CONTINUING THE FIGHT ON BEHALF OF OUR MEMBERS

2018

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NEWSLETTER OF THE HUNTINGTON’S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

EHDN Conference 2018

The European Huntington’s Disease Network held its 2018 Meeting in Vienna, Austria, from 14-16 September 2018.

The EHDN is a nonprofit research network committed to advancing research, facilitating the conduct of clinical trials, and improving clinical care in HD. The EHDN is supported by and collaborates closely with CHDI Foundation, Inc. Anyone who has an interest in HD, including clinicians, researchers and those affected directly by the disease, may join the EHDN and, in so doing, contribute to HD events and research.

http://www.ehdn.org

Every second year EHDN hosts one of the world’s largest HD conferences in Europe. Anne and Deirdre from HDAI (pictured overleaf), attended for the first time and were very impressed by the positive atmosphere and the scale of the event with over 1000 people from around the world taking part.

Presentations over the three days included input from family members, clinicians and researchers. Many of the presentations are available to view on the EHDN website at: https://www.euro-hd.net/html/ehdn2018/programme

A brief summary of selected presentations are outlined below.

Astri Arnesen, President of EHA, gave a talk on ‘Living with Hope and Setbacks - a Family Perspective’. She discussed her own personal experience of having a parent with HD and being previously at risk herself. She recalled how she heard about the discovery of the HD gene in 1993 and the hope that followed.

“We know that we’re on the right path, but we don’t know what’s around the corner, or how far it is to the next breakthrough.” …. “we will continue until we reach the finish line and until we have efficient treatment available for all”.

John Eden, (above) CEO of Scotland’s HD Association, gave a talk on the Implementation of the Scottish National Care Framework for HD. He outlined the purpose of the plan as follows:

- More joined up health and social care
- Clear, local ‘ownership’ of HD
- A single, national model, localised to each region
- Increased profile, priority and engagement
- Greater consistency in quality of care

Dr Ed Wild, UCL HD Centre, in his presentation ‘The Silver Linings Playbook - A Future Outlook’, paid tribute to the brave #hdresearchheroes who have participated in trials to date. His main message was:

1. Look after yourself.
2. Sign up for ENROLL-HD.
3. Stay informed

HDAI were delighted to see an Irish based researcher on the 2018 EHDN conference programme.

Professor Robert Lahue, NUIG Galway discussed his work ‘Multiple therapeutic benefits of isotype-specific HDAC inhibition’.

(continued on page 2)
**EHDN Conference 2018 - continued**

Prof Lahue's lab worked with collaborators in Spain to evaluate a new experimental drug in a preclinical study for therapeutic benefits in HD. They found that early administration of the drug helped block or delay the onset of cognitive problems (motor learning and long-term memory loss).

The compound also stabilised DNA and protein biomarkers, suggesting that the integrity and function of the brain was preserved by the intervention. Prof Lahue and Dr Gines are currently applying for funding to extend these studies. The new proposal is to see if administration of the experimental drug after the onset of symptoms can stabilise or slow disease progression. If the new study is also successful, there is a path forward for initiating future clinical studies using this approach.

**Monica Busse**, Neuroscience Trials Centre, Cardiff, discussed ‘Prospects for exercise and physical activity in HD - what next?’ Significant research shows that exercise and physical therapy improve the ability to conduct daily activities, cognitive function, and quality of life of patients with neurodegenerative diseases. For further information see [https://www.cardiff.ac.uk/huntingtons-disease-centre/active-hd](https://www.cardiff.ac.uk/huntingtons-disease-centre/active-hd)

Dr. Bonnie L. Hennig-Trestman, Huntington’s Disease Youth Organisation, gave a talk on ‘Talking to Kids About HD’. She discussed the benefit of telling children about HD in an age appropriate and supportive manner. She stated that a child has a right to know about anything that affects the family. By not talking about HD, children learn not to trust. They may already sense that something is wrong. By not saying anything, they may have fears worse than the real situation and may develop anxiety and guilt. She considers that not talking may give the message that it is a subject too terrible to be discussed.

She used a quote from Marjorie Guthrie, ‘The more we feel at home with our fears the easier it is to accept the reality of what is or what will be’.

Involving young people also featured on the Breakfast teaching course - ‘Why Working with Young People is Vital: The Tools and Resources you need’, presented by Catherine Martin, Chandler Swope and Matt Ellison from HDYO.

**Gene Lowering Trial**

In December 2017, Ionis and their partner Roche announced that the gene lowering trial of HTTRx was safe and tolerable. 46 patients received monthly spinal fluid injections (some with a placebo) and this was shown to reduce the levels of the harmful huntingtin protein (HTT) in the spinal fluid over 4 doses. Following the success of this first trial, Roche confirmed that it would lead the next trial of HTTRx, now named RG6042.

**Meet the Experts**

HD Family Members and Students had an opportunity to meet experts in workshop sessions:

- Mental Health Problems of HD;
- Everyday Life as an HD Gene Carrier;
- What does it mean to be in a clinical trial and;
- Young People and HD: Getting the support you need.

**EHDN Working Groups**

The conference also included presentations from the EHDN Working Groups:

- Juvenile Onset Working Group,
- Cognitive Working Group,
- Physiotherapy Working Group,
- Young Adults Working Group,
- Driving Task Force

**EHDN Executive committee members Jean-Marc Burgunder and Anne Rosser (Chair), gave an update on EHDN and the results of elections to the EHDN Executive Committee and the Scientific Advisory Committee.**

HDAI congratulate Dr Jennifer Hoblyn, Bloomfield Health Services who was elected to the SBAC committee. This is the first time an Irish clinician has served on an EHDN committee.

They also reported on the Enroll-HD study which now has 18,933 participants in 162 sites world-wide. Of this Europe has 11,230 participants from 103 sites in the following countries:

- UK (2689), Germany (2797), Spain (1422), Italy (1515), Poland (937), France (702), Netherlands (603), Denmark (417), Switzerland (50), Ireland (37), Austria (34), Portugal (14) and Belgium (13).

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EHA Business Meeting

Alongside the EHDN meeting the European Huntington Association’s Business Meeting took place on September 13th. Approximately 70 people participated in the EHA meeting including representatives from recently established Associations from Greece, Gran Canaria and Hungary who joined the EHA. The EHA board was re-elected with Astri Arnesen continuing her job as president for two more years.

HD Presentation by 2018 Researchfest Champion

Inspirefest is an international festival of technology, science, design and the arts which takes place in the Bord Gáis Energy Theatre in Dublin. Margie McCarthy, Science Foundation Ireland, introduced Eoin Murphy as the 2018 Researchfest champion for his overview of HD and some of the research success to date. Eoin is a PhD student in NUI Galway who is researching the biochemical and genetic aspects of Huntington’s disease in Professor Robert Lahue’s laboratory. In addition to trying to develop a better understanding of the biochemical pathways which lead to Huntington’s disease, the team at NUIG aim to investigate potential therapeutic targets. https://www.youtube.com/watch?v=C9_84C3xTV4

In Memory

HDAI were shocked and saddened by the untimely death of Ray Clarke who passed away as a result of a head injury. We all enjoyed Ray’s company at our respite weekend in June. He will be fondly remembered. Sincere condolences to Ray’s family and friends.

Michael Lacey
died on 14th June 2018, in the wonderful care of staff in Clarenbridge Nursing Home. Michael embraced his illness with great courage, and his determination to enjoy life was an inspiration to all who were lucky to have known him. He will be sadly missed and lovingly remembered by his mother Marie, brother David, sisters Siobhan, Angela and Gemma, and all his extended family. Thanks to David’s family, friends and staff at Clarenbridge for their generous donations of €570 in his memory.

Sincere condolences to the family and friends of the late Jason Clarke who died in July.

Thank You

Sunrise up Croagh Patrick

#Sunriseupcroaghpatrick was a great success again this year (June 30th) thanks to the marvellous work of the #Sunriseupcroaghpatrick partnership (Frank Fenn, Joe Condon, Ed Mooney and John Kelly, supported by James Murphy) as well their families, friends and colleagues.

The team worked hard to raise awareness with local media and sponsors. Midwest radio, Shannonside Radio, Galwaybayfm, iRadio, The Western People and The Mayo News featured interviews and @galwayhour gave great support on social media for #Sunriseupcroaghpatrick.

They also put up tonnes of posters in airports, shopping centres and around Westport. Thanks to the company sponsors who donated: Flahavan’s, SeaVite, Glenpatrick Mineral Water, Musgrave SuperValu, Independent Newspapers & Phonotomi. The sun shone for the large group of people who climbed, walked or cycled to raise funds and awareness for HD, Motor Neurone and Parkinsons Disease with over €21,000 raised across the three charities.

On Saturday night the team organised a very enjoyable celebratory dinner in Westport. Volunteers and members of the three charities had a chance to socialise, share experiences and enjoy the positivity of a great day!

A very big thank you to all involved and particularly to the Sunriseupcroaghpatrick team for their wonderful work.

Marathon Support

We continued to receive funds from our wonderful mini-marathon participants:

• Ger & Jacyntha, Martin, Finnola and Zil’s monthly Direct Debit donations.
• Nigel’s generous online donation of €500.
• Sylvia Ayling €100 and Gail Collier €50.
• Mick Scanlon coin collection €190.
• Maire Cussen’s Handknits for HD - €95.

Recently Received Donations

• Handknits for HD - €1,600 for HDAI.

All-Ireland Premium Hurling Tickets

Huge thanks to Michael Moore for his very generous All-Ireland Premium Hurling Tickets which were raffled online raising approximately €1,600 for HDAI.

Community Garda Lynch and Community Garda Pimlott very kindly supervised the draw and drew the winners name - a Limerick hurling fan!
Upcoming Events

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

Joe Doran’s HD Awareness Walk - Lough Key

Joe Doran and his family and friends once again put their amazing energy into making the 2018 Joe Doran HD Awareness walk at Lough Key a wonderful success. A huge thanks to Joe, Pauline and Anne Doran, Joseph (uncle) & Mary Doran and family, Frances Hughes, Pauline’s extended family and their friends. We were delighted once again with the great support from the HD community (family and friends) who travelled from: Longford, Mayo, Galway, Sligo, Roscommon, Leitrim, Limerick, Kildare and Dublin to take part.

The walk raised an exceptional €10,000.

Sincere thanks to all who registered on the day, donated and raised sponsorship. Donations and sponsorship included: Joseph & Mary Doran €5,125, J Coffey Construction Ltd €2,000, Peggy and Phil Fogarty €530, Mary Dennany and friends €105, friends at Longford Primary Care €525, Bank of Ireland €100, Allied Irish Bank €100. Anne and Frances Hughes worked hard taking registrations and keeping track of collections. We were treated to beautiful music from musicians from Carrick who kept us entertained prior to walking.

Thanks to Louise and the team at Lough Key for their support. Lough Key is a wonderful location and we hope to walk again in July 2019 - please join us if you can!

Upcoming Events

Celbridge Craft Fair

Ide and Máire will once again sell their splendid ‘Handknits for HD’ at the Celbridge Craft Fair, The Mill on 24th and 25th November 2018. Their highly sought after HD Snowmen will also be on sale in shops in Celbridge (Walsh’s Pharmacy) and Maynooth (The Elite Bakery).

Tea Dance, Tuam

Della’s Benefit Tea Dance for HD takes place on Monday 29th October at the Ard Ri House Hotel from 3-6pm. Tickets cost €7.00 and can be bought in advance from Ann Hannon or by contacting HDAI.

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Thank You

Acknowledgement Kindness - We want to acknowledge the kindness of Mary Dennany and Frances Hughes Byrne who are so kind and supportive to our family. We also appreciate their ongoing support in helping us raise awareness and funds for HDAI - Joey, Pauline & Anne

HDAI Support Meetings

All those impacted by HD are welcome to join us at our Support Meetings in Cork, Dublin, Roscommon and Limerick.

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