



HDNL 2013 - Issue No 54, Q2 13

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

CHECK OUT OUR WEB SITE

www.huntingtons.ie

SUPPORT MEETINGS

See dates on page 4

GENETICS

The National Centre for Medical Genetics holds genetic clinics in Dublin, Cork, Galway and Limerick. Contact details - Tel: **01 409 6902** and www.genetics.ie

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 hdai@indigo.ie or phone 1800 393939 for more information.

HD featured on RTE1's "Morning Edition"

8th - 14th June, 2013, was HD Awareness Week in Ireland and the UK.

Siobhan and Frankie Lundy, together with Dr Niall Pender, illustrated the devastating impact of Huntington's Disease on the entire family and called for better services in Ireland. Frankie shared the impact HD has on his life while Siobhan discussed the worry of knowing each of their young children have a 50% chance of carrying the mutated HD gene.

Dr. Pender emphasised that Huntington's is a "devastating global progressive degenerative disease" with up to 700 people in Ireland having the condition and a further 2500 at risk.

He stressed that despite there being individual health professionals dedicated to caring for people with HD in Ireland there is a need for an adequate integrated multi-disciplinary service which should include rehabilitative therapy, psychology, neurology and psychiatry.



Comments received following the interview include:

"A brave couple and great awareness raising ... I hope this broadcast hits the hearts of service commissioners".

Bill, UK

"Amazing interview. Well done to Siobhan and Frankie".

Pat

Throughout the world there are integrated multi-disciplinary HD clinics to manage symptoms and support those at risk thus enabling HD families to experience a better quality of life. Concerned health professionals in Beaumont Hospital and Galway Hospital are trying to establish HD Clinics but need more support and awareness to achieve this in the current economic climate. A link to the Morning Edition feature is available on our website and at: <http://www.youtube.com/watch?v=Nc3qo4HU-o>

Annual Members Meeting

Our Members Meeting, Respite weekend and AGM took place on weekend of June 7th - 10th in Cuisle Respite Centre, Co. Roscommon. 60 people attended on Saturday with the majority enjoying the weekend at Cuisle.

Liz held a carers workshop on Saturday morning. Nineteen carers attended the workshop to discuss their concerns and seek support. Liz reminded those attending to contact her if they need individual support.

Complementary relaxation therapies such as chiropody, reflexology and massage were available to all attendees on Saturday. Many people with HD and their family members availed of reflexology and massage from Alice and Mary. Jenny once again very kindly provided pro-bono chiropody for members. HDAL received very positive feedback on these therapies.



Sarah Murphy (above right), Research and Development Officer, National Council of the Forum on End of Life, Irish Hospice Foundation, gave a very interesting overview of the work of the Forum and Foundation which advocates for a broad life cycle approach to end of life. In addition to health care issues, legal, ethical, financial, educational and administrative aspects of end of life need to be considered.

Think Ahead is a public awareness initiative of the Forum on End of Life in Ireland to provide a system whereby people can record and register their care preferences in the event of emergency, serious illness or death when they may be unable to articulate their wishes for themselves.

Annual Members Meeting (continued)

Think Ahead forms allow people to provide information on: Emergency Contacts, Care Preferences, Legal, Financial and preferences regarding their funeral arrangements and organ donation. Forms are available from the HDAI office on request or you can visit the website: <http://www.thinkahead.ie>

Sarah noted that the subject of dying is often difficult to broach but that when addressed it can assist in putting people at ease knowing that their wishes have been communicated. It also reduces anxiety for loved ones.

Sarah reminded attendees that Palliative care: *"Can improve the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other symptoms that may be physical, spiritual and psychosocial"*

Sarah highlighted that Palliative care: *"is applicable early in the course of an illness, in conjunction with other therapies that are intended to prolong life"*

World Health Organisation 2002.

In the past, palliative care was primarily associated with cancer patients but the Irish Hospice Foundation are advocating for access for everyone with life threatening illness. Their mission is *"to achieve dignity, comfort and choice for all people facing the end of life"*

For further information see: www.hospicefoundation.ie/

Family members attending thanked Sarah for her presentation and discussed their own experiences of dealing with the wishes and health care decisions of loved ones.

Our **HOPE Annual Review 2013** was distributed to everyone at our members meeting. Thanks to all who contributed.

The AGM took place on Saturday June 8th. Anne Lennon Bird, HDAI Chairperson welcomed all in attendance and reported on HDAI's activities over the year. Pat Griffin our Treasurer presented HDAI's financial statements and outlined cuts from statutory funding. He thanked those who fundraised throughout the year for their vital support. Pat mentioned the marvelous contribution from Ciara O'Reilly's fundraiser in 2012 and also thanked our regular fundraisers including: Ann Hannon, Rosemary Higgins, Bernie Spellman, Anna Porter Geraldine Martin, Josie and others who are outstanding in their support.

HDAI's 2012 Review and Financial Statements were distributed to members. Our 2012 annual audited accounts were

approved and D.F. Byrne was appointed as Auditor for the coming year. The existing board members resigned and were re elected for 2013. Anna, Jennifer and Yvonne did not go forward for re-election. Anne thanked them for their dedicated service to HDAI over the years.

Anne reminded members that if they wished to find out more about the work of the Board they are welcome to contact the office for more information. Copies of our annual accounts and 2012 review are available from the office. An Extraordinary General Meeting was held following the AGM to approve HDAI's updated Memorandum and Articles of Association.



Members enjoyed a celebratory dinner on Saturday evening. Anne (HDAI Chairperson) presented Anna, Yvonne and Jennifer with a token of appreciation for their years of dedicated service to HDAI on behalf of members.



In addition Christy Clarke and Anne O'Shea were presented with a well deserved bouquet of flowers to acknowledge their tireless efforts to raise awareness for HD.

Our annual raffle raised funds and provided great suspense after dinner.



Thanks to our members and friends who provided fabulous raffle prizes including: Dunnes Stores, Marks and Spencers, Boots Liffey Valley, Flahavans Porridge, Raheen Woods Hotel Athenry, Cuisle Respite Centre, Angelina, Anne O'Shea, Pat O'Reilly and Rosemary Higgins.

Most of our members enjoyed an after dinner dance. There was also excellent musical and vocal talent among members. David generously brought his guitar along and Joan, Siobhan and friends provided a very enjoyable sing song. The team at Cuisle provided us with an excellent service again this year and we are always grateful for their kindness, flexibility and welcome.

HD Information Seminar

To mark European Month of the Brain, HDAI held an Information Seminar for family members in Dublin on Saturday May 18th.

Matt Ellison and Catherine Martin, Huntington's Disease Youth Organisation gave an overview of their work: supporting, educating and motivating young people around the world impacted by HD. Matt and Catherine are inspirational people from HD families who have used their own experiences to reach out to others. HDYO is a non-profit voluntary organisation that provides appropriate information and education, along with support for young people affected by HD.

HDYO is organising the 2013 International HD Youth Camp which takes place in Spain in July. Four young people from Ireland together with Five from Northern Ireland will attend. Their website is an excellent resource for young people and parents.

Check it out at <http://en.hdyo.org/>

Dr Ed Wild, Clinical Lecturer in Neurology at UCL Institute of Neurology, London and co-founder of HDBuzz delivered an uplifting talk on HD. He presented an easy guide to the science of HD and what happens in the brain. He then discussed potential interventions for stopping or slowing down the disease process and outlined the drug development pipeline.

Dr Wild listed his reasons for substantive hope within the HD community:

- HD is the most curable incurable brain disorder - Everyone with HD has the same basic mutation. We know that to treat it we have to get rid of the effects of this mutation.
- Strength of the global HD Community - The HD community is really good at working together to share ideas and best practices.
- Golden Window of Opportunity - Before HD symptoms begin brain cell neurons are not working perfectly, because of early, subtle effects of the mutation. Genetic tests predict who's going to go on and develop those symptoms so if treatments are developed that will relieve some of those pressures on brain cells, this should be able to push forward the age of symptom onset.

- Having symptoms doesn't mean it's too late - If we can slow down progression we hope people may see improvements.
- Science is cumulative - All the research to date adds to the bigger picture.

Keep up with all the latest research news at HDbuzz online at www.hdbuzz.net

Dr Niall Pender, Principal Neuropsychologist, Beaumont Hospital, Dublin is working with colleagues to develop better services for people with HD. He stressed the need for Multi-disciplinary Clinics which should include rehabilitative, neuro psychological and psychiatric care.

Dr Pender gave an overview of the cognitive changes caused by HD and the difficulties this can cause for the person with HD and their families. He stressed the importance of staying positive and being proactive in self-management techniques. Keeping physically and mentally active and getting support when necessary.

Dr Pender urged people at risk not to worry unduly about common memory lapses. Loosing keys or cars (in car parks) is normal and shouldn't lead to unnecessary time spent worrying. If you have reason for concern check it out by talking to your GP or a medical professional and seek the necessary support. He encouraged people to use available resources. He suggested that relaxation and mindfulness training may be helpful for managing stress and referred to Beaumont Hospital's Department of Psychology Mindfulness and Relaxation Centre. See <http://www.beaumont.ie/marc>

Dr Pender announced to those present that he is in the process of establishing an Enroll-HD site at Beaumont while Dr. Counihan is working to establish one in Galway. Enroll-HD is a longitudinal, observational, multinational study with study sites worldwide. Observational trials are studies in which HD-affected people volunteer their information or biological samples for the sake of research. No drugs or other therapies are tested, and the only goal is to learn as much about HD as possible

Dr Pender hopes that Enroll recruitment can start in late summer and he will keep HDAI up to date so that we can inform people impacted by HD on latest developments.

Fundraising

Dublin Women's Mini Marathon

The 2013 Dublin Women's Mini Marathon took place on 3rd June 2013. Thank you to all those wonderful ladies who participated to raise awareness and funding for Huntington's Disease. www.mycharity.ie



Congratulations to Niamh McClelland and Eimear O'Sullivan who completed the Dublin Mini Marathon and raised an outstanding

€1,167.50 for HDAI. HDAI are extremely grateful for your valued contribution.

My friend Eimear O'Sullivan and I took part in the Flora Women's Mini Marathon on Monday June 3rd in aid of HDAI. While we had been told to expect a mixture of feelings, excitement tinged with nerves, pride tinged with sadness, neither of us anticipated just how emotional the day would turn out to be.

From the crowded train journey into Pearse Street in hot sunny weather reminiscent of our childhood summers, to the nervous walk to the starting line - a feeling of trepidation in the air, Eimear and I were constantly reminded of individuals, foundations and charities so important to so many.

From the sound of the klaxon at 2.00pm when Eimear and I stayed in each other's sights for the first two kilometres, to my approach to the finish line knowing my friend had already crossed it, having jogged the entire 10 km in honour of my grandmother, aunt and uncle; my sense of pride swelled and my gratitude deepened.

From collecting our medals individually to being reunited among the crowds, Eimear and I, red faced and beaming, knew that we, along with 44,000 other women, had taken part in something wonderful with the support of so many people for a very worthy cause and that will forever overshadow any sunburned neck, blistered foot or dry mouth! Niamh McClelland



Rebecca Brennan completed the Mini Marathon 10k in 1hr 26mins. Rebecca said,

"I was so proud to run for HD even before it began but even more towards the end as I didn't come across any other people in my vicinity doing it for HDAI. It was something that was special and meaningful to me and I'll never forget it."

Cork City Marathon

Congratulations to Michael Connern who completed the Cork City Marathon on a very hot Monday in June inside the top

400 runners with a superb time of 3hrs 46 mins. Michael also kindly raised over €500 in sponsorship for HDAI.

Tuam Charity Tea Dance

Ann Hannon hosted another very successful Charity Tea Dance on May 26th in the Ard Ri House Hotel, Tuam. This has raised a magnificent €1,810 for HDAI.

Sincere thanks to Ann and her family and friends for their continuous support. Thanks to Rosemary, Eva, Madeline and all who supported the event by selling tickets and providing sponsorship.

There were generous donations of raffle and spot prizes including gift vouchers from Paddy Power, the Ard Ri House Hotel and Barry's Tea, Eve's Hair Salon and HealthWest Pharmacy, Ballindine.

These dances are possible because of Della Dolan and her friends who organise charity dances for a wide number of charities on a voluntary basis.

Thank You

Thanks to Brendan at C&C Cellular for another very welcome cheque of €351.67 for recycled phones.



Thanks to volunteers who are selling Awareness Bands on behalf of HDAI.

Membership

A Big Thank You to everyone who sent in their 2013 membership subscriptions. Your support is very much appreciated.

Hell & Back

Ashling (below) completed the arduous Hell & Back challenge in Jan 2013 and raised an outstanding €3,030.46.



Thanks to friends and colleagues at Glenroyal Leisure Centre who helped raise funds and awareness.

Mamturk Challenge

David and Gary (below) courageously braved severe weather conditions to take part in the Mamturk challenge in Conemara in April 2013. They raised a magnificent €507 for HDAI.



Acknowledge Kindness

We want to acknowledge the kindness of all those who contributed to our accessible house extension.

Clare County Council provided a grant and **friends and family** organised a benefit fundraiser.

Dulux Paints and **Waterford Stanley** also generously contributed.

Particular thanks to **Gerard O'Keefe** who was an absolutely fantastic help and therefore deserves a big bunch of flowers.

Sincere thanks from Frankie and Siobhan



...and Also

We want to nominate **Bridget Kirwan**, Director of Nursing and **all the staff** at Gowran Abbey Nursing Home in Co. Kilkenny for their attention and kindness to Christine Dobbyn.

Sincere thanks from Sean, Yvonne and family.

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



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Fundraising (continued)

Pearse College

Pearse College selected HDAI as their chosen charity for their 2012 Christmas cards and donated €250 to HDAI as a result. We are very grateful for this awareness and support.

Galway's Biggest Loser is a HDAI Winner

Stephen Kerins took on the *Galway Losers* weight loss challenge to raise funds for HDAI. He lost over 30lbs in 8 weeks and raised an impressive €600 for HDAI. Stephen also raised valuable awareness through his fundraising and his interview on Galway Bay FM radio.

Line Dancing

Sincere thanks to Geraldine Martin who continues to raise money for HDAI through her line dancing classes.

Friends will be Friends - Limerick Fundraiser

Margaret Ring, Siobhan and Frankie, together with their friends, are raising awareness and funds for Huntington's Disease and Milford Hospice.

The event takes place on **17th July** in Limerick city at The Strand Hotel. Tickets €10 available at the door, or in advance from Ray on 085 773 0540.

Fibbers Dublin



Sarah and her friends are organising a fundraiser in Fibbers, Parnell Street on **20th July** on behalf of HDAI. Entry €4.00.

Charity Shop Support

Sandycove Classics & Vintage Charity Shop Sandycove, Co Dublin are allocating their proceeds during May and June 2013 to HDAI. If you would like to donate items for HDAI please let us know.

If you wish to support fundraisers online, see the MyCharity link on our website.

Donations

Thanks to all who generously donated to HDAI including Finnola and Martina for their monthly Direct Debits and Marin Aer for a generous donation of €500. HDAI received a private donation of €250 in March from a couple who preferred to withhold their names.

President's Visit

President Michael D. Higgins is patron of the Carmichael Centre. President Higgins visited the Centre in April 2013 and addressed the centre's staff and it's member groups. Two HDAI representatives attended this event.

In his speech, President Higgins reminded people of Carmichael centre's vision which is,

'to achieve a future where charitable, community and voluntary organisations are empowered and enabled to help all people to have access to the range of supports they need to lead fulfilling lives.'

President Higgins stated,

"That version of society which the Carmichael Centre envisages is indeed the best possible version; a society where people commit their time and energies to building together an active, inclusive citizenship, knowing that changes can only be brought about by having the will and the determination to pursue meaningful ideals and turn them into a lived reality."

President Higgins also acknowledged the work of the voluntary groups attending the event:

"I would also like to thank all of the groups represented here today for all you do to enrich and support the lives of so many that need help and are vulnerable. I wish you well in your own endeavours to make our communities and our country a better place to live for all"

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>

Palliative Care Charter

Irish Association for Palliative Care are calling on the public to sign **THE PRAGUE CHARTER PETITION** which can be signed online at www.palliativecare.ie

The Prague Charter aims to raise public awareness about palliative care and make palliative care a human right.

HDAI Coffee Mornings/Support Meetings

DUBLIN

Aug 17th
Nov 9th

CORK

Jul 6th, Oct 5th
Dec 7th

MAYO - Castlebar:

Sept 7th
Dec 14th

LIMERICK

Oct 19th