life, and work, on track

Huntingtin lowering research: what's it all about?

Ask the expert: Preimplantation Genetic Diagnosis

12 top tips: understanding changes in emotions and behaviour

Are you a healthcare professional looking to learn more about Huntington's disease?

Join us for our certificated course in Huntington's disease

20 - 21 November 2018, London

You'll learn about the complexity of Huntington's, the effect of the disease on patients and families, and hear from experts on essential topics such as genetics, neuropsychology, occupational therapy and palliative care.

This is a unique opportunity to meet with fellow healthcare professionals supporting people with Huntington's. You will develop a deeper understanding of the illness, and have the chance to share ideas and discuss the management of complex situations.

For more information and to book your place visit www.hda.org.uk/events

Support the HDA and help raise awareness of Huntington's disease with our new range of merchandise

Visit our online shop www.hda.org.uk/shop

In this edition

Contact us

T 0151 331 5444
W www.hda.org.uk
E info@hda.org.uk
@HDA_tweeting
@hdauk

Suite 24 Liverpool Science Park IC1
131 Mount Pleasant, Liverpool L3 5TF
Registered charity no. 296453

For advice or support from one of our Specialist HD Advisers visit:
www.hda.org.uk/supportnearyou

Welcome

From Andrew Bickerdike, Chair of Trustees and Cath Stanley, Chief Executive

Welcome to this edition of our magazine. We are pleased to share some of the highlights of the last few months with you.

In December 2017, news broke that scientists had made a breakthrough while investigating the first potential treatment for Huntington's disease. While there is still a long way to go, this is really encouraging news. Read about the research and what it means for the Huntington's community on pages 4 – 7.

Thanks to the support of BBC Children in Need, we have recruited an additional youth worker to help support children and young people growing up in families affected by Huntington's (page 12). We have been working with the Treasury and Association of British Insurers to help revise how people affected by genetic illnesses can access insurance. Read about the progress made on page 11.

Increasing awareness is vital so we were delighted to be able to help leading author Catherine Isaac on her new novel about Huntington's (page 17). Huntington's Disease Awareness Week in May saw buildings, landmarks and more houses than ever before lit up in our pink and green HDA colours – thank you everyone for participating to make this a success. Some highlights from the week are on page 13.

We are privileged to work with such an inspirational community and continue to be amazed by our outstanding volunteers, who support us and each other in so many ways – whether through running marathons and raising funds (pages 22-25) or being a listening ear and sharing experiences with others (page 27). A huge thank you to you all.

Thank you

Huntingtin lowering research: what's it all about?

Professor Sarah Tabrizi

The last year has seen unparalleled advances in therapies for Huntington's disease. For decades, attempts to slow its progression have been frustrated because of the difficulty of designing treatments for a disease that affects cells in so many different ways. This is the reason new treatments are targeting as close to the source of the disease as possible; the DNA mutation itself.

The global team of scientists involved in this research, known as huntingtin lowering, is led by Professor Sarah Tabrizi from University College London. Professor Tabrizi explains what is involved and the next steps following the successful first trial.

What is huntingtin lowering?

'Huntingtin lowering' means reducing the amount of the protein that causes Huntington's disease. DNA is the set of instructions our bodies use to produce the proteins that make up our cells. When a cell needs to make a specific protein, such as huntingtin, it copies the DNA into a messenger molecule, called RNA, which it can then use as a template to make the protein. Huntingtin-lowering therapies target that messenger RNA (mRNA), stopping the protein from being made, thereby potentially preventing all its damaging downstream effects.

There are several ways to target RNA, but the leading approach uses an 'antisense oligonucleotide', known as ASO, or just 'antisense'. This is a short synthetic piece of DNA designed to bind and destroy or modify the mRNA. The main benefit of ASOs over the other huntingtin-lowering approaches is the relative ease with which they can get into brain cells.

How can ASOs help in Huntington's disease?

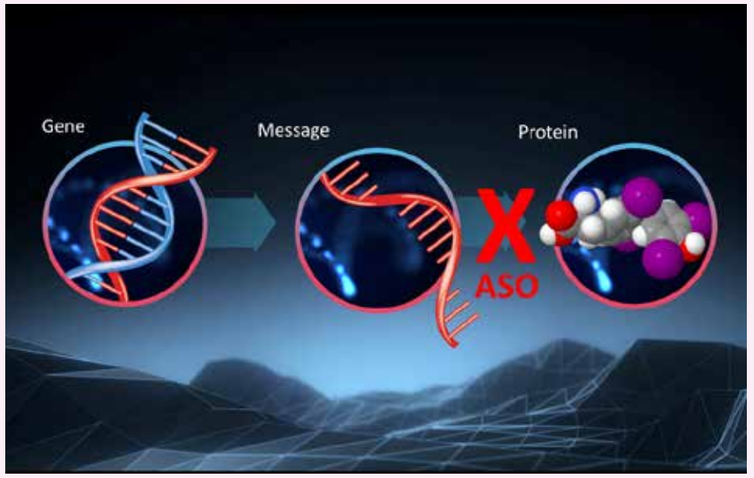
ASOs were first developed in the 1970s, and first used clinically in the 1990s to treat leukaemia and cytomegalovirus (CMV) eye infections that complicate HIV. Since 2000 they have been developed for many conditions including macular degeneration and liver disease.

The drug that pharmaceutical company Ionis Pharmaceuticals has developed is a huntingtin-lowering ASO therapy, which for the time being is called IONIS-HTTRx, or RG6042. It was designed to reduce the level of both the mutant and normal versions of the protein, and was extensively tested before being given to people.

What did the trial involve?

The IONIS-HTTRx clinical trial, which ran from 2015-17, is the only trial to date to demonstrate reduction of the huntingtin protein. It was called a phase 1/2a trial, which means its purpose was to see if the drug is safe to use in people, and was run at nine sites in the UK, Germany and Canada. 46 incredibly brave people with early stage Huntington's volunteered to be the first to receive the drug. This was a short study, with each person receiving four doses of either the active drug or placebo, given at monthly intervals, then followed up afterwards for four months. The ASO was given by injection into the spinal fluid at the lower back in an increasing dose, which means the first participants received a low dose and later participants got progressively higher doses. The drug was safe and well tolerated and there were no serious side effects.

DNA is copied into an RNA message, which is then used to make the huntingtin protein. The antisense oligonucleotide (ASO) binds to the RNA message causing its destruction and preventing the protein from being made.



How do we know it was successful?

We can't take samples of people's brains at the end of the trial, so how can we check that the drug successfully lowered the huntingtin protein level? Well, we can measure the level of the protein in spinal fluid, and an important part of the preliminary research showed that this corresponds very well with the level in the brain itself. It's a bit like checking a loaf of bread is ready by tapping on the bottom of it rather than cutting it open.

As the dose increased, the level of the huntingtin protein in the spinal fluid reduced. At the highest doses, the protein level dropped by half in most patients. The trial didn't find a significant improvement in symptoms, but as only a small number of people were treated for a short three month period, it was not long enough to detect an effect. However, there were encouraging signs that larger reductions in the mutant huntingtin protein were associated with improvements in some movement and cognitive tests.

What happens next?

The study participants are now entering an 'open label extension', which means that everyone who enrols will receive the active drug for over a year, including those previously receiving the placebo. This allows all participants to receive the active drug and will provide information about the longer-term effects of the drug and its safety. Protein levels continued to fall throughout the original study, and it may well be that they can be reduced even further with longer-term dosing.

IONIS-HTTRx is not a 'cure', as it does not correct the genetic mutation that causes Huntington's disease, but we are very hopeful that it could be the first effective treatment for the disease. We cannot cure diabetes, for example, but treatment with medications such as insulin has transformed the lives of patients.

The first trial has shown that this drug can lower the huntingtin protein level. Roche, the large pharmaceutical company who are partnered with Ionis and are now leading the development of this drug, are currently planning the next step; a larger and longer study to determine if reducing the protein will benefit patients.

Keep up to date with Huntington's research news at hdbuzz.net

Huntingtin lowering research: what does it mean for the Huntington's community?

News that the research team leading the antisense drug trial had made a significant step towards a possible treatment for Huntington's disease raised many questions for the Huntington's community. Our scientific adviser, Dr Ed Wild, explores some of the main queries following the research announcement.

Organising and funding clinical trials

The pharmaceutical company that makes the drug is the 'sponsor' of the clinical trial. In this instance it was Ionis Pharmaceuticals, a small Californian drug company. The pharmaceutical company sends the drug to clinical 'sites' – each site is a hospital with a Huntington's disease clinic. A team of researchers and clinicians run the clinical trial, but there are many other people involved. The money to make it happen comes from lots of places, including drug companies Ionis Pharmaceuticals and Roche; the Medical Research Council, which funds some researchers' salaries; the NHS, which pays medical staff; alongside charities who fund scientists, materials and facilities. The next stage of investigating this treatment will be funded by Roche, which has been involved for a number of years.

Getting involved in trials

The next stage of the research and deciding who may be involved is done at the clinical site. After sites are chosen to take part in the trial, the research team will look at their records for people who've expressed an interest in taking part. Many patients that come to the clinic have been encouraged and supported by the Huntington's Disease Association. So the whole Huntington's disease community is in this together.

Research staff will 'shortlist' a group of potentially eligible participants to take part in a screening period. However, the final decision about who is suitable lies with the drug company. There's no private way of paying to get into the trial – you can only be in any trial in the UK if you're eligible for NHS treatment.

Turning research into a treatment

The next step is a longer, larger trial to test the drug's 'efficacy' – we know this drug is hitting its target at the molecular level, but does it actually slow progression of Huntington's? That trial is now being planned by Roche, and may last around three to four years. That's how long will be needed to give the drug the best chance of showing it works.

"It's a testament to the dedication and determination of the Huntington's community that there have been so many thoughtful questions about this research. I've covered these as best as I can, but it shouldn't be interpreted as medical advice."
Dr Ed Wild

Dr Ed's advice if you're interested in clinical trials and have Huntington's or are at risk:

1. Have regular follow ups at a Huntington's disease clinic that has a research interest – either directly or at a site that sources volunteers for other clinical trial sites.

2. Sign up for the ENROLL-HD study (details at **enroll-hd.org**). This large, observational study is used to find participants for clinical trials and is the first place research teams will look once recruitment begins.

3. Look after yourself. The healthier you are, the better the chance of being in future trials. Keep up with clinic visits, GP appointments, psychiatrist visits, physiotherapy, speech and language therapy. Stay active, exercise and eat well. Seek advice early if your symptoms get worse, or if any new medical problems arise.

It would be worse to rush the next trial and get a negative result because the trial was too short. If the drug turns out better than expected, the trial might be shorter – that's something to hope for, but isn't something we can expect.

If the result is good, Roche will apply for a licence to prescribe it, which could push the total time to five or six years – or even longer if there are any difficulties along the way. It's still possible the trial will show that the drug doesn't work – that it doesn't slow the progression of the disease. That would be bad news, and we would have to figure out why it happened and see what we can do about it. But it wouldn't take away the fact that the gene and the protein are the best target for fighting Huntington's.

Genetic testing

Many people at risk of Huntington's have asked if they should have the genetic test following this research news. Getting tested is an intensely personal decision. There are many factors to consider, and they're different for every person. What's happening in research is one thing some people consider, but for most people it should be a very small part of their decision. It's never a bad idea to get referred for genetic counselling. Genetic counsellors are the best people to speak to about what this news might mean and what the future might hold. They aren't interested in pushing anyone into testing – they're there to provide information impartially.

However, there's one thing you can do now to help with Huntington's research and get your name on the list of people interested in future trials, even if you haven't been tested – sign up for Enroll-HD at enroll-hd.org. Your genetic status will never be revealed to you or anyone else at the Enroll-HD research site.

Searching for an effective treatment

This is the first drug that has been shown to lower production of the huntingtin protein, which is the known cause of Huntington's disease. Lowering the huntingtin protein in the nervous system is really good news – but it's not a cure. I think it's better to hope for an 'effective treatment'. We haven't cured diabetes or HIV, but medical advances have dramatically transformed those into manageable conditions and improved life expectancy. But they still exist in the world – progress happens gradually.

This a really important breakthrough at the biochemical level, and a really strong sign that we now need to move into a big trial. We think that lowering the huntingtin protein level with this drug has the potential to make a positive difference, even after symptoms have begun – but we won't know until a larger trial has been run.

Other options to explore

It's important to remember this isn't the only drug in development for Huntington's disease – it's just the one we're most excited about. There are many ways of achieving the goal of lowering the huntingtin protein, expected to start new trials soon or already in early trials. Plus, there are other drugs being developed and tested that aim to slow or prevent Huntington's in other ways, by helping restore normal functioning of the brain.

Sign up for email alerts at hdbuzz.net for the latest information about trials.

Watch our interview with Dr Ed Wild to learn more about this research news and what it means for families at www.hda.org.uk/researchinterview

Ask the expert: Preimplantation Genetic Diagnosis

Advances in medical techniques over the past few decades mean it is now possible for people at risk of Huntington's to have a family of their own without passing the gene onto their child. One of these techniques is called Preimplantation Genetic Diagnosis, known as PGD.

PGD expert Eshika Haque, Principal Genetic Counsellor at Guy's Hospital, London, explains what you need to know about the process.

So what is PGD?

PGD is a technique designed to help couples who are at risk of having a child with a serious genetic condition. PGD involves IVF (in vitro fertilisation) to create embryos in the laboratory from the couple's eggs and sperm. Each embryo is tested for the particular genetic disorder. Usually one unaffected embryo is then transferred into the womb, in the hope that a pregnancy will occur. This technique is currently only offered in a few centres in the UK.

The PGD centre at Guy's Hospital is the largest and most active in the country. The genetics PGD team consists of genetic counsellors, geneticists and trainee genetic doctors. We work very closely with the Guy's Hospital Assisted Conception Unit (ACU) which consists of IVF doctors, embryologists and IVF nurses. In addition to the clinical teams, PGD also requires the expert work of the PGD genetics laboratories.

What are the criteria to be eligible to have PGD through the NHS?

In order to be eligible for NHS-funded PGD in England, patients need to have a confirmed genetic diagnosis from an accredited laboratory and have been seen by a clinical genetics service. The female partner needs to be under 40 years of age at the start of treatment and have a BMI between 19-29. Both partners need to be non-smokers and have lived together as a couple for at least a year. In addition, they should not already have any unaffected children.

If patients fulfil all criteria for PGD, they are eligible for up to three cycles of PGD on NHS England. The policy for Scotland, Wales and Northern Ireland is different, though couples from these areas will need to meet the same eligibility criteria.

What happens during the PGD process?

Once we receive a PGD referral, one of the genetic counsellors will allocate the referral depending on the condition and whether we have a licence for the condition, which we have for Huntington's.

PGD is a lengthy process and can take between 10 - 18 months. If the cycle is successful, it is followed by nine months of pregnancy. At the start of PGD, couples have a one in three chance of success, but if they reach embryo transfer, which is when the embryos have been tested and the genetic condition excluded, then this becomes a one in two chance. However, it is important to note that PGD is not always successful and most couples do have other reproductive options available, which local genetics centres will encourage them to consider before proceeding with PGD.

We also offer PGD with Huntington's disease exclusion testing. This is the process by which you can have a child who is unaffected without having to find out if you carry the gene. This can be offered when someone is at 50% risk of having Huntington's and blood samples and test results are available from their affected parent. We use a technique called DNA linkage to test the embryos for Huntington's. This requires us to obtain blood samples or stored DNA from the couple and, in most cases, also their affected parent.

Where can people get more information?

We recommend that couples ask their GP to refer them to their local genetics centre, which will assess their eligibility and refer them onto the PGD team. More information is available at **www.pgd.org.uk**

"We decided to go through the genetic testing process as I didn't want to put my husband and I through potentially stressful IVF if I didn't have the gene. I had a positive gene result and we were referred to a PGD coordinator."

'Our little miracle girl'

Jenny and her husband Paul had always wanted a family. But as Jenny, whose mum had Huntington's, was at risk of inheriting the disease, they wanted to find a way to have children without the chance of potentially passing on the gene. Jenny shares their experiences of PGD.

The strangest thing about the process is that it disconnects you from the outcome in some ways. Everything is meticulously planned – tablets, injections, timetables, appointments. Having a fridge full of drugs and a strict timetable for taking them was just about okay. I had to tell some little white lies to make sure I could keep to the timetable of injections I had to do at home. It helped to have my manager at work as a 'keeper of secrets', to cover for my many weekday appointments in London!

We had 17 eggs harvested and ended up with ten fertilised. After they were tested, we were left with six. Over the next few days only four progressed well enough for implantation.

On implantation day, only one of the four had progressed well enough to implant. Unfortunately we couldn't freeze any unused ones, so we were lucky that one was just right for implantation. It was put into my womb through a long tube. You can see it happening using an ultra-sound machine. It glowed like a little sparkly light on the screen. And then that was that - off you go home and wait.

Two weeks later we did a pregnancy test on the allotted day and found that we were expecting a baby. It was a bit strange and took a good few months to get used to. Obviously we were over the moon and thankfully all went well through the pregnancy.

We feel so very lucky to have been able to have a child who is free of Huntington's – we feel as though we have a little miracle girl. Obviously we know that the PGD route is not so straightforward for many people. We are just thankful that we were lucky with our try.

Names have been changed in this article

Breaking down barriers to reach South Asian communities

We've joined a group of 12 charities supporting people with genetic disorders on a project to help improve knowledge and understanding of genetics in South Asian communities.

The project, which is funded by the Sylvia Adams Charitable Trust, aims to help organisations to develop new guidelines for supporting families at increased risk of having a child with a genetic disorder. It also helps to address difficulties and inequalities experienced by families in accessing mainstream services.

Organisers of the project said: "At Breaking Down Barriers, we believe that patient organisations and support groups have an important role to play in addressing the challenge of developing appropriate genetic services for the UK's multi-ethnic population. We want to strengthen the ability of patient organisations and support groups to develop supportive and inclusive services for individuals and families affected by genetic disorders.

"There are a small number of projects around the UK focusing on working with families from diverse backgrounds. Many of these are being driven by health professionals and while they may be benefiting small groups of people in specific locations, there is a clear need for a national project to benefit larger numbers of people. Breaking Down Barriers can provide a model of good practice whereby patient organisations and support groups can demonstrate a key role in providing effective support to families affected by genetic disorders."

Research shows that patients and families experience problems accessing services, so providing information about genetics that is easy to understand, and informing people about the different reproductive choices available, can help them make informed choices.

Through this project we've developed a new guide to give clear and concise information for families. Bill Crowder, Head of Advisory Service at the Huntington's Disease Association, said: "We have learned and shared a great deal by getting involved with this project and we are grateful for the investment from the Sylvia Adams Charitable Trust. I would also like to thank the families and professionals who gave their time and knowledge to help us create the new guide."

Download a copy of the new guide from our website at www.hda.org.uk/breakingdownbarriers or contact us on 0151 331 5444 to request a copy in the post.

Step forward in Huntington's disease insurance talks

Left to right: John Glen, Cath Stanley (HDA), Ruth Abuzaid (HDA), John Eden (SHA) and Gavin Newlands.

Many people have raised concerns with us about the issues and unfair treatment they feel they've faced when trying to get insurance.

Earlier this year we met with John Glen, Economic Secretary to the Treasury, alongside the Scottish Huntington's Association and Gavin Newlands, SNP MP for Paisley and Renfrewshire North, to put across the concerns that families have shared with us. We also met with the British Insurance Brokers' Association (BIBA) and the Association of British Insurers (ABI) to raise your concerns directly with these leading insurance bodies.

Thank you to everyone who shared their experiences with us. While insurance is always based on risk and that won't change, we have been exploring ways we can influence the system to make it as fair as possible.

As a result of our positive conversations, BIBA, 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 for travel insurance.

To use this service to find travel insurance for your next trip, visit www.biba.org.uk/find-insurance or call 0370 950 1790.

Sad news of the death of our Patron

We were very sad to hear that our Patron, the Dowager Countess of Harewood Patricia Lascelles, died peacefully at home on 4 May 2018 after a long illness.

The Dowager Countess of Harewood was a passionate and dedicated supporter of the Huntington's Disease Association and was involved for over 20 years.

Cath Stanley, Chief Executive, said: "The Dowager Countess of Harewood cared so much about the Huntington's Disease Association and even in her later years we were in regular contact. She was committed to families living with Huntington's disease and took a keen interest in the charity's activities. We are grateful for all she has done for the HDA. She will be greatly missed."

Welcome Lilly, our new Specialist Youth Worker

We are delighted that Lilly D'Cruz has joined us as a Specialist Youth Worker, helping children and young people growing up in Huntington's families.

Lilly will be working with children and young people in the South of England and South Wales, and will work in tandem with James O'Connor, our Specialist Youth Worker for the North of England and North Wales.

If you would like to make a referral to Lilly or speak to her about how the youth service could help your child, please call her on 0771 100 4146 or email lilly.d'cruz@hda.org.uk

Huge thanks to BBC Children in Need for funding our Specialist Youth Service.

Supported by BBC Children in Need

Hi, my name is Lilly!

I have a background in theatre, caring for people with Huntington's disease in a specialist residential home setting, and in education. I have a degree in performing arts as well as a PGCE in Primary Teaching. In my spare time I love to read and write and fundraise doing silly things such as walking the Malvern Hills dressed in an inflatable hippo costume! I love movies, music and the outdoors. I am half Burmese and own two adorable sister kittens. I am excited to meet some amazing people and be a part of their journey in any capacity. I have been welcomed massively into the HDA and am ready to hit the ground running.

Park Regis to support the HDA until 2020

We're delighted to have been chosen by Park Regis Birmingham, a city centre hotel, as one of its two supported charities for the next two years.

The HDA was chosen after staff submitted suggestions close to their hearts. The second charity to benefit is children's organisation Molly Olly's Wishes. Since opening in March 2016, Park Regis Birmingham has raised over £100,000 for local charities.

"We felt it was important to give our staff an opportunity to have their say on which charities we choose to support," said Mark Payne, General Manager at Park Regis Birmingham. "We usually have a single nominated charity but we made the unanimous decision to support two causes this year because they both do incredible work, supporting individuals and their families.

Left to right: Mark Payne (Park Regis), Kate Davis (HDA), Rachel Ollerenshaw (Molly Olly's) and Kathryn Rouse (Park Regis)

"We're looking forward to raising funds for the Huntington's Disease Association and Molly Olly's Wishes over the next two years and raising awareness about both of these fantastic charities."

Kate Davis, Head of Fundraising at the Huntington's Disease Association, said: "We're thrilled to be partnering with Park Regis as one of their nominated charities. We are a small charity that makes a big difference. Working with Park Regis will enable us to reach more people living with Huntington's and bring the disease out of the shadows, raising much needed awareness of this misunderstood disease."

Huntington's Disease Awareness Week
14 - 20 May 2018
#HDAwarenessWeek

Isle of Man

Plymouth Hoe

Mersey Gateway Bridge

Shining bright for Huntington's disease

Huntington's Disease Awareness Week returned earlier this year to bring our community together and unite against Huntington's disease.

We joined forces with Huntington's disease 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, the Gateshead Millennium Bridge and the new Mersey Gateway Bridge all lit up in pink and green during the week. While up and down the country, people lit up windows in their homes and workplaces with pink and green lights.

Huge thanks to everyone who took part in helping to raise awareness of this misunderstood disease – together we're helping to bring Huntington's out of the shadows.

Spinnaker Tower Portsmouth

Gateshead Millennium Bridge

Football legends

How one woman and her supporters keep life, and work, on track

Above: Emma gives a team talk to her players at the FA Youth Cup

Right: Emma with her manager John Eades

Emma Fletcher, 36, from Oldham near Manchester, has a demanding, fast-paced and varied full-time job. She is Girls' Football Development Manager for Manchester United Foundation, the famous club's charitable arm, using football to inspire young people and unite communities. Emma also has Huntington's disease.

A strong character who loves football, banter, hard work and a laugh with colleagues, it's been something of a journey for Emma, and her employer, to figure out how to adapt to Huntington's. It has not been easy, and they know it will get harder in times to come. But they've learned a lot along the way, and her story shows that a positive diagnosis doesn't have to mean a sudden end of someone's potential, or their career.

Emma's path to her future career started early. She explains, "I played football growing up, then at 13 I started playing for Oldham Athletic Ladies under 14s, then on to Oldham Athletic Ladies Senior team. I got a lucky break when the manager at Oldham Athletic, who worked where I am now, managed to get me two weeks work experience when I was still at school. I had the opportunity to coach and visit schools – that was it, I never wanted to do anything else."

Emma eventually got a job at what became Manchester United Foundation, got married, had a daughter, and continued to progress at work. She now manages 23 staff, three of whom deliver girls-only sessions of football in schools, and the rest, including a technical director, coaches, physios, strength and conditioning coaches, and psychologists, look after the club's Girls' Regional Talent Club, an elite girls programme. "The best thing about my job", says Emma, "is working with young people and developing them. Seeing them not only become better footballers, but also grow as young women."

A role like this involves a lot of hard work and hours, with evening and weekend work part of the job. When Emma found out about her diagnosis, for years she said nothing. "I was dreading telling them for a long time", she says. But a hospital consultant referred her to the Huntington's Disease Association and Specialist Huntington's Disease Adviser Debra Robinson came to see Emma and her family at home. "She was, and is, brilliant", says Emma. "She went through a lot of things – finance, all sorts of practical stuff – but she also encouraged us to prioritise and get things into perspective. When I felt it was time, she went to my employers and talked to my boss and HR."

Emma's manager John Eades, Operations Director for Manchester United Foundation, says he'd heard of the disease but didn't know much about it. "But after talking to Emma and the meeting with Debs, I was more able to understand what she was going through and how this might impact on her going forward. Between us we thought about ways to give Emma the support she needs. I was able to ask very direct questions and we all agreed the way forward was always to be frank and honest. But most of all, to talk."

Since that first meeting, many more conversations and plans have been put in place. For example, to help Emma avoid an exhausting rush-hour journey, she works her hours differently and sometimes works from home. She can work in her own space quietly when needed and controls her own diary to decide what she needs to do when, to enable her to manage her symptoms. The staff working for Emma have also been given an information session to help them understand the disease. Debs explains, "It took time to build trust, but we can be very open now. Emma's employers have been exceptionally good – she's still fulfilling her role but with a lot less stress and pressure."

Emma's boss John adds, "I said to Emma, you are the best person for this role, delivering highly successful football teams, elite girls and a grassroots programme that's growing every year. How can we keep delivering that momentum and the quality? Speaking with Debs, the HDA and occupational health, we implemented changes that have made this possible."

Emma says she couldn't have asked for any more support than John and Debs have given her. "They said you don't have to worry about work – we'll look after you and that's exactly what they've done."

The Huntington's Disease Association funds 23 full time specialist advisers across England and Wales, helping people live well with Huntington's. Support takes many forms and is tailored to need.

To find your local adviser, go to www.hda.org.uk/supportnearyou

Emma's five top tips for living and working well with Huntington's

1. It's not that I wanted to keep my illness a secret but I'm the joker of the pack, the crazy one and I didn't want people to change around me, or for it to be awkward. Initially I only wanted to tell one or two people, but once you start having those conversations, it gets easier.

2. Work isn't the be all and end all but it's a massive part of my life. Get your work-life balance right. Don't think because Huntington's is changing you, you can't be happy and enjoy the time you've got now, because that's what we have to do.

3. At one point three years ago, I didn't even want my job – my standards are very high and thought if I couldn't do things to my standards, that would drive me mad. I was wrong – I've massively changed my approach to work.

4. We are developing the team I have around me now, so if there are times I'm very tired or need to work at home, the staff can pick things up. It's been very positive for them, but it's also made it easier for me to work.

5. Don't think that change is for the worst all the time – flexibility in my working week now works for me and for everyone else. I also know there will come a time when I have to stop working, but I think I'll know when the time is right. Everything changes, but you keep going.

Admiration for friend inspires leading novelist's new book about Huntington's

Author Catherine Isaac is no stranger to writing about relationships, having penned romantic comedy for ten years as bestselling author Jane Costello. But when her friend found out about Huntington's in his family, she was inspired to step away from her usual genre and tackle this meaningful subject.

Catherine said: "The idea for *You Me Everything* came to me after someone I know discovered his mum had Huntington's disease. All these strange symptoms she'd had for years suddenly started making sense – the jigsaw fitted together.

"I was struck by the lack of understanding about the disease. That's why it came out of the blue for my friend. I learned there was a genetic test and my friend had the dilemma of whether to have it. He's chosen not to and lives a very fulfilled life. I admire him so much for that, and so my thoughts about it began to form a story."

The fictional tale explores the challenges of a family living with Huntington's disease. It follows the story of single mum Jess, who spends a summer in the French countryside with her son and ex-partner, after learning about her mother's Huntington's diagnosis.

Painting a realistic picture of the disease was really important to Catherine, so while researching the book, she contacted the HDA. "The initial thing that struck me about it was not just how devastating it is to the individual, but the ripple effect it has. I wanted to write a book about love and family and relationships. Yes, it's this disease that's running through the narrative, but the strongest message is the love they have in such difficult circumstances.

"It took a lot of research, as every stage of the disease is depicted in the book. I searched online, as well as speaking to my friend and the HDA. There's a lot of information available about the science, but I was conscious it would be easy to get something wrong. The HDA were so helpful, I'm immensely grateful." Cath Stanley, Chief Executive, said: "*You Me Everything* raises many of the dilemmas faced by Huntington's families. The importance of accurate information, even in fiction, cannot be underestimated, so having the opportunity to work with Catherine on this was invaluable."

Huntington's can be really negatively portrayed, so Catherine hopes her book will help to raise awareness and redress the balance. But it's the messages from readers that have made the biggest impression: "I had a lovely email from a lady who has decided not to get tested, but who has gone through the same experiences in the book. She said 'everything your character's been through, I've been through'. It meant a lot to me."

You Me Everything has been translated into 20 languages and movie rights optioned by Lionsgate.

Special offer

To order a hardback copy of You Me Everything for the special price of £10.99 (usually £12.99) with free delivery visit www.efcbookshop.com

Inherent: a Huntington's disease story

We collaborated with award winning social documentary photographer Stephen King to create an impactful awareness exhibition, giving our contributors the chance to tell their story and curate their own portrait. The exhibition is currently touring the UK.

Julie's story

"I'd never heard of Huntington's in my life. One night I say to the husband, Peter, to go to the doctor's about his legs. He was saying it was just because he'd worked on the roofing his whole life. "There's nothing wrong, it's just me legs are done in," he said.

With my husband, it wasn't so apparent because it wasn't anything mentally or in his manner. I'd see him coming down the road I'd think, "Has he had a pint?" He was doing crosswords up until the day he fell downstairs.

Peter died a short time later.

At the same time I was also having problems with one of my sons. He'd stay out, he was in a depression, wouldn't shave – he had this beard and his hair grew long. He wouldn't clean his teeth, he wouldn't get a wash. He was in this depression thing, and when we would bring a meal up to him and he'd say, "That's poison!"

It was only after the diagnosis and death of Peter that Paul was diagnosed with Huntington's disease. Julie discovered she had cancer at this time too, so Paul went into residential care.

Our Paul; you couldn't meet a nicer fellow. He was lovely, and for that to happen to him, I feel so sorry for him. I really do. But the only way I can comfort myself is by saying if they have fast cars and if they have an accident, you lose your child. If they get cancer, you lose your child. I've still got him. He's not telling me he's unhappy in his situation. He's getting along with it. I don't know whether I'm protecting myself because I don't want to lose him. I just don't want my kids to go before me and that's why I tried to get it all in order that Paul would be looked after, after I've gone.

He can't tell you how he feels, so me, as Mum, I'm going to be there on top of this watching what's going on. I'm his Mum and I'll make sure that he gets looked after.

I am the matriarch of this family, and they can all tell you that. I've got my cloak around them all. I have to protect my whole family, or they could crumble under, couldn't they? With my own illness, I'm not the type of person to crumble under. I was going through cancer, and I would still walk out with my head up in the air. The police would be outside taking Paul off to get him diagnosed… I'd still put my little bit of lippy on. I'll still get my hair done and live my life. I'm a good mother. A good grandmother and a good person.

We've been hit with this illness and I speak about it now. I openly tell people that I've got a son in care with Huntington's. I don't hide things. There's nothing to hide. So why people shove it under the carpet, as if it's not happening, I just don't understand. You've got to be aware of it, because it's in the family.

12 top tips: understanding changes in emotions and behaviour

Above: Professor Hugh Rickards

There's more information on our website to help make living with Huntington's that little bit easier – visit www.hda.org.uk/getting-help

Changes in the way we feel and act are common in Huntington's and can sometimes be difficult for other people to recognise. Understanding these changes can help improve life for the person with Huntington's and those around them.

Neuropsychiatrist Professor Hugh Rickards explains 12 ways Huntington's disease can affect mental health. "Huntington's disease can affect emotions and behaviour in different ways, including irritability, apathy, depression, anxiety and problems with remembering. When this is coupled with changes in posture, and facial expression, it can make emotions difficult for others to spot and adjust to. Understanding these symptoms and their effect can go a long way towards improving quality of life for people with Huntington's, their families and carers."

Getting overloaded
Sometimes people with Huntington's find it difficult to multi-task so they may find some situations, including social gatherings and some types of work, difficult to cope with.

Difficulty with getting started
Sometimes people with Huntington's may not get started with activities. This may be because they have difficulty in imagining things to do, or in getting going.

Grumpiness
People with Huntington's can have short fuses. This is usually because they're feeling anxious about dealing with situations, especially if there's a change in the plan or too much happening.

Being content
Quite a lot of people with Huntington's can be mentally content throughout the illness, even if they don't appear to be doing much. They may well be quite happy living in a world with less going on.

Anxiety
People with Huntington's can often get anxious at all different stages of the disease. In the early stages, people commonly worry about the future and in the later stages anxiety often comes with overload or changes in routine.

Treatments really help
With a proper assessment, many mental and behaviour changes in Huntington's disease can be managed really well. This might include medicines, changes in the environment or with talking treatments.

Understanding what's going on
Some people with Huntington's can find it difficult to pick up what's going on in social situations and this can result in them appearing rude or uncaring.

Physical problems can lead to behaviour changes
If there's a change in a person's state of mind or behaviour, it's important to make sure there are no other physical triggers, like infections, pain, or constipation.

Getting a bee in your bonnet
It's really common for people with Huntington's to keep thinking about something long after everyone else has moved on.

Depression
Depression is more than just being sad. The main thing to watch out for is if people don't get any pleasure in everyday things (like a cup of tea or a favourite TV programme) and this is there almost all the time for a few weeks.

Wait during conversations
People with Huntington's can have difficulty processing stuff so you may need to wait after you've said something before rushing in to say the next thing. They may not be able to get a word in edgeways if you don't slow down a bit.

It's not always about Huntington's disease
All of us have changes in the way we feel and behave all the time; it's a normal part of life. Don't assume that changes in a person with Huntington's are caused by the Huntington's – they might just be fed up with a bunch of non-Huntington's things that affect us all!

Whether it's baking, biking or bingo, our dedicated supporters do so much to raise funds and awareness. Thank you to each and every one of you for helping to make a better life for people affected by Huntington's disease.

Memorial golf day reaches fundraising milestone

An annual golf day in memory of Susan Clayton, who had Huntington's disease, has now raised over £100,000 for the HDA.

Susan's husband Neville Clayton and his daughter Lisa set up the Susan Clayton Memorial Fund to honour and remember Susan, and have organised the popular tournament each year for many years. Along with their fellow trustees, the dedicated family from Surrey have recruited teams of golfers, arranged celebratory after dinner speakers, organised highly successful auctions and have continued to find new ways to raise funds.

Last year their event raised £4500 and they hope to raise even more funds at this year's golf day, which will be held at Guildford Golf Club at the end of July.

Huge thanks to Neville, Lisa and all those involved for the amazing effort they have put into raising this incredible amount of money in Susan's memory.

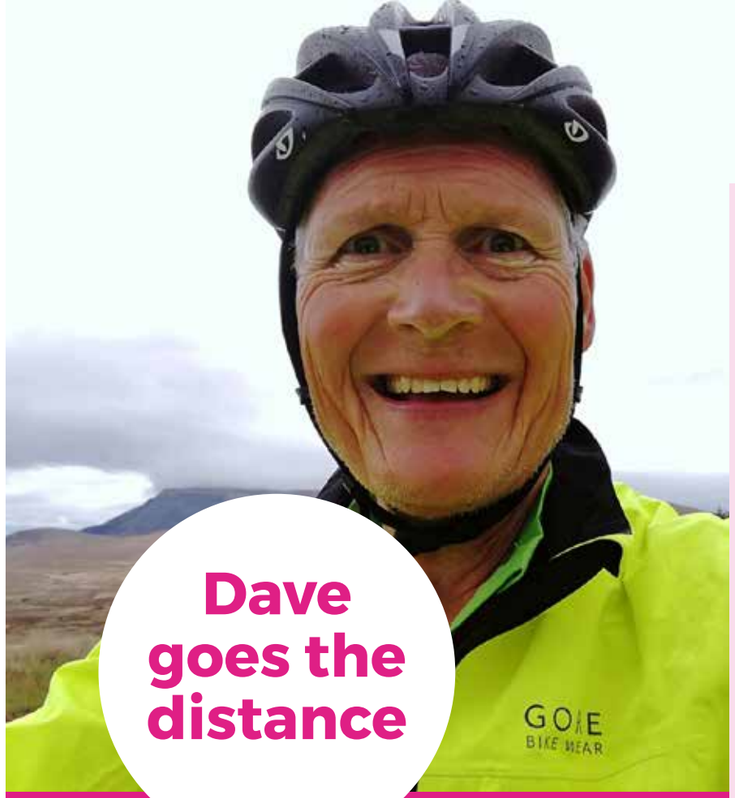
Sixth form students smash it!

A group of sixth form students from Ashton on Mersey School in Manchester dedicated a whole fortnight to raising funds and awareness of Huntington's throughout their school.

Sixth Form Manager Gill Fox said: "Every year the students select a charity to support, and this year they chose a charity close to the heart of one of our students and their family.

"The group worked tirelessly raising awareness of Huntington's disease and fundraising for the Huntington's Disease Association. They visited every year group and explained what Huntington's is and how it affects people. They sold doughnuts, counted sweets, sold ice-creams, played football, table tennis and arranged a pool tournament and even washed 35 staff cars to raise as much money as possible.

"They actively promoted and supported the charity every day over a two week period in March and were rewarded with an amazing amount of £5161.21 to donate to the HDA."



Dave goes the distance

Cyclist Dave Goater had a very personal reason for setting off on an epic cycle from John O'Groats to Land's End, after the partner of his close friend sadly died from Huntington's disease.

Dave, who was joined during his challenge by his friend Jon, said: "Jon and I set off on our cycling challenge on 20 May. The route took us on quieter roads travelling roughly 100 miles a day. Our journey took us through the magnificent countryside of the Scottish Highlands including Loch Ness, Fort William, along Loch Lomond, to Glasgow city centre and on to the Lake District. Leaving the Lakes behind us, we headed for the Forest of Bowland, on to the Shropshire Hills, Monmouth, across the Severn Bridge and over the Mendip Hills in Somerset. In the West Country we headed for Dartmoor, climbing up and over the moors down into Plymouth. We crossed the river Tamar and embarked on the most gruelling and hilly day of the journey, finally reaching our destination of Land's End late evening on 29 May.

"There's no doubt that the support from strangers, encouragement and messages from family and friends along the way helped us complete the challenge. We could not have achieved our aim without it. A big thank you to everyone who helped and donated."

HDA chosen as charity of the year

We are honoured to have been nominated by the new President of the National Association of Funeral Directors (NAFD), Abi Pattenden, as the organisation's charity of the year.

Abi (pictured above) has both personal and professional reasons for choosing to support the Huntington's Disease Association during her year as NAFD president. She explains: "One of my first, and still most memorable, funerals was for a gentleman who had died of Huntington's. His wife had cared for him for many years and I will always remember the dedication she had to him in the face of the obvious difficult experiences they had shared."

Abi's experiences outside her career have also influenced her decision: "I have a close friend whose family is affected by Huntington's and, through her, I have learned about all the research being carried out. This is inspirational work and shows how progress can be made when people ignore conventional approaches and work together. Finding new and collaborative ways of working is one of my real interests and I couldn't think of a better way to reflect this than to promote such a worthwhile cause."

As well as offering support through raising funds, Abi is keen to raise awareness of the disease among funeral directors across the UK, and to promote the significance of tributes and legacies that can be made in honour of a loved one.

Marathon success for #teamHDA

Kevin Hooper

Paul Hooper

Kevin Hooper with his dad

"Raising awareness through wearing the HDA vest out and about during training allowed me to become more open and confident to talk about the illness."

The London Marathon is a huge highlight in the HDA fundraising calendar. It's a true challenge and a wonderful opportunity to raise awareness. With only ten charity places up for grabs each year, we always receive many more applications than spots available.

This year, a further 17 fantastic HDA runners gained a place through the public ballot, joining #teamHDA to make our largest ever London marathon team. With strength in numbers on their side, the group raised over £67,000 – beating the current HDA record for the largest fundraising total at a London Marathon.

Two members of #teamHDA, cousins Kevin and Paul Hooper, share their story about what motivated them to lace up their trainers to raise funds and awareness for the HDA.

Paul: 'So why are you running the London Marathon again?' That seems to be the question I got from everyone. I guess the easy answer would be that I'm trying to raise as much money as possible for the Huntington's Disease Association. The truth however is a little more complicated.

I was about 14 when Huntington's came into our lives, at which time I had no idea what lay ahead. Over the next few years, we discovered how unforgiving and completely devastating this terrible disease is. As a family, we grew close, but there was also loneliness, fear and confusion about how to express my emotions. Over the years we learnt to live with Huntington's, as so many people do, trying desperately hard not to allow it to dominate our world.

As the years passed following my dad's death, Huntington's became less dominant in all our lives and its voice became just a whisper, hardly heard. Maybe it was still there but we had just decided not to listen for a while. Life goes on and if I've learnt anything it's that we must live each day to the full.

Running together

Kevin: Running the London Marathon with someone who has a direct link to our family meant a great deal to me. The illness can cause some families to isolate themselves from each other and we are no different, so it's been a great chance to reconnect with each other.

Paul: Over recent years I've not had much contact with Kev, as we both left Cornwall where we grew up and set up lives elsewhere. Huntington's ripped through our family and this had such an impact on us all. We have both lost our dads, aunties and uncles to Huntington's so there is a real understanding of what it meant to run the marathon. We did it for them, but also for those affected now and in the future.

Getting a place on #teamHDA

Kevin: I was delighted to get a HDA charity place, as I've tried for the last six years through the ballot but have never been successful. To be chosen makes me feel proud because I know that any money and awareness of the illness is brilliant. As a teacher, it has given me a platform to give assemblies at school to talk about the illness and my training.

The amount of support I received from a huge variety of people, some of whom I've never met, and my family has been brilliant. While I was training my son Sam asked, "how far are you going tonight?" and then made a face, which made me chuckle.

Paul: I've run the London Marathon twice before. Running for the HDA means so much to me and I am so proud to have done it again this year. I was lucky enough to get a ballot place which is fantastic as it means more money for the HDA.

I have quite a full on job as Head Teacher of a large London primary school, so getting out on the training runs was really good for me. It gave me a lot of time to think and de-stress which was great.

Making an impact

Kevin: Raising awareness through wearing the HDA vest out and about and being able to talk to 1800 pupils plus staff at school about the illness allowed me to become more open and confident to talk to anyone about the illness. It's also enabled me to actually talk about how I'm feeling and not to be a typical stubborn male.

Paul: Running the marathon had lots of positives. The support I received from friends and family gave me the biggest boost. I grew up feeling quite alone at times, afraid to share my Huntington's story, so getting such great support meant a lot to me. I want to help the fight against Huntington's disease and so supporting the HDA is the best way I can see to do this.

Have Kevin and Paul inspired you to take on a fundraising challenge of your own?

Visit www.hda.org.uk/fundraising for information and inspiration.

Join us for our Family Weekend

"A relaxed atmosphere of companionship and fun."

12 - 14 October 2018 Radisson Blu Hotel, East Midlands Airport

Your chance to learn more about Huntington's and meet others who are also living with the disease, as well as finding out what's new in Huntington's care, research and management.

Find out more

For more information please call 0151 331 5444 or email info@hda.org.uk or tweet us @hda_tweeting using hashtag #HDAFW18

* Formal notice of the AGM can be found on our website
Speakers and workshop topics may be subject to change

Talks

Professor Anne Rosser from Cardiff University shares latest research news and updates on clinical trials

Harry-Jon Morgan gives a family perspective on Juvenile Huntington's disease and talks about his family's loss and fight with Huntington's

Cath Stanley, Chief Executive, speaks about the work of the HDA

Workshops

Genetic testing for Huntington's

Understanding mental health

Practical aids and equipment

Talking to children about Huntington's

Relaxation techniques

What else is happening?

Saturday evening is a formal dinner with a country and western theme disco

An offsite trip and activities will be available for children and young people

We'll also be showing the film Dancing at the Vatican about the families who inspired the audience with Pope Francis in May 2017

This weekend incorporates our AGM and the chance for questions to be put to our board of trustees*

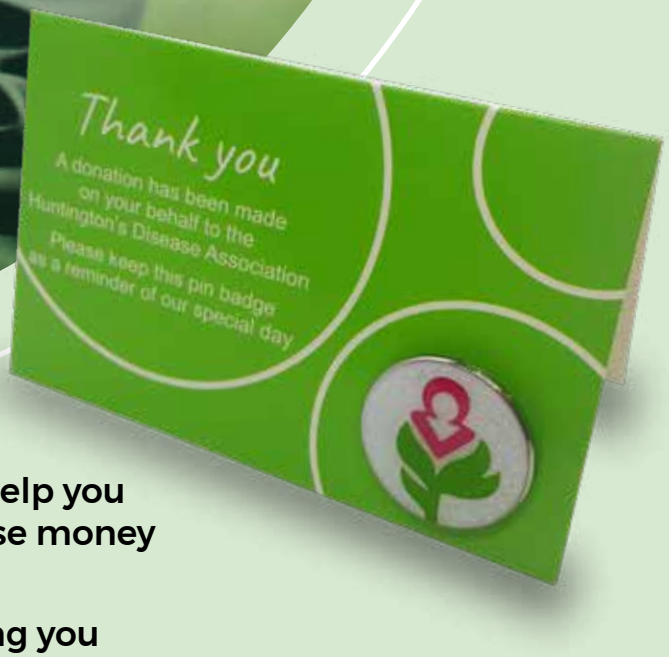
There for each other. Branches and support groups

Local branches and support groups are an essential lifeline to people across England and Wales who are living with Huntington's or caring for a loved one. These groups give an opportunity for people to get together and share their experiences; something that is so important in rare conditions like Huntington's.

Many groups arrange talks, social events and fundraisers, which can offer support and respite for local families, and also help to increase awareness of Huntington's disease and raise vital funds.

If you're interested in getting involved with a local group, or finding out more about what's happening in your area visit www.hda.org.uk/branches or call 0151 331 5444.

A heartfelt way to celebrate your special occasion



Our occasion favour is the perfect addition to help you celebrate your special day, while helping to raise money and awareness for Huntington's disease.

It's a perfect way to thank your guests for joining you in your celebrations and to honour the memory of or support a loved one.

Buy online at www.hda.org.uk/shop

Get in touch

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

Email: **info@hda.org.uk**
Phone: **0151 331 5444**
Web: **www.hda.org.uk**

Get involved

Become a fundraising volunteer

Email: **fundraising@hda.org.uk**
Phone: **0151 331 5445**
Web: **www.hda.org.uk/fundraising**

Design and print by Captiv8. www.captiv8uk.co.uk 01892 611500