



HDNL 2016 - Issue No 66, Q3 16

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www.huntingtons.ie

SUPPORT MEETINGS

See dates on page 4

GENETICS

For information on Genetic testing, contact the Genetics Centre. Tel: **01 409 6902** and www.genetics.ie

ENROLL HD

You can express your interest in participating by emailing enrollhd@beaumont.ie

Enroll-HD A worldwide observational study for Huntington's disease families



Christmas Cards 2016

HDAI Charity Christmas Cards are available again this year. A pack of 15 cards costs €8.00 per pack which includes postage.

To order online go to:
www.huntingtons.ie

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

European Huntington's Disease Network (EHDN)

The 9th European Huntington's Disease Network (EHDN) Plenary Meeting took place in The Hague in September. The 900+ attendees included family members, researchers, clinicians and health care professionals.

HDAI representatives were inspired by the level of collaboration in the HD research community and by the degree of optimism regarding current and future clinical trials.



A wide range of presentations featured updates from basic laboratory research, clinical trials, studies on exercise and brain training alongside personal stories from people

impacted by HD. A summary of some of these presentations is included below.

For more information on the EHDN meeting and on HD research, see HDBuzz - an excellent research news resource written in plain language - <http://en.hdbuzz.net/>

Dr. Doug Macdonald, CHDI foundation pointed out the large number of huntingtin-lowering studies done in HD animal models. A range of companies are now pressing forward with both antisense oligonucleotides (ASO) and viral approaches to achieve HD message lowering in HD patients.

Professor Sarah Tabrizi informed attendees that the on-going IONIS-HTTRx gene silencing Phase 1 trial to measure safety is meeting expectations. This ASO approach involves injecting the drug into a person's spinal fluid. Normally, this initial safety study would be followed by two additional studies to see if the drug actually works.

However, the possibility of a single follow up trial to establish if the drugs are effective in HD is now being considered. This would enable HD patients to get these drugs as quickly as possible, providing that they prove to be safe and effective.

Prof Francesco Muntoni, Univ College London develops treatments for degenerative diseases such as Duchenne Muscular Dystrophy and Spinal Muscular Atrophy. In both these diseases, Muntoni uses ASOs to modulate messages for specific genes.

An ASO drug called Nusinersen is now being tested in infants with SMA, who receive spinal fluid injections of the drug. Similar delivery is being used for the ASO drug currently being tested in adults with HD, so we can learn a lot from SMA. Muntoni describes really exciting results from SMA trials that show kids treated with Nusinersen do much better than expected.

Matt Chiocco, Shire Pharmaceuticals - discussed their gene therapy approach to lowering huntingtin. Science has discovered that Zinc Finger proteins can recognise and bind to specific DNA sequences. This enables the regulation of those genes to which they are attached. Shire and Sangamo have developed tools called "Zinc Finger Protein Repressors".

When delivered to cells, the proteins physically block the machinery required to copy the gene into its message. No message, no harmful protein. Shire's approach is to create viruses which teach cells how to stop the HD gene from being copied into its message. When they deliver these viruses to the brains of HD mice, they see improved symptoms.

Dr Ed Wild is Chief Investigator of HD Clarity, a research study using cerebrospinal fluid, to investigate biomarkers and pathways with the aim of developing novel treatments. They have announced they need 600 people to take part (both HD and non-HD patients) - check out HDClarity.net to find out more.

Dr Emma Yhnell, Cardiff presented data showing that training HD mice in advance improved their performance later on. Dr Yhnell will now work on a project which explores personalising brain training computer games for people with HD.

Once complete, tests of motor and cognitive skills will be used to determine any benefit of this cognitive training intervention.

(continued on page 2)

European Huntington's Disease Network (continued)

Claudia Testa presents data from the First-HD trial of a modified form of tetrabenazine. SD809 was beneficial for reducing unwanted movements and made people feel better. The ARC-HD trial looked at what happened when people switched from tetrabenazine to SD809. The top line results of ARC-HD showed chorea control was about the same after switching to SD809.

Prof Anne Rosser of Cardiff University studies whether replacing lost brain cells is a feasible approach to treating HD. Previous 'cell replacement' studies have shown mixed results but give a glimpse that the right cells in the right place can work. Cell replacement isn't currently reliable. The injected cells can die and the responses are highly variable. Rosser has formed the Repair-HD consortium to look at other sources of cells to try to fix the problem. The science has moved on a lot - it is now possible to make brain cells from skin tissue - known as induced pluripotent stem cells.

Prof Monica Busse and **Dr Lori Quinn** presented evidence that physical activity can benefit people with Huntington's disease, leading to improvements in their symptoms and quality of life. To find out more about the exciting work on exercise therapies for Huntington's disease currently going on at the Cardiff university Centre for Trials Research see the physical activity in HD blog. <http://blogs.cardiff.ac.uk/active-huntingtons-disease/physical-activity-in-huntingtons-disease-ehdn2016/>



Anne Lennon-Bird on the podium at the EHDN Conference

Enroll-HD's role in advancing human research in HD, facilitating the conduct of clinical trials and improving care featured consistently.

HDAI was delighted to have a speaker from Ireland included on the EHDN programme. **Anne Lennon-Bird** was invited to speak on the topic *'Living with HD - a Mother's perspective'*.

Anne captivated attendees by bravely sharing her personal experience with HD, and her struggles as a mother and wife. She and her husband took a very open approach to communicating with their children about their father's HD diagnosis.

She spoke about the unfairness of children having to become caregivers for their parents suffering from HD and how she empowered her children by involving them in decisions about their father's care.

Anne discussed her difficulty in dealing with the hereditary aspect of HD and movingly reflected that, while HD is a horrible tragedy for her family, it *"has made us who we are, and what we are"*.

The European Huntington's Association business meeting also took place in The Hague on 15th of September. Thanks to Dave who represented HDAI at that meeting. Astri Arnesen from Norway (below left) has replaced Bea de Schepper as President.



Bea (above right) has made a very significant contribution to the HD community in Europe and internationally. Bea was applauded and presented with a gift in recognition of her dedication to EHA. For more information see the EHA website - <http://eurohuntington.org/>

Model of Care for Neurological services

A new Model of Care for Neurological Services in Ireland was launched by the HSE in partnership with the Royal College of Physicians on September 27th.

Written by Professor Tim Lynch, Clinical Lead for the National Clinical Programme for Neurology, the model was developed in collaboration with key stakeholders including neurologists, health and social care professionals, patient support groups and the Neurological Alliance of Ireland.



Over 700,000 people in Ireland have a neurological illness. People living with neurological conditions need access to services from all areas of the health service - acute hospitals, mental health, social care, primary care and health and wellbeing via an integrated service approach.

The National Clinical Programme for Neurology aims to provide equitable access to a high quality service to provide accurate diagnosis, appropriate treatment, and management for all neurological conditions.

Mini Marathon Support

Funds continued to arrive from mini marathon support. Melissa Brennan and Nicola Mc Quaid (pictured below with Melissa's mother Elizabeth) raised €835 from their participation in the Mini marathon.



Elizabeth also received great support from her cousin George who nominated HDAI for a very generous donation of €2,000 from MACS Golf Society.



Lough Key Awareness Walk



Our Awareness Walk in Lough Key on July 16th brought many people together under blue skies. Joe, Pauline and Anne Doran together with relatives and friends were once again the driving force in making this



a successful event. We were delighted to welcome those who travelled from London, Dublin, Kildare, Meath, Kilkenny, Longford, Mayo, Galway, Leitrim, Sligo and of course Roscommon! Special thanks to Joe Doran, Christine Dempsey and David Coyle for motivating participants and also to our volunteers who helped out on the day: Anne Doran, Frances Hughes, Eric Piggott and Evie Murphy. The walk raised

€1,850 from sponsorship raised in advance and generous donations on the day. There were also donations raised through Carol Lee's online fundraising page. Throughout the summer Carol and her family and friends worked hard to raise an incredible €4,519.50 in total through an online auction, their Clara market stall, Mini-Marathon sponsorship and the awareness walk.

Sincere thanks to Carol and all the team for their tremendous support. Lough Key was an ideal setting for the Awareness walk and we hope to make it an annual event - **you are welcome to join us in 2017!**

Fundraising Thank You

Killmallock Charity Cycle

HDAI are very grateful to Caroline Wallace and Will Whelan for all their hard work in organising another very successful HD cycle in Killmallock, Limerick on July 10th. There was a great turnout from local cycling enthusiasts, and from family and friends of Caroline, Will and the O'Shea family.



Anne and Christy (above) travelled to Limerick to show their appreciation to all involved. Thank you to Jack O Shea for his photography, to Margaret O'Sullivan of Deebert House Hotel for hosting the post cycle gathering, to Killmallock Cycling Club for covering insurance for the event and to all the marshals and support cars for keeping everyone safe on the road. In addition to vital awareness, the cycle raised €2,360 in aid of HDAI.



This included a generous donation of €250 from Wyeth Nutritional Ireland Ltd.

Sunrise up the Reek in memory of Eleanor Breen

Family and friends of the late Eleanor Breen organised a sponsored climb of Croagh Patrick on 16th July in her memory. Part of their motivation in climbing the Reek was to highlight the lack of HD specialist services and to encourage medical practitioners to champion HD.



"We'll be climbing Croagh Patrick, to symbolise the climb needed to put the support structure in place to help Irish patients and their families". The event raised an incredible €5,125 for HDAI. This includes a very generous donation of €1,780 from The Parasol Foundation. A further €1,272 was donated in Eleanor's memory earlier this year. Sincere thanks to John Kelly and the Breen family and to all who so generously contributed.

Carne Charity Day and Cycle

Sincere thanks to: Wally McCormack, Christy Mahon, Marlo Brien and Ernie McAuley for organising an enjoyable fundraiser at Carne. They raised great awareness and funds of €1,333 for HD. We are also very grateful to Betty and Fran, to Sean McDermott and to all the volunteers in Carne who helped. Thanks also to the Doyle family for their support.

HDAI received additional funds from Maurice Keating and Darren Brennan's cycle from Dublin to Carne, Wexford bringing the total contribution to €3,385.

Mark Bunce D8 Fitness



Mark Bunce, Director of D8 Fitness, a sports and fitness retail store in Dublin 8 chose to raise funds and awareness for Huntington's Disease at the DB Fitness booth at the Waterford Throwdown competition in July. Mark is himself impacted by HD and wanted to show his support. They raised €352 which included a generous donation of €150 from the shop. Sincere thanks to Mark and to all involved.

Recently received donations include:

- Martina, Finnola and Zil for their monthly Direct Debit donations.
- Edina Ltd, Swords - donation of €1,000.
- Macs Golf Society - \$2,000 dollars (€1,762).
- In Memory - Family of the late Ita McCarney donated €750 in her memory.

Seasonal Gifts



Dee and Anne. Good value for the chilly season - €20.00 each plus postage.

HDAI have purple hoodies available for sale as worn by models

(For upcoming events - please see over)

UPCOMING EVENTS

Tuam Tea Dance

Ann Hannon and friends are once again kindly organising a Charity Tea Dance on Sunday **November 13th** at the Ard Ri House Hotel, Tuam. Tickets are €7.00.

Contact HDAI if you would like to buy or sell tickets.

Craft Fair

Ide Cussen and friends will once again host a craft stall in aid of HD at the Celbridge Craft Fair on **November 20th and 21st 2016**.

In Memory of Eleanor Breen - The Reek (part 2)

July 1st 2017 - Because we had such great fun and sun on the 16th July this year - next year we are going up Croagh Patrick (The Reek) on **Saturday July 1st**. We have friends coming from abroad to experience Ireland for the first time.

Everybody is welcome to join us, we promise a laugh or your money back; for more details, email: john@hansonregna.com

The articles which appear in this newsletter may not necessarily represent the views of HDAI.



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HDYO Euro Camp 2016



HDAI was delighted to be a partner in the very successful 2016 HDYO Euro Camp which took place in Kent, England, with over 40 young people from several EU countries in attendance. Erasmus provided EU sponsorship and HDAI contributed to the cost of

participation for 3 people from Ireland. We would like to extend a big thank you to Dave who volunteered as group leader and to Matt and Cat from HDYO for their incredible contribution. See highlights from the HDYO website <http://en.hdyo.org/eve/videos/511>

Robyn, a participant from Ireland shares her summary:

On Sunday 7th August I flew from Dublin to London to attend the HDYO youth camp at Kingswood Camp in Kent. On arrival we were shown around and given our rooms.

Then 5 groups were selected and I was part of an all girls group and our leader was Michelle.

During the week we took part in different activities like Rock climbing, free fall, swimming, team building and my favourite the giant swing! I made really good

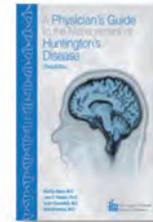


friends at the camp including Ross who celebrated his 18th birthday with us. There was a lot of interesting talks during the week. Ed Wild gave a very promising update on HD research and spoke about clinical trials taking place in the UK.

Charles Sabine spoke about his life and work and how he deals with HD. He spoke about his own children not being at risk due to PGD. Some participants movingly shared their own experience of predictive testing.

There was a lot of support given throughout the week, I met people who were such an inspiration to me and I have made friends for life. Overall I really enjoyed the camp and I would love to go again next year!! Thank you to Matt, Cat and Michelle for being camp leaders.

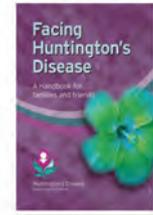
HDYO hope to host another camp in 2018 so if you are under 26 years and interested in attending please get in touch.



Information on HD

Huntington's Disease Society America have launched a 3rd edition of the Physicians Guide available online via

HDAI's website.



The HDAI Booklet, *Facing Huntington's Disease*: A handbook for families and friends, together with the handbooks: *The Caregivers Handbook*,

Physicians Guide and *Understanding Behaviour* Information booklets are available on our website or you can contact the office for a hard copy.

Standards of Care for HD

The Euro HD Network working groups, are working on guidelines for Standards of Care for HD. These are available from our website <http://www.huntingtons.ie/content/information-0>

HD ID Card

A free Huntington's ID card is available. Please send your photograph, address, phone number and an emergency contact person's phone number to the HDAI office and we will take it from there.

Follow HDAI on Social Media

Facebook: https://www.facebook.com/pages/Huntingtons-Disease-Association-of-Ireland/121707387897701?ref=br_tf
Twitter: @HDAI_ie

Thank you to our hardworking volunteers for their social media work.

HDAI Support Meetings

You are very welcome to join us at our Support Meetings from 11.00am to 1.00pm on a Saturday in Cork, Mayo, Dublin and in Limerick from 10.30am. Our Family Support Officer or a HDAI representative will host the meetings. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information.

DUBLIN

Dec 5th

CORK

Dec 3rd

WEST

Dec 10th

LIMERICK

Jan 2017

This is your Newsletter - Please contact us if you wish to contribute.