

# Huntington's Disease Association Newsletter

Summer 2017



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## Global Huntington's community joins together for audience with Pope

"May none of you ever feel you are alone" was the powerful message given by Pope Francis I to the Huntington's community.

On 18 May, Pope Francis hosted the largest global gathering of the Huntington's community at a special event at the Vatican. The occasion took place during Huntington's Disease Awareness Week, with people from all over the world in attendance.

He is the first Pope and prominent world leader to recognise the difficulties faced by the families affected and raise the issue on a global scale. His message was one of hope, resilience and a need to end the stigma that has long been



*Kevin Orrick from Liverpool travelled to Rome with his family to receive a blessing from the Pope*

attached to the disease, which has kept it hidden.

The families were joined by researchers who are searching for a cure and representatives from organisations across the world who support people with Huntington's.

Kevin and Gloria Orrick from Liverpool were among the families from the UK who were

blessed by the Pope.

Gloria said: "When our son Kevin was diagnosed with HD it was devastating news, both for Kevin and also the family. Learning about the trip to the Vatican was brilliant. It means the world to us and to Kevin, as it provided us with the chance to meet other people who are affected by HD. It is a constant reminder to us that there are other families in the same situation as us. It gives Kevin and our family hope and faith for the future. No one should have to face HD alone and it is important for everyone to reach out for support."

After meeting the Pope, Kevin said: "I felt blessed, epic, awesome and not alone."

**To watch Pope Francis' special message for the Huntington's community visit: [hddenomore.com](http://hddenomore.com)**

## Bringing Huntington's disease out of the shadows

Thank you to everyone who helped to shine a light on Huntington's disease during Huntington's Disease Awareness Week. By sharing information, organising an event, raising funds and taking part in the #LightItUp4HD campaign, you've all helped to get people talking about Huntington's.

**Want to get involved? Look out for information about next year's activities on our website early next year.**



We were delighted to see so many people proudly lighting up their homes as part of the international awareness campaign, #LightItUp4HD. You were in good company, with famous landmarks up and down the country including Blackpool Tower, Gateshead Millennium Bridge, Spinnaker Tower in Portsmouth and Plas Heli in North Wales turning pink and green during the week.



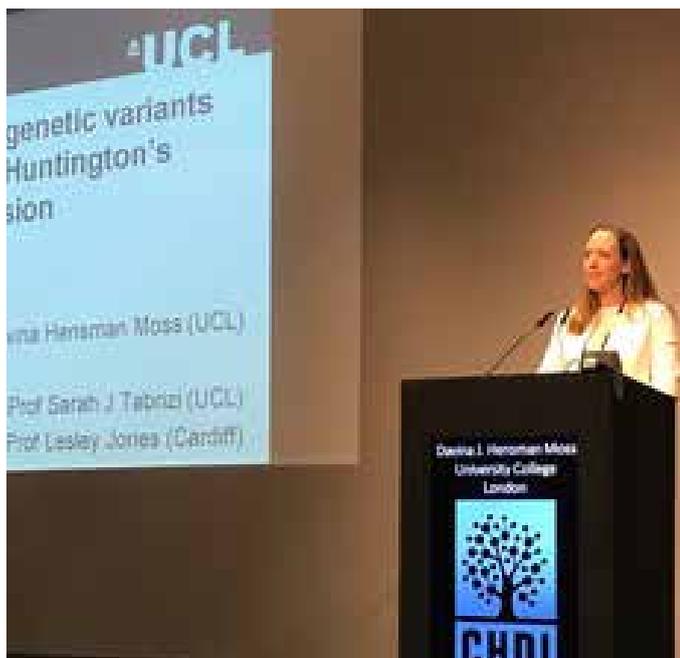
Throughout the week, our volunteer ambassadors shared their experiences of HD on the radio and gave interviews to local press, reaching new audiences who may never have heard of Huntington's before. Thank you to everyone who has shared their story to help others get a better understanding of the disease.



Thank you to everyone who shared, tweeted and posted online throughout the week. Our information about Huntington's disease reached over a quarter of a million people on social media, helping to educate the public about the disease.

# Research update from CHDI's HD Therapeutics Conference

Each year, CHDI (Cure Huntington's Disease Initiative), the independent Huntington's disease research foundation, hosts a conference to share the latest knowledge in HD research. **Cath Stanley**, Chief Executive of the Huntington's Disease Association, summarises news from the conference below.



## Genetic variations

We know that people with HD don't all have the same number of CAG repeats. We also know that the length of the CAG repeat is the main thing that tells us why people's first symptoms of HD start at different ages. But, researchers wanted to find out why people with the same number of CAG repeats can have the onset of symptoms at different ages. A major finding from a study called GeM-HD found that mutations in the genes involved in repairing damaged DNA influence the age when HD symptoms occur.

Another finding based on work carried out from a study called TrackHD discovered genetic variations outside the HD gene led to alterations in the rate of disease progression. The molecule RNA is a chemical 'ferry' that messages information from DNA to make proteins in cells. Work at producing models of the 3D shape of the RNA made from the HD gene open the potential to look at new ways to stop cells from making mutant huntingtin protein, which is the most likely culprit for making cells sick in HD.

## Huntingtin lowering therapies

Huntingtin lowering therapies aim to reduce the effects of the mutant huntingtin protein, which is

known to cause HD. Developing an accurate way of tracking the progression of HD is important for monitoring the effect of any treatment. As brain cells get sick they release their contents into cerebral spinal fluid and some of this debris leaks into the blood. The research team at University College London, led by Dr Ed Wild, have discovered a marker in the blood that increases as HD progresses, which will enable us to track the health of brain cells.

New gene editing tools designed to reduce levels of the HD gene are being developed. Using viruses these tools have been able to enter the brains of mice with HD and scientists say they have seen a reduction of huntingtin protein in the animals' brains. CHDI are investigating over 130,000 different chemicals to try and find a molecule that will result in lowering the huntingtin protein. So far they have identified four different chemicals that result in lowering the protein.

## Brain cells and connections

Scientists brought updates on research into understanding how HD affects the brain, and explained breakthroughs in using brain cells to understand and treat HD. Studies looking at how connections in the brain are altered in HD can give insight into changes in movement, mood and motivation. Studies looking at a process called 'inflammation' show that specialist cells called microglia act as an immune system in the brain, activating in response to damage. Excess brain cells are made during normal brain development and when they die the microglia clear them. This process also happens when brain cells are damaged and offers researchers a potential new method of trying to slow degeneration in the brains of people with HD.

Researchers have also developed a way to convert skin cells into the type of neurons which are most vulnerable in HD. These neurons are usually hidden deep within the brain so this is an exciting discovery.

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**This information was adapted from HD Buzz – Huntington's disease research news written in plain language by scientists. To keep up to date with the latest research news visit: [hdbuzz.net](http://hdbuzz.net)**



## Dates for your diary

**Family Weekend and AGM**  
Friday 13 – Sunday 15 October 2017

Radisson Blu Hotel, East Midlands Airport, Derby  
Join us for a weekend of workshops, information sessions and a 'night at the movies' party. Hear from scientist Dr Ed Wild about latest research. Learn from executive coach Paula Meir about her experiences of Huntington's and how she's overcome challenges. Gain tips from practical sessions such as relaxation and understanding benefits.

**Certificated course in Huntington's disease for healthcare professionals**  
Tuesday 21 – Wednesday 22 November 2017

Friends Meeting House, London  
An essential course for any healthcare professional, covering topics including genetics, neurology, communication and the impact of HD from a family perspective.

**For more information or to book onto either of our upcoming events, please email [info@hda.org.uk](mailto:info@hda.org.uk) or call 0151 331 5444.**

## New care home quality project to be launched

Deciding to move into a care home is one of the most difficult decisions someone with Huntington's disease and their family may ever have to make.

For some people, the move can make a huge difference to their quality of life. But we know not everyone shares this experience, and we want this to change.

We're launching a new project which aims to help families have confidence when it comes to choosing a care home. The project aims to create an accreditation scheme for care homes that look after residents with Huntington's. By successfully completing the accreditation process, care homes will show that they give the right care needed by those who have the disease.

Cath Stanley, Chief Executive said, "Families living with HD often tell us that one of the biggest decisions they have to make is when their loved one can no longer be cared for at home. The idea of the scheme came from carers who have made this difficult decision, and felt that such a scheme may have reassured them at a challenging time."

While there are examples of excellent standards of care around the country, quality of care can vary from place to place. This project aims to tackle these differences and recognise the care homes giving great service.

Personal experiences of families who have experienced a care home environment will be at the heart of the project. These experiences will help identify adjustments that can be made to improve the understanding of Huntington's disease, making sure that residents get the best care possible.

**If you'd like to help by sharing your experiences of the care your family has experienced, or you'd like more information about the project, please get in touch with Ewan McHenry, Project Coordinator, by email: [ewan.mchenry@hda.org.uk](mailto:ewan.mchenry@hda.org.uk) or telephone: 0151 230 2171 or mobile: 07841 037625.**

## Have your say and help families living with Huntington's



### Do you have experience of Huntington's disease?

Would you like to be involved in planning and commenting on HD research and literature? We're looking for volunteers to help us learn more from the families we work with to join our HD Voice group. There are two ways you can get involved:



**Research Panel** Have your say by helping to select the research projects the HDA gets involved with or by working with researchers to plan and develop their investigations.



**Reader Panel** Help us make sure our information about Huntington's is useful by reviewing our materials, such as guides and website updates.

To find out how you can get involved please contact Ruth Abuzaid by email: [ruth.abuzaid@hda.org.uk](mailto:ruth.abuzaid@hda.org.uk) or telephone: 0208 446 9879



# Marathon success for #TeamHDA

**Congratulations to the 20 fantastic runners who took part in the London marathon in aid of the HDA earlier this year. The dedicated group have raised over £55,000 between them! This fantastic amount will make a great difference to families facing Huntington's disease.**

Experienced runner Linda Cullin Moir, who has Huntington's disease, already had six London marathons under her belt before embarking on this year's challenge.

Linda said: "I was diagnosed with Huntington's disease in December 2012. I was the first person in my family to be diagnosed. I initially thought I was suffering from work related stress and fatigue. I had to retire from work and now cannot drive either.

"My father was subsequently tested and found to have the faulty gene. He had passed it on to me unknowingly. There is also a 50% chance of it affecting my sons at some point in the future.



*Left: 12 of our fantastic #TeamHDA runners who conquered 26.2 miles across London. Above: Inspirational marathon runner Linda Cullin Moir with her finisher's medal*

"After diagnosis I was supported by the Huntington's Disease Association. By running the London Marathon, my seventh and last, my aim was to raise awareness and funds to help the HDA and others."

**Fancy taking on your own challenge? Get in touch with our fundraising team by email: [events@hda.org.uk](mailto:events@hda.org.uk) or telephone: 0151 331 5445 to request your fundraising pack.**

## Helpful hints

 Finding things to do with a loved one when their memory and concentration skills get weaker can be difficult sometimes. Winslow Resources have some great books, games and other resources to help keep the mind active. Find out more at: [www.winslowresources.com](http://www.winslowresources.com)

 Looking for a getaway this summer? A new fully accessible holiday cottage has opened in Derbyshire. The site is welcoming, spacious and flexible and is run by a couple who have experience of working with people with disabilities. Find out more at: [www.vicaragefarm.co.uk](http://www.vicaragefarm.co.uk)

 We know how difficult it can be when someone dies. If you are struggling with funeral costs, sometimes the British Gas Energy Trust can help. Find out more at: [www.britishgasenergytrust.org.uk](http://www.britishgasenergytrust.org.uk) Information on other support available can also be found at: [www.gov.uk/funeral-payments](http://www.gov.uk/funeral-payments)

**If you need advice, information or support about Huntington's disease, our Specialist Huntington's Disease Advisers can help you. Please call 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)**

**Huntington's Disease Association**  
Suite 24, Liverpool Science Park IC1  
131 Mount Pleasant, Liverpool, L3 5TF  
0151 331 5444 | [info@hda.org.uk](mailto:info@hda.org.uk)  
[www.hda.org.uk](http://www.hda.org.uk)  
 @HDA\_tweeting  
 @hdauk