



HDNL 2016 - Issue No 65, Q2 16

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



Jimmy Pollard speaking at our annual Members meeting in Cuisle on June 11th, 2016

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

Members Meeting and Respite Weekend

HDAI's Annual General Meeting is held in conjunction with the Members Meeting. HDAI's new Chairperson Thomas Lillis welcomed all and delivered the Chair's report. The Annual Financial Statements were presented by the Treasurer and are now available online <http://www.huntingtons.ie/content/about-us>

Jimmy Pollard, International HD Speaker and author of *Hurry Up and Wait*, spoke at our annual Members meeting in Cuisle, Co Roscommon on June 11th. Jimmy gave a very engaging talk on *"Thinking About Thinking with Huntington's Disease"*. He provided thought provoking examples of what it might feel like to think with HD and demonstrated the challenges that people living with HD constantly face. Jimmy gave practical suggestions as to how care givers, family and friends can lessen these challenges. Here is a summary:

Wait - Thought processing slows with HD so give the person more time to respond.

Recognition is easier than Recall - Ask questions carefully - multiple choice or yes/no questions are easier than open ended questions.

Maintain Focus - You can help the person to focus by avoiding interruptions and distractions, and keeping communication clear.

Organising and Planning - Routine helps! Remember **KISS - Keep It Same and Simple**

Hurry Up - HD can affect inhibition and impulse control. Try not to leave a person with HD waiting. If you can't respond straight away let them know how long it will take.

Jimmy also shares poems and quotes from those impacted to relay his message, *"I hate this short temper of mine several times worse than you hate the damn thing"*

Woody Guthrie

In his **Enroll-HD presentation**, Jimmy gave us a very interesting history tour of the progress of HD research from Dr George Huntington's first paper on the condition in April 1872, to the present day.

Jimmy reminded us of the importance of family members working with physicians and researchers to improve treatment and knowledge of the condition. George Huntington benefitted from the contribution of his father and grandfather who were also physicians in the same family practice. It was their combined observations of a HD family in Long Island, New York over generations, which led to the clinical classification of the condition.

Woody Guthrie's second wife Marjorie, reached out to other HD families and physicians in the late 1960s and this led to the establishment of the first HD Society. The marker for the HD gene was identified in 1983 due to the collaboration of the Jensen family with Professor Mike Conneally (originally from Co Galway), Professor James F Gusella, and their colleagues. Later Professor Nancy Wexler and her team gathered data from numerous HD families in Venezuela and eventually identified the gene in 1993. Today there are thousands of people impacted by HD who have shared their data and experience to progress HD research.

Jimmy reminds us that *"Science is a cumulative process: new facts get stacked onto other facts, new observations prove or disprove hypotheses and understanding grows as more is learned and our measurement and analysis progresses further"*.

He also noted that 86% of all clinical trials in the United States fail to recruit on schedule. Similarly with HD studies most start later than planned. He stressed that some current studies would be farther along today if there were more volunteer subjects.

Enroll HD, sponsored by the CHDI Foundation has now enrolled 10,707 participants (June 1st) at 135 sites in 14 countries around the world. Jimmy reminded us that many, many more volunteers are needed. The journey has always been about families...finding other families...and partnering with docs and scientists.

We've come so far...

Everyone from a HD family can play a part in the quest to find a cure!

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Liz, HDAI family Support Officer facilitated a Carers workshop on Saturday morning. This was followed by a relaxation session for carers provided pro bono by psychotherapist Valerie Ritson.

"I found the relaxation session very good and I have used the CD every day since" Elizabeth

Chiropody, reflexology and massage therapies were also available on Saturday thanks to Jenny Shanley, Mary Finnegan and Kathleen Finnegan.

Dinner, socialising and dancing followed on Saturday evening. Our annual raffle generated €410. Thanks to all who sponsored raffle prizes including: Boots Liffey Valley, Butlers

Chocolates and Tesco Lucan. It was lovely to see old friends extending a hand of friendship to those attending for the first time. As usual the team at Cuisle excelled with their friendly and helpful service.

"It was our first time...we will definitely come again...we were surrounded by such positive people, not only from HDAI but also the staff at Cuisle... we made lots of new friends"

Sarah & John

"Enjoyed my weekend, dancing all night, coming again"

Michelle

"Lovely place, great craic and we really enjoyed everything"

Ide & David

HD: Cognition and Care Seminar

Bloomfield Health Services and HDAI held a seminar entitled 'Huntington's Disease: Cognition and Care' for health and social care professionals working with people living with HD on June 14th. Jimmy Pollard delivered an interactive presentation on **'Thinking About Thinking with Huntington's Disease'**. Anne Lennon Bird gave her perspective as a HD family member. Speakers from Bloomfield Health Service's multi-disciplinary team included Dr Jennifer Hoblyn, Neuropsychiatrist & Clinical Director, Aoife Gallaher, Assistant Director of Nursing, Susan O'Neill, Senior Physiotherapist, and Aisling Doyle, Occupational Therapist.

"We need to have more events like this"

"All presentations were excellent"



Cork Family Caregivers Seminar

Dr Sean O'Sullivan, Consultant Neurologist, Cork University Hospital, joined health professionals from Bloomfield Health Services to speak to family carers at the HD Care Giver's Seminar held in Cork on May 20th. Dr O'Sullivan gave a very informative talk on **'HD in the Out-Patient Neurology Clinic'**. He spoke about the genetic implications of Huntington's disease, the range and variance of symptoms and the treatments needed to manage symptoms. Non-drug treatments such as speech and language, adequate hydration and nutrition, physiotherapy and psychological support are essential in managing HD symptoms. Socialising and maintaining interests and activities is important for the person with HD and their family. He referred to the benefit of accurately informing ones physician of the type of symptoms being experienced so that appropriate treatments can be considered.

Speakers from Bloomfield Health Services multi-disciplinary team included: Susan O'Neill, Senior Physiotherapist, who spoke about the role of the physiotherapist in helping to maintain function, Aoife Gallaher, (HD) Clinical Nurse Manager, discussed *'Caring for and Nursing a Family Member'* and Dr. Andrea Higgins, Neuropsychologist, talked about *'Thinking skills and Behaviour'* Feedback included:

"All the speakers were very informative, I appreciated Dr O Sullivan's down to earth approach and the time he gave to answering our questions" **ES**

"I found all the information helpful and it's great to meet up with other HD care givers"
Elzbieta

HD Café at Bloomfield

Minding Your Mental Wellbeing -

Dr Andrea Higgins, Senior Neuropsychologist delivered an insightful talk on the importance of looking after our psychological health at the HD Café evening in Bloomfield Health Services on April 27th. Stress can impact negatively on thinking, memory and concentration. It is important to avoid catastrophising and aim for our emotional best. Cognitive Behavioural Therapy skills can assist in challenging negative thoughts and rationalising negative feelings. Dr Higgins suggestions for minding mental wellbeing include: connecting with those around us, doing things we enjoy and seeking help when we need it. You can read Dr Higgins article on this subject in Hope Annual 2016.

Thirty family members attended the event and expressed an interest in future Café evenings on topics including: Psychiatric symptoms and Management of HD, Planning Ahead, Enduring Power of Attorney and addressing the issue of diagnostic testing with other family members.

Dr Sean O'Sullivan



Fundraising

Killmallock Social Night

Eileen and Timmy O'Brien organised a charity fundraiser in Bulgadden Castle in February and raised a massive €3,000 for HDAI. We are very grateful to Timmy & Eileen (below) and to the O'Shea family and their friends for this marvellous support.



Mini Marathon

HDAI salute all the wonderful women who took part in this year's mini-marathon to raise funds and awareness for the charity.



Mary Lee, Tara Belle, Peg Fogarty, Carol Lee, Pauline Doran and Christine Lee (left to right above), joined forces and have raised over €3,000 from sponsorship and from their Clara Market stall. Monica Doyle raised €500. Grainne Allen raised €250. Bernie Shanahan and Catriona Harty raised €1,175. Dee Jones raised €725. Angela and Siobhan Lacey raised €1,286.



Rohanna and Shauna Rahman (above) €325. Olivia Doyle and Aoibhinn Moran €555.

Clara Market

In addition to their mini marathon endeavours, Carol, Christine, Pauline and Peg joined Joe Doran and other family members and friends to hold a successful stall at Clara market in May.



Thanks to all who lent a hand including: Anne, Claire, Emma, Michael, Mark, Declan, Davy Connell (for loan of van) and Edel (printed posters). Through mini marathon sponsorship, the market stall and the upcoming Lough Key walk a massive €3,300 has been raised so far. Thanks so much for your marvellous hard work and support.

Seamus Birthday Gifts

Seamus celebrated his birthday earlier this year and asked for donations to HDAI in lieu of birthday gifts. HDAI received an extremely generous €1,190 in donations. Thank you!

Elmgreen Golf Club

Huge thanks to Elmgreen Golf Club in Castleknock and to their Captain Mr. Alan Greene for nominating HDAI as recipient of their Captains Drive-In which raised a marvellous €700 earlier this year.

C&C Cellular Mobile Recycling

Brendan Chambers of C&C Cellular continues to support HDAI through his Trash for Cash phone recycling and recently send a cheque of €535.65 for phones we collected. Thanks to all who have donated used phones and in particular to Ann Hannon and to Jerome who have recently collected phones on our behalf.

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 2016.

UPCOMING EVENTS

Killmallock, Limerick HD Charity Cycle - July 10th

HD Awareness Walk - Lough Key, Boyle, Co. Roscommon - July 16th

Croagh Patrick Climb - July 16th

Dublin to Wexford Charity Cycle

Massive thanks to Maurice Keating and Darren Brennan (below) who cycled a phenomenal 164 Kilometers from Dublin to Carne Holiday Centre, Wexford on June 4th to raise awareness and funds for HDAI. They have raised €2,065.91 on their online fundraising page.



Monami Construction kindly donated a further €250 bringing the total to €2,315.91. Family and friends welcomed Maurice and Darren to Carne Beach following their long distance cycle.

Membership

Thanks to everyone who sent in their 2016 subscriptions.

Donations

HDAI greatly appreciates the very generous donations received recently including:

- Martina, Finnola and Zil for their monthly Direct Debit donations.
- Patrick & Mary Alice Lennon €1,000
- Anonymous donation of €20 received by post
- Cuisle Donations - George Driver €100, Noel €15,
- Donations received online €160 - Tony O'Rourke, Therese Gleeson
- Aileen and Moira €200
- Shirley Finn €50
- Coin Collections - Porters Desk, Pearse College €38.86, Rose Wren €41.28, Madeline Egan €136.48

In Memory

HDAI would like to express condolences to family and friends of **Tommy O'Reilly, Kenneth Murphy** and **Joan Peters**, who died recently having struggled with Huntington's disease in their later years.



Tommy O'Reilly



Kenneth Murphy

Donations in remembrance of deceased loved ones include: Joan Peters €200, Eleanor Breen €70 (€1,273 in total), Tommy O'Reilly €835, Kenneth Murphy €150 and Gertie O'Reilly McHale €265.

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.



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Video Updates on International Research

At the 2016 Huntington's Disease Society of America Convention in Baltimore, Jeff Carroll and Ed Wild of HDBuzz presented their regular research update, entitled **"The Best Time to Plant a Tree"**, including updates on the Teva Pride-HD and Legato studies, Pfizer's Amaryllis study, and Ionis Pharmaceuticals' HTRx 'gene silencing' trial. See links at www.huntingtons.ie and https://www.youtube.com/watch?v=8oS_GJQMyNQ

CHDI's 11th Annual HD Therapeutics Conference took place February 22 - 25, 2016, in Palm Springs, California. Charles Sabine interviewed a selection of participants - check out the Video Postcard - <http://chdifoundation.org/video-postcard-from-2016-hd-therapeutics-conference/> or see links at: www.huntingtons.ie

We Need Our Heads Examined

There is a dire shortage of rehabilitation services in the Irish healthcare system. People in Ireland with conditions including Huntington's disease, Parkinson's disease, stroke and acquired brain injury are without essential services including speech & language therapy, physiotherapy and psychological support. Neuro-rehabilitation is the norm in other countries but Irish people struggle to get the basic essential services they need. People with neurological conditions are at greater risk of pneumonia and injuries from falls. Many young people are forced to live in nursing homes.



Frustrated by a decade of broken promises, the Neurological Alliance of Ireland and fifteen of its member groups including HDAI have launched a campaign **"We Need Our Heads Examined"** to call for action on rehabilitation. To share your experience and see further info see: www.nai.ie



Anne O'Shea Clarke shared her and Christy's story on The Pat Kenny Show, Newstalk Radio on June 23rd 2016 in support of the launch of **"We Need Our Heads Examined"** - <https://www.youtube.com/watch?v=90Ys45wkjKs>

'Light It Up' for HD Awareness

HDAI joined the international HD community in a campaign to raise awareness for Huntington's Disease by illuminating landmarks in May 2016.



Ardmhéara / Lord Mayor of Dublin, Críona Ní Dhálaigh (far right) showed her support for the **'Light It Up'** campaign and met with representatives of HDAI. **Huge thanks to Dublin buildings for lighting up in purple:** The Mansion House, Dublin City Council Civic Offices, The Generator Hostel, Smithfield, Bloomfield Health Services, Byrnes Pharmacy Ballsbridge and The Convention Centre, Dublin for lighting. Family members from around the world contacted landmark buildings, took photos and shared on social media using **#LightItUp4HD**. Hopefully the campaign will continue to grow and we can encourage buildings nationwide to light up. Let us know if you have suggestions for 2017.

Information on HD



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>

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 Coffee Mornings/Support Meetings

DUBLIN

Aug 6th

CORK

Oct 1st

WEST

Sept 3rd

LIMERICK

Oct 15th