



HDNL 2015 - Issue No 61, Q1 15

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

CHECK OUT OUR WEB SITE

www.huntingtons.ie
e: info@huntingtons.ie

SUPPORT MEETINGS

See dates on page 4

SHOW YOUR SUPPORT

Membership forms for 2015 enclosed with this newsletter

GENETICS

For information on Genetic testing contact the Genetics Centre - Tel: 01 409 6902 or www.genetics.ie

SAVE THE DATE

Members Meeting and Respite Weekend - Cuisle, 5th-7th June, 2015



OLD MOBILES?

Have you any **old mobile phones?** If so please send them to us. If we recycle them we will get much needed funds. Please email info@huntingtons.ie or phone 1800 393939 for more information.

HD Awareness

Anne and Christy Clarke were featured on UTV Ireland's 10pm News on March 3rd. They highlighted the impact of HD and the benefit of availing of HD specific information and support and in getting to know others impacted by HD through HDAl's support meetings and events.



Anne and Christy's consistent advocacy work helps to raise awareness and greater understanding of the impact of HD. HDAl are very grateful for their tremendous voluntary work. The interview is available on HDAl's Facebook page: <https://www.facebook.com/pages/Huntingtons-Disease-Association-of-Ireland/121707387897701?ref=hl>

Anne and Christy's interview was part of a feature on the 25th Anniversary Celebration of the Carmichael Centre for Voluntary Groups where HDAl has been a resident member since the Centre's establishment in 1990. Diarmaid Ó Corrbuí, CEO of the Carmichael Centre for Voluntary Groups was interviewed on the news programme and outlined the importance of the work carried out by the small voluntary groups within the Centre. He highlighted the difficulties faced by groups who were unsure whether their funding under the Scheme to Support National Organisations (SSNO) would continue beyond June 2015.

Earlier in the day Senator David Norris lead a parade from Christchurch across the river Liffey to the Carmichael Centre "in solidarity and celebration with the 45 charities and

voluntary groups which make up the Carmichael Centre, to shine a light on the important work each and every organisation undertakes on a daily basis".



HDAl was one of 23 disability/caring focussed organisations to have 3 year funding withdrawn through the Scheme to Support National Organisations (SSNO), run by the Department of the Environment, Community and Local Government in June 2014.

Shortly after his appointment as Minister for the Department, Minister Alan Kelly restored funding for one year pending a review of funding to the health and disability organisations who were rejected under the SSNO scheme.

HDAl has received €19,000 per annum in 2014 and 2015 in SSNO funding. This contributes to vital core services and facility costs including: a national advocacy and helpline service, counselling, regional support meetings, carers meetings, assistance with specialist aids and equipment, quarterly newsletters and an annual magazine, training and information seminars, youth support, website maintenance and information distribution.

The Disability Federation of Ireland (DFI) and the Neurological Alliance of Ireland (NAI) are calling for an extension of the current bridging scheme to the end of December 2016, along with a commitment to implement a disability inclusion funding scheme commencing January 2017.

Enroll-HD in Ireland



Despite resource and capacity constraints, Dr Niall Pender's determination to establish an Enroll-

HD site at Beaumont Hospital has now met with success. Ms Eleanor Moran (pictured) has been employed as a part-time research assistant to work with Dr Pender to commence Enroll-HD registration at Beaumont. The HDAI Board have approved a grant towards this project following a request from a voluntary fundraiser, who asked that part of their contribution would be considered for a research project.

Information on Enroll-HD

Source: <https://www.enroll-hd.org/sponsor-and-partners/>

Enroll-HD is a worldwide research project that aims to involve as many as 20,000 people who either have HD or are at risk of HD. It is an observational study, meaning that its purpose is to closely track how the disease emerges and changes over time, rather than to test a specific treatment. The study measures mental abilities such as attention and memory, mood and quality of life. It also collects a blood sample so that researchers can analyse DNA and other biological measures.

Enroll-HD goals:

- To make new discoveries about how HD affects the mind and body. The data collected during the study will be made available to all qualified researchers with legitimate projects, to encourage more scientists and doctors to get involved in HD research.
- To develop a global database of people with HD or at risk of HD who might eventually be interested in volunteering for studies that test new drugs. This will make it much easier and faster to test new drugs in the future.
- To compare the way people with HD are currently cared for in different parts of the

world, in order to identify the best treatments and improve care for everyone.

Overall, the aim of Enroll-HD is to develop new, effective treatments for HD as quickly as possible.

Any member of a HD family can take part, including:

- People who know they have the HD gene, whether or not they have symptoms or have officially been diagnosed with HD,
- People who know they are at risk, but haven't taken the genetic test to find out whether or not they carry the gene,
- People with a family history of HD but know they do not carry the expanded gene,
- Spouses/partners (not blood relations) of people with HD.

How is data protected?

When you join Enroll-HD your name is not entered into the study database. Instead, your information is associated with a special 9-digit HDID number that is unique to you. The only people who can see your name are the people at the clinical site you visit.

The data itself is stored on a secure system in the UK - the same type of system used by banks and hospitals. The blood sample is sent to a special biorepository facility in Milan, Italy. Before the blood sample is sent out, it is recoded again for an added layer of security.

Enroll-HD is sponsored by CHDI Foundation, a privately funded nonprofit biomedical research organisation dedicated to rapidly and collaboratively developing therapies for HD. In addition to sponsoring Enroll-HD, CHDI funds academic researchers focused on HD, conducts research to develop new treatment ideas, and partners with biotechnology and pharmaceutical companies to develop novel drugs and therapeutics. The goal is to accelerate the development and testing of new therapies for HD so they can be made available in the fastest possible time.

Joint Oireachtas Committee on Health and Children

Joint Oireachtas Committee on Health and Children - Coping with Challenges of Huntington's Disease

HD representatives met the Joint Oireachtas Committee on Health and Children to discuss the challenges of HD on January 15th 2015.



(Left to right): Patricia, HDAI, Dr Niall Pender and Dr Jennifer Hoblyn at Leinster House

Dr. Niall Pender, Principal Clinical Neuropsychologist, Head of Department of Psychology, Beaumont Hospital, Dr. Jennifer Hoblyn, Clinical Director Bloomfield Health Services, Clinical Senior Lecturer Department of Psychiatry TCD, Anne Lennon Bird, HDAI Chairperson and Patricia Towey, HDAI Information and Services Coordinator, discussed the challenges for people diagnosed with Huntington's Disease (HD) and their family members. Dr. Tim Counihan, Consultant Neurologist, University College Hospital Galway, had hoped to join the meeting but was unable to attend on the day.

The group outlined the complex nature of HD and the urgent need to develop vital HD specialised services in Ireland. The treatment and management of HD necessitates a flexible multi-disciplinary approach across medical, disability, psychiatric and social care services.

Patricia Towey spoke about the impact HD has on the entire family and provided case studies to highlight the psycho-social consequences it can bring to affected families.

"It is impossible to overstate the devastating nature of this condition on the patients and their unaffected family and friends" Dr. Niall Pender

Dr. Pender has worked directly with HD patients and their families for over 17 years. He related his experience of working in London as part of an experienced HD multidisciplinary team, where he saw first-hand, the benefit to patients and families of a timely and responsive treatment and support service.

Dr. Pender noted the difficulties for people impacted, to talk openly about HD and the consequent lack of a voice for the HD community. *"We must ensure that we care for and help the most vulnerable people in our community in a dignified and appropriate manner."*

Dr. Hoblyn commented on the scarcity of multi-disciplinary care, from diagnostic services to day services, specialised clinics and short-term assessment programs.

The group stressed that essential HD dedicated services currently in development are restricted due to funding and resource limitations.

These include:

- Beaumont hospital Cognitive-Behavioural Clinic;
- Galway University Hospital Neurology service;
- Bloomfield Hospital MDT Mental Health assessment services and long term care.

The development of HD multidisciplinary services is crucial for the management of HD, as is the urgent need to develop a national HD care pathway.

The group informed Committee members that Ireland is lagging behind most European countries where European Huntington's Disease Network (EHDN) study sites have been in existence for many years.

Dr. Hoblyn advised the committee that Bloomfield Health Service clinicians have recently joined EHDN working groups including: a nurse-psychiatry; physiotherapy and cognitive psychology group. It is vital to establish study sites here so that Irish people can participate in international studies and future clinical trials.

Dr Niall Pender advised that Beaumont Hospital have very recently signed up to the Enroll-HD project which is an international observational study aiming to accelerate the development of therapies for HD.

The group submitted the following recommendations to improve the management of Huntington's Disease services:

- To secure the financial future of Huntington's Disease Association of Ireland in its role as the national resource centre for people impacted by HD;
- To support the development of multi-disciplinary HD clinics in Beaumont Hospital, Dublin and University College Hospital Galway and establish a further site in Cork;
- To facilitate access to Bloomfield Health Services' 16 week assessment multidisciplinary programs, specialised long term care and the development of day services;
- To clarify and increase funding streams to enhance urgently needed access to appropriate individualised care;
- To develop and clarify evidenced based clinical pathways across regions in an equitable transparent manner;
- To support Research to ensure people in Ireland can participate in international HD research developments;
- To support a sustainable, accessible national genetic service;
- To ensure access to Medical Cards for all individuals with HD.

Vice Chair of the committee Deputy Ciara Conway chaired the meeting. Committee members in attendance included: Deputy Caoimhghín Ó Caoláin, Senator Jillian van Turnhout, Senator Colm Burke, Deputy Catherine Byrne, Deputy Sandra McLellan, Senator John Crown, Deputy Séamus Healy and Deputy Billy Kelleher.

HD representatives and those present in the public gallery were encouraged by the interest shown from members of the Joint Oireachtas Health and Children committee.

Fundraising - Thank You



The 2015 Vhi Women's Mini Marathon (Dublin, Monday 1st June 2015) is officially open for entries from 11th February. If you would like to participate for HDAI please contact us.

Charity Shop Support



Sandyco Vintage & Classics Charity Shop, Sandyco, Co. Dublin have once again nominated HDAI as their chosen charity for March and April 2015. (They generously raised €546 for HDAI in 2014). The more items they receive the more they can sell! <https://www.facebook.com/events/137152443118123/>

Mini Marathon - Limerick

Thank you to Mary McNamara who raised an excellent €450 for HDAI by participating in the Limerick Mini Marathon in 2014.

Music and Comedy



Dee Jones organised a very enjoyable night of music and comedy in The Sugar Club, Dublin, on February 4th to raise awareness and funds of €146 for HDAI.

A Big thank You to Dee and to all the performers who very generously donated their talent and time including: Fiach Moriarty; Testify; comedy improv. group The Imps and comedienne Margo Carr.

Celbridge Craft Fair

Marie and Íde Cussen raised a marvelous €800 for HDAI at the 2014 Christmas Craft Fair in Celbridge, Co Kildare by selling handknits with the Sinn Féin North Kildare Cumann. HDAI are very grateful for this remarkable hard work and generosity.



Fabulous knit wear on display - Íde with another volunteer

Awareness Bands Sales

Thank you to Cora who raised €100 for HDAI by selling HDAI awareness bands.

Donations and Membership

HDAI is very grateful to members and friends for their very generous support and they include:

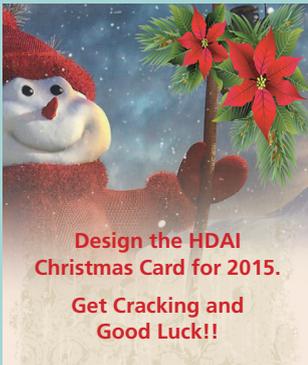
- Martina and Finnola who both contribute monthly direct debit donations
- Joe Doran for his ongoing support and his €100 donation before Christmas
- Pauline Doran for her donation and support of HDAI Christmas Cards
- Patrick & Mary Alice Lennon for their extremely generous donation of €1000 in February
- Deirdre and her friends and colleagues at Mary Immaculate College for Christmas Card sales of €180
- Pat Davis for her donation of €100, her wonderful knitted hats and her HDAI Christmas Card sales
- Mick Scanlon and family for their very generous donation of €200

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 HDIA office and we will take it from there.

Submit a photo or other artwork for HDIA XMAS Cards

Do you have a Christmas themed photo or artwork you would like to feature on HDIA's 2015 Christmas cards? If so we would welcome your contribution. We will ask newsletter readers to choose their favourite image later in the year so you may win a prize.



Please email your submissions to info@huntingtons.ie or post to us at Carmichael Centre, North Brunswick Street, Dublin 7.

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



Huntington's Disease Association of Ireland

Carmichael Centre
North Brunswick Street
Dublin 7

Tel: 01 872 1303

FreeFone: 1800 393939

Email: info@huntingtons.ie

www.huntingtons.ie

Social Media: A Volunteer's Perspective

The phrase social media is so over-used that it can feel like it's lost all meaning. However, it probably just needs a renaming ceremony. What started as online places used mostly by groups of friends; sharing everything from their love life to their breakfast (with accompanying pictures!) has grown into a real, transparent global network. Niche communities can find each other, share experiences, find support, work on ideas together, lobby political representatives and really start to make a change.

A case in point was recently, the HDA in England and Wales had a long awaited, all party, parliamentary group meeting. They wanted to discuss the crossover between the medical and social supports for HD. To progress the discussion in parliament the meeting had to be quorate, so, they needed to have 6 MPs attend. They were worried as though people had expressed an interest, there had been very little concrete RSVP-ing to guarantee attendance...

Enter social media. Each MP that had expressed an email was sent a tweet, that aimed to reaffirm their interest. The tweet was polite, encouraging but most importantly, public! Each MP responded on twitter and there ended up being 10 in attendance, including the Shadow Health Minister. It was a triumph for the HD community through social media.

The public nature of social media makes it a very handy way to boost public awareness of HD. Since HDIA have been on twitter, we have been retweeted by Joe Duffy, Miriam O'Callaghan, The Rubber Bandits, Norah Casey, Sean Moncrieff, George Hook, Fintan O'Toole, Daniella Moyles, Dave and Dermot from Today FM, Niall Breslin, Baz Ashmawy, John Butler, Tara Flynn, Joe O'Shea, Paul Galvin to name but a few. Each have thousands of followers, so increasingly more people will know about HD.

As importantly, we have established an international network in the online HD community. This means we can share news of upcoming trials, media strategies, carers support tips, new therapies from the academic sources almost as soon as they have been announced. We call this our Community of Hope.

It means too, that we can use these networks to promote and support any fund or awareness raising ideas we come up with in the future (ALL your ideas are welcome!). There is an international community dedicating themselves to the hunt for a cure and supporting HD families. Facebook and twitter allow us to share each other's efforts, learn from each other, support each other and let the wider world know about HD and how they can help. Facebook, Twitter provide a quick fix, high dose information share that allows us all to stay connected, to be hopeful and to engage. Let's see what 2015 will bring and we'll see you online! Please find us, like us on Facebook, follow us on twitter and join the conversations:

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.

Information on HD



The HDIA 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>

In Memory



Family and friends of Willie Grant kindly donated €300 in his memory following his untimely death last year. Willie very bravely fought his illness with dignity. He will be lovingly remembered by his family and friends.



HDIA Coffee Mornings/Support Meetings

You are very welcome to join us at our Coffee Mornings/Support Meetings from 11.00am to 1.00pm on a Saturday in Cork, Mayo, Dublin and Limerick (dates below). Our Family Support Officer or a board member will host the meetings. Tea, coffee and scones are provided. Contact the HDIA office on 1800393939 for more information.

DUBLIN

May 9th
Aug 8th

CORK

Mar 21st
July 4th

THE WEST

Cusle, Roscommon (AGM), June 6th
Longford, April 25th

LIMERICK

April 11th
Oct 17th