



HDNL 2018 - Issue No 73, Q2 18

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

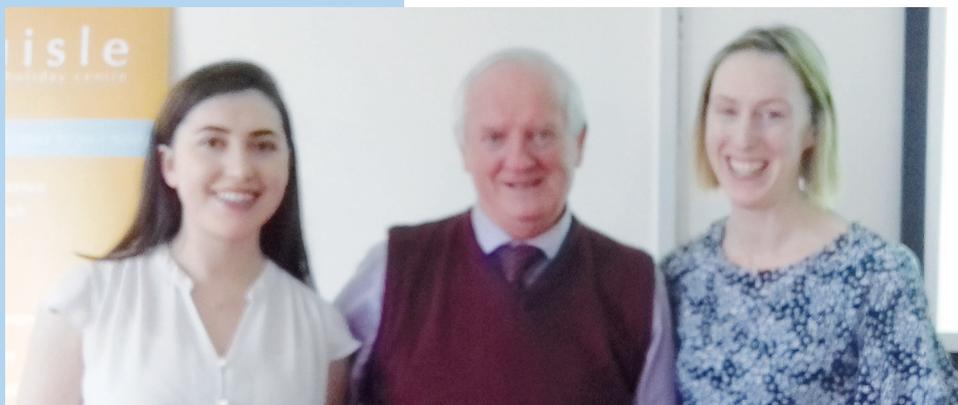
CHECK OUT OUR WEB SITE

www.huntingtons.ie

This newsletter has been published with financial assistance from the **Hospital Saturday Fund**

GENETICS

For information on Genetic testing, contact the Genetics Centre - Tel: **01 409 6739** and <http://www.olch.ie>



Michaela Hammond (left), Tom Lillis and Marie Duff at Cuisle, 2018

ENROLL HD

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



SUPPORT MEETINGS

See dates on page 4

Members Meeting and Respite Weekend 2018

HDAI's annual members meeting, respite weekend and AGM took place in Cuisle Holiday Centre, Donammon, Co. Roscommon over the weekend of 8th -10th June.

Speakers at HDAI's 2018 meeting included: **Michaela Hammond**, *Research Assistant and ENROLL-HD Co-ordinator, Beaumont Hospital*, **Marie Duff**, *Genetic Counsellor, Department of Clinical Genetics, Our Lady's Children's Hospital, Dublin* and **Anne Lennon Bird**, *family member and Ireland's HD Cope representative.*

Michaela Hammond gave a very informative presentation on the Enroll-HD study and outlined the aims:

- To better understand HD as it happens in people and to give insights into developing new drugs,
- To improve the design of clinical trials to give clear answers more quickly. We want better, smarter, faster clinical trials so that we can move as quickly as possible to find the treatments that work,
- To improve clinical care for HD patients by identifying the best clinical practices across all Enroll-HD sites around the world and then working to ensure that all families get that standard of care.

Michaela explained that the study protects the privacy of individuals. Names are never entered into the study database instead each participant is assigned a unique 9-digit HDID number.

The dataset is stored on a secure system in the UK while blood samples are stored in a special biorepository facility in Milan, Italy.

Huntington's disease researchers around the world can apply to work with the data collected through Enroll-HD. This is to encourage as many scientists as possible to work on HD.

There is no drug or other therapy being tested in this study but information gathered helps to progress research and improve care. The study is also developing a comprehensive database of people who may be interested in volunteering for future studies, including drug trials, with all the necessary information about them already in place.

To date over 15,000 participants world-wide have joined Enroll-HD. There are 161 sites in 18 participating countries. There are 29 sites across UK & Ireland, with Beaumont Hospital being the only Irish site.

Anyone from a HD family can join the study. Participants are asked to attend an annual appointment and travel expenses can be covered. Michaela outlined the benefits of participation:

- Many people involved in medical research report that they feel empowered,
- Help researchers come up with new ideas to develop novel therapeutic approaches,
- Help improve HD care by identifying the most effective ways to treat the disease.
- Meet with different healthcare professionals at your Enroll-HD annual visit and find out more about HD,
- Become familiar with some of the type of assessments commonly administered in clinical trials, and perhaps also find out about upcoming HD research studies and new drug trials,
- Help us build a database of people who could be invited to participate in clinical trials.

If you are interested in taking part in research studies please contact the Enroll-HD team at the Psychology Department, Beaumont Hospital by email enrollhd@beaumont.ie or call (01) 809 2223.

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Marie Duff, Genetic Counsellor, Department of Clinical Genetics, Our Lady's Hospital, Crumlin, gave a presentation on the HD predictive testing process.

Genetic counselling is a communication process where individuals and families at risk of an inherited disorder can assess the chance of a disease occurring, learn how it is inherited and the options open in terms of testing and management. The HD genetic counselling clinic was set up in Ireland in 1999 by Rosemarie Kelly who has now retired.



Annual Conference Dinner 2018

Clinics are held in the Department of Clinical Genetics, Our Lady's Hospital, Crumlin, Dublin and there is one regional clinic at University Hospital Cork. Genetic counsellors are trained in both genetics and counselling skills. Marie and her colleague Tara Clark specialise in HD genetic counselling.

A person who does not have symptoms but who has a genetic risk of Huntington's disease can avail of genetic counselling and pre-symptomatic testing.



Annual Conference Dinner 2018

The uptake for HD predictive testing worldwide is currently about 5-20% of eligible individuals. This is less than was expected prior to the gene discovery in 1993.

Factors which may change the demand for predictive testing include:

- Availability of techniques such as PGD (pre-implantation genetic diagnosis) in Irish Fertility Clinics. Treatment where couples undergo IVF with an extra stage where one cell is taken off each embryo and genetically tested. Only embryos that are HD negative are implanted,
- Exclusion PGD (need blood sample on affected grandparent) At risk parent does not have to have a HD genetic test but can have children who are not a risk of HD,
- If treatment becomes available. Clinical trials are ongoing.

Marie emphasised that the decision to have the test should be well informed and a free and personal decision. Just because the test is available does not mean you have to have it. People availing of genetic counselling can change their minds or postpone getting their test results.

Marie outlined the perceived benefits of testing and not testing as follows:

Perceived benefit to having HD predictive test:

- Just want to know - get rid of the uncertainty
- To help make decisions such as whether to extend or start a family. Avail of tests such as Pre-implantation Genetic Diagnosis (PGD), PGD Exclusion testing, Prenatal testing.
- Future practical planning - if an unfavourable result, build downstairs shower/ bathroom etc.
- Decisions re employment - stay in job with good pension/ change job.
- Financial planning
- Hope for future treatments
- Worry re: Symptoms - I forget where I put the car keys etc.

Perceived benefit to not having HD predictive test:

- We all get something - why would I want to know when I can't do anything about it. No treatment currently.
- Find it easier to live knowing there is a chance that I don't have the HD gene alteration.
- Test only replaces one uncertainty with another, still don't know how or when it will present.
- Avoidance: Individuals who use 'avoidance behaviour' regarding HD and their risk.

People undergoing predictive testing are offered three appointments with a genetic counsellor and one appointment with a consultant psychiatrist. Valid consent (voluntary, informed with decision making capacity) is sought before a person's blood sample is taken.



Annual Conference Dinner 2018

Separate appointments are now offered to the partners of individuals considering testing. Follow up calls are offered following genetic test results.



Anne Lennon Bird: Anne is a family representative of the Huntington's Disease Coalition for Patient Engagement (HD COPE). She gave an informative overview of HD Cope explaining that it was established to give families who are impacted by HD a direct voice in HD clinical research. HD Cope held its first meeting in London in February and the group gave advice to representatives from Roche pharmaceuticals who are currently preparing for the next phase of the HTT_{Rx} clinical trial.

Carers support group: A carers support group facilitated by Liz (Family Support Officer), took place on Saturday morning.

Therapies available for people with HD and caregivers included Chiropody, reflexology and massage thanks to Chiropodist Jenny Shanley and massage therapists Mary Finnegan and Kathleen Finnegan.

Comments from weekend included:

"Weekend was wonderful. Carers meeting reminds me that I'm not alone...Looking forward to next year"

Eva

"Excellent weekend. An opportunity to meet people and just chat and/or get advice. The talks were great. Informing us of the bigger picture and what's been happening on the medical front"

K & S

Invest in Neurology

On 13th June, the Neurological Alliance of Ireland and eleven other national charities including HDAI held a presentation in the AV room Leinster House to highlight the crisis in Ireland's neurology services as part of the "Invest in Neurology" campaign.



Decades of under investment have resulted in the lowest ratio of consultant neurologists per head of population in the developed world with waiting lists of up to two years to see a neurologist.

Anne O'Shea Clarke (above) spoke movingly about the delays in getting the services and supports needed for her late husband Christy. She spoke about Christy's determination to make the most out of life and the value of peer support from other families in the HD community. Anne also called for a much needed specialist clinic for Huntington's Disease in order to improve treatment and progress research.

She commended Professor Hardiman (who also spoke on the day) for establishing a national specialist clinic for Motor Neurone disease.

You can help support the campaign by sending an email to your local TDs asking them to support the **Invest in Neurology** campaign.

See http://www.nai.ie/go/neurology_campaign/get_involved

Fundraising - Thank You

Marathon des Sables

Fergal O'Neill took part in the Marathon des Sables, the toughest foot race on Earth on April 8-13th 2018. He ran this 250Km marathon across the Sahara Desert over 6 days in extreme heat and raised around €7,000 in funds to be split between Huntington's Disease, Young Parkinsons and Motor Neurone Disease. Sincere thanks to Fergal and his supporters.

Bingo Night

Massive thanks to Nuala O'Brien and Dawn Little who together with their family and friends raised a magnificent €3,000 from a Bingo Night in Dunmanway, Co Cork.



Dawn and Nuala receiving a cheque from Ger O'Donovan

Thank also to Siobhan O'Donovan for co-ordinating the event.

Tesco Community Fund

Thanks to Lavinia and colleagues in Tesco Ballincollig for their €285 contribution to HDAI from the Tesco Community Fund.



A big Thank you to Brian and Mary Mulcahy for nominating HDAI.

Mobile Recycling

Thanks to Brendan Chambers at C&C Cellular for recycling mobiles to the value of €275.82 for HDAI. Unfortunately, Brendan is no longer able to recycle old mobile phones. HDAI are extremely grateful for all his generous support over the years.

Recently received donations

- Ger & Jacyntha, Martina, Finnola and Zil for their monthly Direct Debit donations.
- Thanks to Ernie McElroy for his generous donation of €250.
- Lock 13 Flanagan's Mill - thanks to Barry, Orla and Sergio for their HD collection of €93.
- John Kelly, Sunrise up Croagh Patrick 2017, €400 (additional).

Mini Marathon

We are extremely grateful to all the wonderful women who took part in this year's mini-marathon to raise funds and awareness for HDAI:

Aisling raised €410, Adrienne Boyle, Marian Healy and Ann Healy (below, left to right) raised €160 in support of their friend Triona.



Roisin Donnelly (left) raised €200, Shannon Hayes and Nicole Whelan (right), raised €1050.

In Memory



The late Tom Connern pictured with his daughter above. Tom's family and friends have donated €381 in his memory. Many thanks to all.

Events

Sunrise Up Croagh Patrick took place on June 30th 2018 - photos and report in Q3 Newsletter. See <https://www.sunriseupcroaghpatrick.com/>

SATURDAY JULY 28th 2018



Awareness is the Key

Joe Doran's HD Awareness Walk will take place at Lough Key, Boyle, Co. Roscommon.

We will gather from 10.00am to start walking by 10.45am. Suggested donation €5 per person or we have sponsorship cards available.

Follow HDAI on Social Media

Facebook: See: **Huntingtons Disease Association of Ireland**

Twitter: @HDAI_ie

Thank you to our volunteers for their social media work.

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.

All-Ireland Family Conference 2018



Conference takes place in Newry, Co. Down on Saturday 29th September, 2018.

Monkstown Hospital Fund

Monkstown Hospital Fund awarded HDAI a generous grant of €2,000 towards the provision of specialist seating and equipment for people with HD in 2018.

HD Chair

Let us know if you need a HD Chair for a family member or if you have one that needs repair. Alternatively if you have one you don't need and would like someone else to make use of it we can arrange this. Please contact the office.



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HD Awareness Week

Huntington's Disease Awareness week took place on May 14th -18th, 2018.

HDAI launched an updated Information leaflet and an Awareness Infographic for our annual awareness week. You can find these on our website www.huntingtons.ie

Thank you to our members who contributed feedback to our updated leaflet and infographic.

#LightItUp4HD

HDAI received marvellous support for our 2018 Light It Up For HD initiative.

Sites from Kerry to Donegal generously supported us including: *County Council County Buildings, Killarney Municipal District Office, Town Hall, The Rock of Cashel, Tipperary, Arás Chill Dara, Kildare Co Council* and locations in Buncrana and Dungloe lit up by Donegal County Council.

Dublin sites included: *3 Arena, the Convention Centre Dublin, the Mansion House, Dublin City Council Civic Offices, City Hall Dublin, Carmichael Centre and Irish Life Fountain.*

Ardmheara Mícheál MacDonncha kindly joined us for a photograph outside the Mansion House.



Huntington's Disease was mentioned on Martin King's weather report on TV3 when a photo of the purple Rock of Cashel (credit: Chris O'Reilly) was featured.



Thanks to all who took and shared photos, devoted their social media skills. We hope to continue with this growing international **#LightItUp4HD** campaign next year. You can get involved by contacting prominent buildings in your area or by organising an imaginative purple event. Please contact info@huntingtons.ie with your suggestions.

HD Café Evening

The Association hosted a HD Café evening for family members on May 16th in Dublin City Centre. Caroline McDonagh, DHN, DHPM, MIAHM Holistic and Clinical Nutritionist, Holistic Health Coach and Life Coach was guest speaker and gave a very informative talk on nutrition and the role our minds play in our health and well-being. She discussed the negative effect of excess sugar in our diet and the impact it can have on physical and mental wellbeing.



Caroline spoke of the benefit of unprocessed foods including fruit, vegetables, wholefoods and oily fish. She shared her personal experience of ill health and the role that nutrition and positive thinking played in her return to improved health.

Caroline believes that having anti-stress resources at our disposal can help us remain positive despite the challenges we face. It is possible to find something good in our day (a relaxing bath, our favourite comedy, a blue sky) and if we concentrate on the positive we can find more to be positive about.

Positive feedback from attendees included:

"A brilliant talk, I want to hear more! Accessible and sensible information on nutrition and wellness for carers and patients alike"

Bernie

"I loved the whole night, the talk and the meditation exercise was brilliant and it was great to chat to everyone. My mother was delighted to meet the Lord Mayor, a friendly face from Crumlin"

Lynette

HDAI Support Meetings

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

Aug. 11th
Nov. 3rd

CORK

Oct. 6th
Dec. 1st

WEST

Sept. 8th
Dec. 8th

LIMERICK

Oct. 13th