Huntington's Disease Association

WINTER 2022

Newsletter

Huntington's Disease Association

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Huntington's Disease Association

A message from Cath Stanley

Chief Executive

It is fair to say given the current economic and political uncertainty, we are facing some difficult times. We are really aware of the impact the cost of living crisis is having on the Huntington's community and have gathered some resources which we hope will help in some way. Please visit the cost of living hub which can be found on our website.

hda.org.uk/getting-help/information-resources

This means our work supporting those affected by Huntington's disease is more important than ever. It also means that we have expanded the ways we can do this. We have recruited more Specialist Advisers and an additional Youth Worker to be able to support those in the community. We heard you when you told us you would like more immediate access to support and have introduced a dedicated Helpline Adviser who can be contacted on **0151 331 5444** or **info@hda.org.uk**. We have increased our reach through social media by introducing new channels, and we have begun engaging politicians and policymakers through our new Policy and Public Affairs post – which will raise the issues that families face right at the heart of where change can happen.

None of this would be possible without your support, whether you fundraise, enabling the charity to develop new roles, or you have written to your MP or encouraged them to attend events like the Westminster Hall debate, or you have got involved in HD Voice to offer your lived experiences and expertise to a wide range of stakeholders wanting advice. You have all played a part. If you would like to know more about HD Voice please visit **hda.org.uk/get-involved/volunteering**. All of the above help us to continue to grow and develop the support we can offer you – so thank you.

Cath Stanley

Welcome to the Huntington's Disease Association

Stacey Ennis

Volunteer Manager

Stacey has a wealth of experience in supporting and managing volunteers. "With a lived experience of Huntington's disease, I understand the difficulties, complexities, and challenges individuals and families face. I hope with my personal and professional experience, I will work collaboratively with families and individuals and do the role the justice it deserves."

Kimberley Doyle

Helpline Adviser

Kimberley joined the Huntington's Disease Association in August in our brand new role of Helpline Adviser. This role has already proven really valuable for the community. Kim has multiple years of experience working on helplines and supporting people with a variety of needs.

Charlotte Gerada

Policy and Public Affairs Manager

Charlotte has over 12 years campaigning experience. She has a personal connection to Huntington's disease and is most excited about tackling the discrimination and challenges the Huntington's disease community faces. Charlotte is privileged to have the chance to use her skills and experience to campaign for better outcomes for those affected.

Delia Roberts

Specialist Adviser

Delia is bilingual in English and Welsh and will cover all of North Wales. Delia has a long background in nursing and midwifery before working as a Senior Nurse for District Nursing, Locality Matron and Operations Manager in the out of hours. Delia retired in 2022 before returning part-time which has led her into this role.

Jack Crockford

Youth Worker

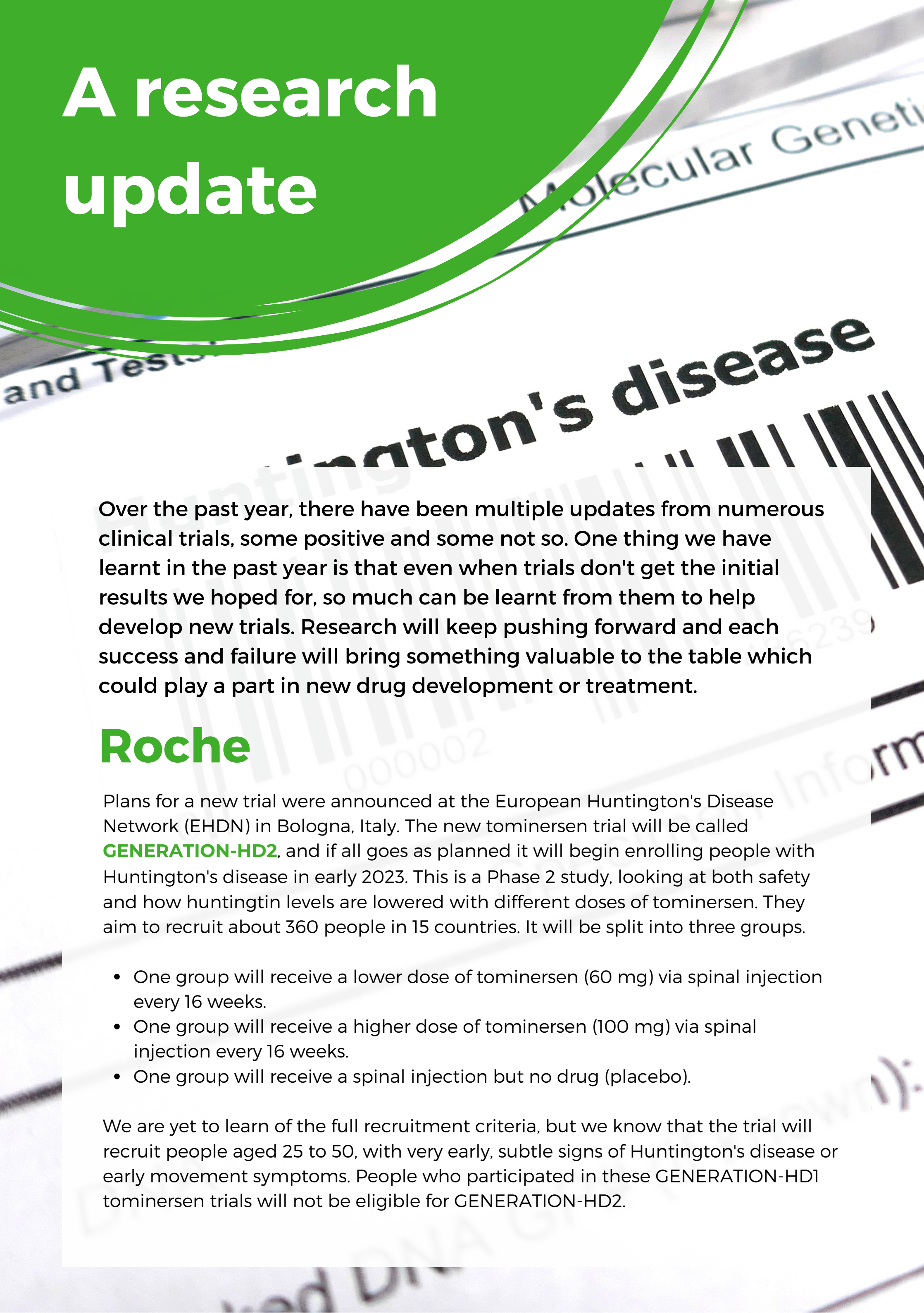
Jack is the new Youth Worker covering the South West of England. At university, Jack volunteered with young people which is what led him to pursue a career working with children and young adults.

Justine Barkas

Specialist Adviser

Justine previously worked for Devon Carers and is covering Devon and Cornwall.
"I was also shocked at the lack of awareness about this disease with many professionals. During this time I also saw the benefit of early support intervention and the improvement to quality of life when there was a multi-disciplinary approach, which really inspired me."

A research update



Over the past year, there have been multiple updates from numerous clinical trials, some positive and some not so. One thing we have learnt in the past year is that even when trials don't get the initial results we hoped for, so much can be learnt from them to help develop new trials. Research will keep pushing forward and each success and failure will bring something valuable to the table which could play a part in new drug development or treatment.

Roche

Plans for a new trial were announced at the European Huntington's Disease Network (EHDN) in Bologna, Italy. The new tominersen trial will be called **GENERATION-HD2**, and if all goes as planned it will begin enrolling people with Huntington's disease in early 2023. This is a Phase 2 study, looking at both safety and how huntingtin levels are lowered with different doses of tominersen. They aim to recruit about 360 people in 15 countries. It will be split into three groups.

- One group will receive a lower dose of tominersen (60 mg) via spinal injection every 16 weeks.
- One group will receive a higher dose of tominersen (100 mg) via spinal injection every 16 weeks.
- One group will receive a spinal injection but no drug (placebo).

We are yet to learn of the full recruitment criteria, but we know that the trial will recruit people aged 25 to 50, with very early, subtle signs of Huntington's disease or early movement symptoms. People who participated in these GENERATION-HD1 tominersen trials will not be eligible for GENERATION-HD2.

Wave Life Science

Wave has created a new gene silencing treatment. They are now running a trial called **SELECT-HD** which will test whether this new selective ASO (gene silencing) drug can lower the mutated protein. The aim of the first phase of the study is to test safety and to understand dosing. They will look to recruit around 36 participants. If successful, the next trial would be to understand whether the drug will work to silence the gene and therefore affect the symptoms. At this stage, the safety of the drug must be tested on a small scale before they can move forward with a second phase of the trial.

Sage Therapeutics

Sage Therapeutics has started recruiting for their latest drug trial, **Dimension Study**. This trial will be testing the drug, SAGE-718 in order to test the safety and effect that is has on the cognitive symptoms of Huntington's disease. The Dimension Study is a Phase 2 clinical research study and the first study in a group of clinical studies in the **Perspective Program**. The program is evaluating the safety and efficiency of an investigational oral drug in adults with early Huntington's disease.

The Dimension Study will be recruiting in the UK and we will share further details when they are released.

uniQure

Their clinical program is designed to evaluate the safety and tolerability of **AMT-130** and to determine the optimal dose to advance into a late-stage clinical trial. The study will look at its ability to lower the huntingtin protein and any related effect this might have on the disease.

During the summer, uniQure was made aware by the Data Safety Monitoring Board (DSMB) of some unexpected severe reactions shortly after the administration of AMT-130 in the higher-dose group in the trial. It is important to note that all of the unexpected safety events in the three patients have been fully resolved.

Ricardo Dolmetsch from uniQure said in this year's CHDI Conference:

> *"Diseases are never cured by any individual or even a single company, it requires this really complicated ecosystem and you need as many shots on goals as you possibly can."*

One huge challenge. Two days. Three of the UK's highest peaks. Four friends.

These four members from the Huntington's disease community travelled 1150 miles, elevated 10,129 feet, hiked 78,000 steps and raised over £5000 for Huntington's disease charities.

At the start of 2022, Carly, Chloe, Rebecca and Charlotte had never met each other or spoken to one another. They met online, through a mixture of the HDYO Online Congress and their Instagram accounts, where each had shared about their connection with Huntington's disease. They started a group chat after realising that they all wanted to do a fundraising hike.

> *"We were brought together by sharing our lived experience of Huntington's disease and our shared passion for making positive change. We are all impacted by Huntington's, in different ways but during the challenge, we put the world to rights, shared memories of loved ones lost to Huntington's disease, those currently battling it and our own futures with it. We learned about each other's struggles and coping mechanisms to deal with the disease but what an incredible, inspiring, and memorable few days we had."*

They started the challenge in Darlington, where they travelled hundreds of miles by train to meet for the first time. They were driven around the country by Charlotte's dad, Paul, also a carer and somebody heavily impacted by Huntington's disease. From Darlington to Fort William in Scotland for Ben Nevis, onto the Lake District in England for Scafell Pike and finally to Llanberis in Wales for Snowdon.

They experienced rain, hail, freezing cold temperatures and even injuries. Upon waking to complete their first climb up Ben Nevis at 5am, the rain was so heavy that they were unsure if they would make it up. Before long, the sun burst through the clouds.

"To say we have completed a challenge of this scale and made friends for life is amazing. We are so grateful to now be connected, young people who understand everything that a life impacted by Huntington's disease brings. Being able to come together share our experiences and most of all complete this massive challenge has been the biggest achievement and they have supported me through the toughest time of my life and I will always be thankful for that. We hope to go on some more adventures, to raise more awareness and funds for Huntington's disease. We are sure our loved ones were looking on us, as we were willing to go through anything to complete the hikes."

"When I was about 13/14 I met with the Specialist Youth Coordinator from the Huntington's Disease Association who provided my brothers and I support while we were at school, up to my first year of university. Ever since James started he has been so supportive with everything, from dad moving into the care home up to now. The support has been so important whilst growing up and dealing with Huntington's disease - knowing there is someone there who will listen and completely understands makes such a difference! I am extremely lucky to have received such a high level of support from the Huntington's Disease Association, and other charities such as HDYO. I hope that by raising money, they can help and support other young people impacted by Huntington's disease."

The Huntington's community is a strong one. We hope that as a charity, through our branch and support groups, online events such as sharing sessions, family voices and carers support groups and in-person branch events that more of our community can connect and form bonds.

Campaigning

With so many decisions about the treatment of Huntington's disease made by the government and politicians, we have started working with people who can really make a difference. We are campaigning to make sure more people know about Huntington's disease by raising awareness of the disease and building a strong profile with decision-makers. We will ensure our messages about priorities for the community are recognised.

Early Day Motion

This year we worked with the Scottish Huntington's Association to target MPs to sign an Early Day Motion.

It was a call to expand specialist services for families impacted by Huntington's disease and has been backed by more MPs than any other Early Day Motion tabled so far this parliamentary year.

Hilary Benn MP, who tabled the Early Day Motion, said:

> *"I am delighted that our EDM has secured such strong cross-party support from throughout the UK. Huntington's disease is rare and extremely difficult to manage. It has an enormous impact on the physical, mental and cognitive health of those who have it, and a devastating impact on the family and friends who care for them. I hope this will encourage governments and health and social care providers to make sure that Huntington's families get the support they need and deserve, which does not happen in too many cases at present."*

Thank you to those who wrote to their MP. It really made a difference, the Early Day Motion now has 94 MPs who have signed and we couldn't have achieved this without the perseverance of the Huntington's community.

Westminster Hall Debate

Left - Hilary Benn, MP
Right - Charlotte Gerada,
Policy and Public Affairs Manager

Thanks to Hilary Benn MP, the Huntington's Disease Association, the Scottish Huntington's Association and the Huntington's Disease Association of Northern Ireland secured a Westminster Hall Debate on the topic of Huntington's disease and the challenges the community face.

On 9 November, Hilary Benn MP represented the Huntington's community in a Westminster Hall Debate. This is the first time Huntington's disease has had this sort of exposure in parliament and it is a monumental moment for our community.

Hilary provided an in-depth speech which noted the many factors someone with Huntington's disease might face in their life. It included how it affects not only the person with the disease, but also at-risk children, carers and family members that may test negative. The speech also included powerful quotes from the Huntington's community which really moved the MPs at the debate.

Post-debate, the Minister will look further into the topics raised. These include a request for care co-ordinators in all communities; investigation into the lack of National Institute for Health and Care Excellence (NICE) guidelines for Huntington's disease and the lack of mental health services; and discussion with the Defence Secretary regarding the issues faced by many people from Huntington's families in joining he armed services; and finally funding for Huntington's research.

Read the full debate: **hda.org.uk/news/hilary-benn-westminster-hall-debate**

Cost of living crisis

Huntington's
Disease
Association

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HM Treasury
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Westminster
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26 October 2022

Dear Chancellor of the Exchequer,

We are writing to you as representatives of charities s
affected by neurological conditions ahead of the Medium-Terr
highlight the challenges many people living with neurological
are facing in relation to the cost of living crisis.

One in six of us across the country live with a neurological conditi
expensive to live with one. Extra costs associated with a neurologic
condition, including higher heating bills, buying specialised equipn
paying for taxis to get around or covering higher insurance premiun
estimated to cost at least an additional £200 a week.

These higher costs come at a time when the general cost of living has
exponentially. While the Energy Price Guarantee was both welcome an
necessary, many deep concerns persist about affordability. Energy prices
still over 50% what they were this time last year and according to latest C
gures inflation is at 10.1% with food prices up 14.5%. This is causing many
ack on basics, increasing the risk of people getting into debt and
sness – with the right support, this could be prevented.

We have been working hard to speak with decision-makers to appeal for more funding in the Autumn fiscal policy (government spending review). Thanks to our community, over 100 people filled out a cost of living survey which has provided us with valuable data and evidence which has used to back up this campaign.

We created a cost of living hub on our website that is regularly updated with useful information and details of where to access assistance with rising living costs.

We wrote an open letter to the Chancellor which was co-signed by members of the Neurological Alliance policy group. **38 neurological charities** signed the open letter that was sent on 26 October.

A joint press release from the Huntington's Disease Association and the Neurological Alliance was sent out to highlight the need for more financial support for the one in six people who live with a neurological condition.

This issue was raised in the recent Westminster Hall Debate and the Minister was asked to encourage the Chancellor to respond ahead of the Autumn financial meeting which takes place Thursday 17 November.

Read more on this campaign: **hda.org.uk/get-involved/campaigning/cost-of-living-crisis**

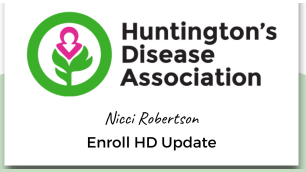
Events and Fundraising

We have a range of video resources that are available to watch on our YouTube channel or on our website. You can see all of the speakers and presentations from our recent Huntington's Family Conference and AGM or watch one of our light-hearted family voices episodes or informative webinars.

hda.org.uk/getting-help/information-resources/videos

Family voices

In conversation with Charles Sabine



Huntington's Disease Association

Nicci Robertson

Enroll HD Update

HDMove

#HDMove is a great way to start the new year and get your body moving after the festivities. Taking place throughout **January**, we are rallying up fundraisers old and new to join #TeamHDA in our inclusive community fundraiser. You can swim, jump, dance, walk, squat, hula hoop, you name it, as long as you're moving then you are doing it right!

hda.org.uk/get-involved/fundraising

This year our runners raised over £115,500

London Marathon

The London Marathon is our biggest charity event of the year and each year raises an incredible amount of money for the charity. This year we had 29 runners who pushed themselves to the limit on the day of the event and the month leading up to it.

> *“It was the most incredible day of connection, courage and community. Filled with positivity and energy that was truly infectious. Humanity at its finest and I shall never forget it"*

THE JINGLE JAM

Jingle Jam is the world’s biggest games charity event and we have been chosen as one of the 12 charity partners. Since 2011, their events have raised over $25 million for charities. Jingle Jam runs 1 - 14 December. Find out more on our website and if you're a gamer or streamer, get in touch.

hda.org.uk/get-involved/fundraising/jingle-jam

Order your charity Christmas cards and support people affected by Huntington's disease. You can find these on our online shop by visiting **www.hda.org.uk/shop** or calling us on **0151 331 5444**.

Jolly Wild

This year, we have partnered up with Jolly Wild to sell some of their wonderful hand-drawn gifts on our shop. Jolly Wild has a connection to Huntington's disease so please take a look at their items on our shop. We have mugs, tea towels, oven gloves and notebooks.



KEEP IN TOUCH

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