



Huntington's
Disease
Association

Newsletter

Winter 2018

Latest in research news from the European Huntington's Disease Network

The 2018 European Huntington's Disease Network conference took place in Vienna from 14 - 16 September. This fantastic gathering brought researchers, clinicians, families and patient associations together to learn about the latest news in Huntington's research. Our Chief Executive, Cath Stanley, shares updates from the conference.

"The opening session of the EHDN conference was a reminder that with all the recent progress into Huntington's disease research it is important to remember the history and stories that have gone before. It was pointed out that it is 25 years since the gene was isolated.

"Gene therapy was the focus of the days' talks with researchers talking about both protein lowering and gene editing techniques. There was discussion about balancing realism against hope and the importance of having hope. Researchers talked about the importance of biomarkers - these are ways of measuring both disease progression and any benefit of prospective treatment.

"Further presentations focussed on keeping brain cells functioning

and how we slow disease progression. Talks looked at the importance of having an enriched environment and regular exercise, which may have an impact upon progression of the disease.

"The definition of Juvenile Huntington's was discussed as often the person or child may be an adult whilst still displaying symptoms.

"The results of the Pfizer Amaryllis and Legato studies showed that they had failed in their primary goal to improve the motor function. This is a reminder that scientific trials are just that - to test a theory that something might happen. Lessons will be learned that may help further studies to become successful.

On the positive side, Wave Life Sciences showed a different approach that really is cutting edge and we look forward to the outcome of the trial in patients which should hopefully be early next year.

"The final session was the one



"I'm always heartened by the closeness of the Huntington's Community and this Conference was no different. I came away with new knowledge, new contacts, new friends and renewed optimism."

**Steve Duckett,
family member**

that we were all waiting for - the Ionis (now RG6042) trial and Roche Pharmaceutical's announcement of the beginning of the recruitment of over 600 patients worldwide for the phase 3 trial. Trial sites have not yet been identified. RG6042 has the potential to provide clinically meaningful effects on disease progression in people with Huntington's. This is just the beginning and there may be challenges along the way but there is now real optimism within the Huntington's community."

Top tips for a Huntington's home

The home can be a hazardous environment for someone with Huntington's, but there are many ways to minimise risks and make things easier around the house. There are things you can do at little or no cost that will make a big difference to someone living with Huntington's disease.

Occupational therapist Alex Fisher shares her tips on aids and adaptations that can help life in the home.

Maximise light and space



People with Huntington's have different perceptions of space, so make sure there's plenty of light and a clear space around them to help minimise accidents in the home.

Think 'house of hazards'



Decluttering can help maximise light and space in the home, making things easier to access and helping to reduce the risk of falls and accidents. Start thinking of what could be a hazard to a person with Huntington's, such as sharp corners and trip hazards. Corners of furniture can be protected using corner bumpers, which can be bought from shops like Ikea. Use cable ties to gather loose wires and make sure any rugs are stuck down securely with rug tape to minimise trips and falls.

Specialist equipment isn't always necessary



You don't need to spend a fortune getting specialist equipment. Things like a simple sports cup with a one way valve will help stop spills when drinking, and will limit the amount of liquid being swallowed at once, making it easier to keep hydrated.



Introduce changes early



Try to introduce aids and ideas early on while the person still has reasoning. If you make these changes part of a routine, it will be easier to keep them in place when they are needed in the future.

Enrichment



People with Huntington's need mental stimulation, so keep the place homely with pictures and mementoes, even when decluttering. Try and make a space with no distractions for activities they enjoy, such as a crossword, puzzle or watching a movie.



ICE

In Case of Emergency (ICE) is an easy way for first responders such as paramedics and police to contact your next of kin. Record their name and number in your mobile phone in a contact called ICE as a way to help yourself in an emergency. Voice controlled devices, such as Amazon Echo, can also be set up to ring someone in your mobile contacts when asked. This can be helpful for people in the earlier stages of Huntington's as it's controlled by speech rather than needing to use your hands, and devices can be positioned around the home for easy access.



Fire

Some fire services can provide disabled or vulnerable people with fire retardant blankets, duvet covers, smoke alarms and other fire prevention equipment. This is helpful for people with Huntington's who like to smoke in bed. Contact your local fire service to see what they provide. You can also let them know if someone with a disability lives at the address, which may help if they attend an emergency at your home.



Find more information and advice on living with Huntington's on our website at www.hda.org.uk

Fundraising success stories from #TeamHDA

Do it for Dom

Our community fundraiser
Hannah Longworth met up with Suzanna Mavity to find out more about the amazing fundraising ventures she, her friends and colleagues are involved in, their inspiration and progress to date.

What is your connection to Huntington's?

Our friend Dominic was diagnosed with the disease last year.



Kerri Mullaney with Kate Davis (centre) and Kelly Norton (right)

Glamorous fundraising ball raises thousands

Dedicated fundraiser Kerri Mullaney gathered family and friends together in Northallerton to help her say 'Balls 2 HD' at a glitzy gala dinner, complete with raffle, magician and live music.

Kerri said: "Huntington's has affected my family for generations and still continues to do so. My father was the only one in six siblings not to inherit the Huntington's gene. He's been a great inspiration within our family to fundraise.

"When we were young we believed that we were the only family in the area affected by Huntington's, but through our fundraising we have met many other families. The support provided by the HDA is invaluable to these families and without fundraising this support would not be available.

"We were honoured to have Kate Davis from the HDA attend the ball and give a deeper insight into how funds are used to provide support to anyone affected by Huntington's disease. We are planning another ball for summer 2019."

What motivated you to start fundraising?

Unfortunately the disease made Dom feel depressed, consequentially we not only wanted to help raise money, we wanted to show Dom how important he was to all of us.

What did you do to raise funds?

We are known in the industry for our nights out rather than fitness related events! So we decided if we were going to raise a lot of money it needed to be something different and challenging. So we took 49 people up Snowdon and raised both individual and corporate sponsorship.



How did it go?

It was a challenge! But 49 people went up and 49 came down! The event was emotional to say the least and it certainly took some work but every single person was proud to have taken part.

How much did you raise?

We originally wanted to raise £50,000, but to date we are on £69,000 and still going, we are striving for £100,000.

Lindsay's Great North Run

Lindsay Ford was one of 31 #TeamHDA runners who took part in this year's Great North Run. This epic team raised a huge combined total of over £24,000. Lindsay shares her story about why she took on the 13.1 mile challenge in aid of the HDA.

"My husband Gary began displaying Huntington's symptoms about 6 years ago. Mainly mood swings and lack of coordination at first but that was enough to confirm his suspicions that Huntington's disease was rearing its ugly head again after seeing his late mum suffer with the disease.

"Gary struggled to cope when he could no

longer work and activities of daily life became more difficult. I reduced my working hours and we began making the most of life with lots of trips and holidays making memories with our son.

"I completed the half marathon with Gary's brother Chris, who gave me words of encouragement along the way. It was a difficult run emotionally and physically but we got to the finish line together. Together we raised nearly £3800. We are so grateful and overwhelmed by the support and generosity of family friends and strangers."

Lindsay with her husband Gary (centre) and brother in law Chris (right)



Meet our new trustee

We are delighted to welcome Steve Duckett to the Huntington's Disease Association's board of trustees.

Steve brings with him a wealth of experience with a degree in Microbiology and Genetics, a diploma in Environmental health and prior experience of leading a department dealing with public health, housing and planning. Steve now cares for his wife who has Huntington's disease and recently became chair of the Dorset HDA branch. He is also an active member of HD Voice, the HDA's patient engagement group and HD Cope the global patient engagement initiative. He will certainly be an asset to the Association.



Dates for your diary

The Inbetweeners day

16 February 2019 - London

An informative event for those aged 35-45 with Huntington's in the family. Discussion topics will include mind and body wellness, forward planning and there will be opportunities to share experiences.

Young adults' weekend

23 - 24 March 2019 - Telford

A weekend for those aged 18-35 with Huntington's in the family. Two days of informative workshops, talks and an opportunity to meet others facing similar dilemmas and decisions.

Huntington's disease Awareness week

13 - 19 May 2019 - Shining a light on Huntington's.

Look out for information about planned activities and how you can get involved on our website early next year.

Certificated course in Huntington's disease

21 - 23 May 2019 - Liverpool

An essential course for any healthcare professionals covering topics such as genetics, neurology, behaviour and communication.

JHD weekend

31 May - 2 June 2019 - Calvert Trust Lake District

An activity weekend for children or young people affected by Juvenile Huntington's and their families.

For more information or to book onto these upcoming events, please visit our website www.hda.org.uk or contact us on info@hda.org.uk or 0151 331 5444.

Helpful hints



Innovative 'red bags' that help care home residents admitted to hospital be discharged

quicker are being rolled out across the country. The bags, which contain key paperwork, medication and personal items like glasses, slippers and dentures, are handed to ambulance crews by carers and travel with patients to hospital where they are then handed to the doctor. If your loved one is in a care home and

you think they would benefit from this speak to the care home manager.



If you paid to register a Power of Attorney in England or Wales between 1 April 2013 and 31 March 2017, you're owed a refund of up to £54. You can claim it online at www.gov.uk/power-of-attorney-refund or call 0300 456 0300. The deadline for applying is 31 January 2021.

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

We'll be there

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