

CONTINUING THE FIGHT ON BEHALF OF OUR MEMBERS



HDNL 2016 - Issue No 67, Q4 16

HOPE

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

IRELAND

CHECK OUT OUR WEB SITE

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

Thanks to all who have supported and / or sold HDAI's Charity cards. We welcome

Christmas themed photos or paintings for our Christmas Cards for 2017.

Save the Date

HD Seminar with Guest Speakers Dr Ed Wild and Dr. Niall Pender in Dublin City Centre on Saturday March 4th, 2017



Dr. Ed Wild will give a HD Research Update to family members in Dublin on Saturday March 5th, 2017. Dr.

Wild is a Medical Research Council Clinician Scientist at University College London's Huntington's Disease Centre, his research aims to accelerate the development of new therapies for HD. He is a Consultant Neurologist at the National Hospital for Neurology and Neurosurgery in London's Queen Square. Dr. Wild also co-founded HDBuzz, an online source of reliable, impartial, easy-to-understand information about HD research



Dr Niall Pender, Head of Dept of Psychology & Principal Clinical Neuropsychologist at Beaumont Hospital and

current President of the Irish Brain Council will provide information on living with Huntington's disease. He will also give an update on Beaumont's Enroll-HD study site which he established in 2015.

The Seminar programme will be available soon, in the meantime you can reserve your seat by sending an email to:

info@huntingtons.ie or call: 1800 393939.

Enroll-HD



As of November 1st, 2016 a total of 12,175 participants have been enrolled at 137 Enroll-HD study sites in 14 countries around the world. Enroll-HD

at Beaumont Hospital is now in operation for one year and approximately twenty people have registered to date, this is impressive considering resource limitations. A further twenty people have expressed their interest to join and they will be contacted in the coming months. Those already participating in the study will receive a follow up appointment in due course. Enroll-HD relies on people impacted by HD signing up and maintaining their annual appointments as the following excerpts' from a recent article in the Enroll Newsletter Autumn 2016 explains:

Sticking With It - For Enroll-HD, signing up new volunteers is only the start. The most valuable information gathered by the study will come from collecting data on the same people followed over a long period of time, to track and compare changes that take place over years. For that reason, retention - helping people stick with the study - is just as important as signing them up to begin with.

"In Enroll-HD we want to collect good data to get a good portrait of HD," says neurologist Tiago Mestre, assistant professor at the University of Ottawa and medical director of Enroll-HD. *"For that we need to know how things change over time."*

Enroll-HD is also intended to be a platform to enable further research and clinical trials of drugs—studies that require good data collection and consistent participation.... Researchers want to be able to track people's motor performance and cognitive abilities, for example. And they want to understand how sleep or diet affect quality of life and how the disease progresses over time. The only way to get that information is if people come back repeatedly.

You can read the full article and other articles about the study in the 'Enroll!' newsletter published quarterly by CHDI. It includes stories about the ideas, people and projects behind the Enroll-HD study -

www.enroll-hd.org/news/

Ask the Doctor

The European Huntington's Association website now has an **'Ask the Doctor'** facility where you can email for specific information on HD. See:

<http://eurohuntington.org/>

Pre-implantation genetic diagnosis at Cork Fertility Centre

Pre-implantation genetic diagnosis (PGD) is a variant of In Vitro Fertilisation (IVF) treatment that is offered by Cork Fertility Centre to couples who are known to be at risk of having a child with a specific genetic condition.

Genetic counselling is required prior to visiting Cork Fertility Centre. The steps involved in the IVF treatment are carried out on site in Cork Fertility Centre while the genetic testing of the biopsied material is carried out by our partners Reprogenetics, based in Oxford.

Cork Fertility Centre was licensed in 2012 by the HPRA (Health Products Regulatory Authority) to carry out embryo biopsy facilitating PGD. Performing PGD prior to transfer of embryos while not eliminating entirely will almost completely remove the risk of an affected pregnancy for that condition.



The Centre has successfully performed PGD for a number of single gene disorders including Huntington's. Approximately 1 in 3 couples who reach the stage of embryo transfer will have a successful outcome. Treatment cost is €11,650.

For further information please contact our team on 021 4624436, email advice@corkfertilitycentre.com or visit www.corkfertilitycentre.com

In Memory of Christy

On 18/11/ 2016 the HD community lost a dear friend and great role model with the untimely passing of Christy Clarke.



Christy and Anne worked tirelessly over the years to raise awareness for HD. In their daily lives they demonstrated the power of love over adversity and together they campaigned for improved services and greater awareness for HD and other neurological conditions. Christy's indomitable spirit and determination to enjoy life was an inspiration to many. He will be fondly remembered. HDAI extend our deepest sympathy to Christy's wife Anne, their families and many friends.

Extraordinary General Meeting

HDAI held an EGM in The Maldron Hotel, Smithfield, Dublin 7 on Saturday 5th of November 2016 following the Dublin Support Meeting. The EGM was called to approve a new Constitution for Huntington's Disease Association of Ireland which is compliant with the Companies Act 2014 and to maintain the official and legal name of the company as: Huntington's Disease Association of Ireland.

Twenty two current 2016 members attended the EGM and passed the above resolutions.

HD Tips

Christmas can be a hectic time of year. Your loved one with HD may find the frenzy challenging.

It may help to:

- Limit Distractions
- Maintain a Routine
- Slow Down

Top Tips for Brain Health

-  Get physically active
-  Stay socially engaged
-  Challenge your brain
-  Manage stress, think young, think positive
-  Adapt your lifestyle to protect your brain

www.hellobrain.eu



Support Meeting and Annual Lunch

HDAI hosted annual lunches following the end of year support meetings in Dublin, Cork and Mayo.



Fundraising

Hell & Back



The Keating family and their friends were exceptional in their efforts to raise awareness and funds of €5,400 for HDAI through their participation in the arduous Hell & Back challenge in September. Huge thanks to Colin, Elaine, Fletcher, Louise, Rachel and Rebecca. Thanks also to Askea Credit Union, Carlow for their support.

Hell & Back in the Dark



Emily Fleming & Amy Walsh took part in a Hell & Back in the Dark challenge and raised a marvellous €1,400 in addition to vital awareness.

Casual Day at Dunnes Stores

Sincere thanks to everyone at Dunnes Stores Head Office who contributed to the Casual Friday collection in October which raised 3,345.00 for HDAI. We greatly appreciate Martina O'Reilly's tremendous support.

Croke Park Memorial



Garda Greg McGovern and friends organised a memorial football match in Croke Park as a tribute to the late Padraig Moran (pictured left).

Proceeds of the event went to charity including a very generous contribution of €2,000 to HDAI. Sincere thanks to Fiona and family.

Tuam Tea Dance

Ann Hannon's November Charity Tea Dance at the Ard Ri House Hotel in Tuam raised an excellent €1,910 for HDAI. We greatly appreciate this continuous support from Ann and her family and friends.



Thanks to everyone who bought and sold tickets, and donated. Local businesses donated raffle prizes including: Eve's Hair & Beauty, Milltown, Jimmy Flynn's Chemist, Claremorris, Tom Kelly at Tierneys Pub, Foxhall, Niall Heffernan, Claremorris, Brendan Egan, Castlereah Mart, Dermott Lyons Mace Castlereah, Cahills Supervalue, Castlereah, Corrib Oil Roscommon and Noel Flanagan Castlereah. Thanks also to Della Dolan and her team for organising the event.

Half Marathon



Josie (right) and Sinead Leavy pictured with their friend Patricia Keenan have once again participated in a half marathon to raise funds for HD. Josie and Sinead raised €730 and Patricia raised €500. HDAI are extremely grateful for this continuous support.

Lough Key Walk Mary Carty raised €100 in sponsorship for Joe Doran's Lough Key Walk

Celbridge Craft Fair



Marie (centre) and Íde (left) Cussen once again sold much sought after handknits and snowmen at the Sinn Féin North Kildare Cumann stand at the annual Christmas Craft Fair in Celbridge, Co Kildare. They raised an amazing €1,035 and great awareness. Maire was featured in the local newspaper and the famous snowmen are now on sale in some Celbridge shops.

Donations

Recently received donations include:

- Martina, Finnola and Zil - monthly Direct Debit donations.
- Patrick & Teresa O Sullivan €1,000
- Mick Scanlon €180
- Donations in memory of Teresa Clarke €235
- St James & St Philips Badminton Club, Booterstown, Dublin €200
- Dr Joe and Helen Cremin €200
- Anne Lennon Bird and Bernadette Jordan Christmas Gift donations

Christmas Cards

Thanks to all who have supported and/or sold HDAI's charity cards. Special thanks to Pat Davis and Angelina O'Shea who sold cards to the value of €212, to Deirdre, Ann Hannon and to Mary Murphy in Gurteen Post Office €128.

Purple HDAI Hoodies



HDAI have purple hoodies available for sale as demonstrated by models Anne and Dee. Good value for the chilly season - €20ea plus postage.

Upcoming Events

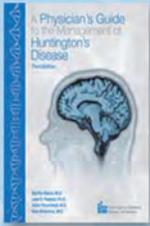
Sunrise up the Reek 2017

Family and friends of the late Eleanor Breen are planning another Reek climb in her memory.



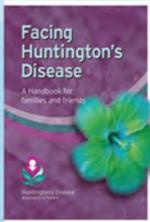
The Croagh Patrick Climb will take place on **Saturday July 1st 2017** and everyone is welcome to join in. The group promise a laugh or your money back! If you want more info email: John@hansonregan.com

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.

Save The Date

Members Meeting
and Respite
Weekend Cuisle
9th -11th June, 2017

DO YOU HAVE ANY ARTICLES TO CONTRIBUTE OR TOPICS YOU WOULD LIKE DISCUSSED? THIS IS YOUR NEWSLETTER.



Huntington's Disease Association of Ireland
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 1303
FreeFone: 1800 393939
Fax: 01 872 9931
Email: info@huntingtons.ie
www.huntingtons.ie

Help us Light up the World



In May this year HDAI joined the international HD community to raise the visibility of Huntington's Disease by illuminating landmarks in Dublin and posting pictures on social media using #LightItUp4HD.



Former Lord Mayor of Dublin, Criona Ni Dhálaigh with HDAI Chair Thomas Lillis



The Mansion House, Dublin City Council Civic Offices, The Generator Hostel, Smithfield, Bloomfield Health Services, Byrnes Pharmacy Ballsbridge and The Convention Centre, Dublin all lit up in purple in support of HD (above).

We want to increase awareness in 2017. The more buildings willing to light up around the country the more attention we can create. Can you ask a building in your area to go purple during the week starting May 15th 2017?

Can you post pictures on social media? If so please get in touch as we need your support.

Acknowledge Kindness



Do you have a friend or neighbour who deserves a bunch of flowers or a Thank you voucher? If so please let us know.

Joe and Pauline Doran nominated **Carol Lee** for flowers to acknowledge her kindness and support to them. In addition to her friendship Carol has also recruited family and friends to fundraise and raise awareness for Huntington's Disease.



Impacted by HD?

If you are impacted by HD and need information or support, please contact us on our Freefone Helpline 1800 393939.

Confidentiality is assured.

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 volunteers for their social media work.



HDAI Support Meetings

All those impacted by HD are welcome to join us at our Support Meetings in Cork, Dublin, Longford 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

Feb 4th

CORK

Mar 18th

LONGFORD

Feb 18th

LIMERICK

Jan 14th