



HDNL 2017 - Issue No 69, Q2 17

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

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



Joe meets Pope Francis

HDDennomore HD Papal Audience

Pope Francis is the first pope (or head of state) to publically recognise Huntington's Disease (HD). Families from Ireland and around the world gathered for the historic HDDennomore event at the Vatican, Rome on May 18th.

Charles Sabine thanked Pope Francis for his wisdom and compassion in *'shining a light'* on Huntington's Disease *'Today marks a new chapter in the history of a forgotten disease'*

In his address Pope Francis said,

"May none of you ever feel you are alone; may none of you feel you are a burden; may no one feel the need to run away. You are precious in the eyes of God; you are precious in the eyes of the Church!"

In addition to the South American families sponsored to attend by HDDennomore, there were attendees from 26 countries while thousands more watched the event world-wide. Families from Ireland also attended, with most receiving a personal greeting from Pope Francis.

"It was an incredibly moving and overwhelming experience to actually get to meet Pope Francis face to face and shake his hand. His kindness and compassion were shining through and he gave each person his full eye contact and attention while he was with them.

It was also wonderful and very humbling to meet all the other HD families, especially those from South America. Overall it was an experience we will never forget".

Mary

HD Clinicians and researchers from around the world attended including Professor Elena Cattaneo and Dr. Ignacio Munoz-Sanjuan of HDDennomore, Dr. Nancy Wexler and Dr Ed Wild. Dr Niall Pender, Principal Neuropsychologist and Dr Tom Burke (Beaumont Hospital) attended in solidarity with Irish families

"This was an incredible and very inspiring event. I think it has given everyone a lot of drive and motivation"

Dr Pender



Family members at the Papal Audience (photo courtesy of Gene Veritas)

The HDDennomore organisers are committed in their efforts *"to raise awareness about HD and to lift the stigma of it in every part of the world"*. They ask for help from the HD community to support their efforts in raising awareness. You can keep up to date and support HDDennomore via their social media channels. A highlights video and photographs from the Special Audience with Pope Francis is available in addition to inspiring videos with the South American families specifically invited at <http://hddenmore.com/>

Members Meeting and Respite Weekend

Cuisle, Co Roscommon - 9th-11th June.

A Carers support group, facilitated by Liz (Family Support Officer), took place on Saturday morning. Chiropody, reflexology and massage therapies were also available throughout the day thanks to Jenny Shanley, Mary Finnegan and Kathleen Finnegan.

HDAI's Annual General Meeting was held in the afternoon. 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>

Family members Mary and Anne who attended the Papal Audience in Rome gave a moving account of the event. Mary described how overpowering it felt to be part of such a special audience and in particular to personally greet the Pope. She is extremely grateful to Pope Francis for bringing HD into the public arena.

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She also recounted how thrilling it was to randomly meet Dr Nancy Wexler (who was involved in identifying the HD gene) on a pavement in Rome. Mary also met with Ambassador to the Holy See Emma Madigan (below) while in Rome to discuss the impact of HD and the need for greater awareness.



Anne was particularly inspired and uplifted to meet Dilia - a 79 year old grandmother from Colombia who has already lost her husband and 5 adult children to HD. She continues to care for her family and was delighted to be chosen to meet Pope Francis.

The HDdenomore highlights video was shown at Cuisle to a captivated audience.

Members Meeting Speakers:

Dr Emma Yhnell, Aine Ennis and Caroline Gallagher.



Dr Emma Yhnell, Health and Care Research Wales Fellow at Neuroscience and Mental Health Research Institute, Cardiff University, delivered a very interesting talk on her work at our annual Members

Meeting. Her work involves exploring computerised cognitive training (brain training) for people with Huntington's disease.

Dr Yhnell demonstrated some of the types of brain training exercises she is currently studying in the hope that people with HD might be able to improve their thinking skills. She cautioned against using expensive brain training games which have not been researched and encouraged the use of readily available brain exercises such as Sudoku, crosswords and board games. She also agreed with a keen Bridge enthusiast in the audience that card games can be useful in keeping our brains active.

Dr. Yhnell completed her PhD in Behavioural Neuroscience and Huntington's disease and informed us that her career aim is to improve the lives of people living with HD. As a STEM (Science, technology, engineering and mathematics) ambassador, Dr Yhnell participates in events to raise

public understanding and engagement in science and research. She regularly engages in public speaking to promote HD awareness and spoke in the UK parliament in 2016.

Dr Yhnell also discussed the benefit of the Enroll-HD project and the importance of people with HD, families and researchers working together to progress research. She encouraged us to "be very proud of the HD community that you have in Ireland" and for us all to do what we can to raise awareness and advocate for HD research here. She also recommended keeping up to date with HD research developments and in particular with HDBuzz as a trusted and informative source of research news.

We wish her every success in her research and look forward to inviting her to Ireland in the future to get an update on her inspirational work.



Aine Ennis, Senior Social Worker, Bloomfield Health Services, gave an informative talk on 'Supporting Families'.

Aine is part of the multidisciplinary team in Bloomfield where there is a specialist unit for the care of people with HD. In this context she has experience of working with HD families and is familiar with the issues that arise for them.

She discussed the uniqueness of each family and that 'Family' can mean our biological family, in-laws, civil partners, cohabiting partners or family of 'choice' such as close friends. Family is made up of individuals who may react differently to challenges and trauma. Families experiencing stress may lack cohesiveness and closeness among members and may also lack positive conflict-management skills. Aine reminded us that "It is important that we put on our own oxygen mask first and tend to our own needs before trying to assist others"

She discussed the stages of grief as outlined in the **Kübler-Ross Grief Cycle:**

- Denial:** Avoidance; Confusion; Elation; Shock; Fear
- Anger:** Frustration; Irritation; Anxiety
- Depression:** Overwhelmed; Hopelessness; Hostility; flight
- Bargaining:** Struggling to find meaning; Reaching out to others; Telling one's story
- Acceptance:** Exploring options; New plan in place, Moving on



Aine discussed the importance of gaining information, communicating with others impacted and having emotional support. Each of us deals with issues and

challenges differently - one size does not fit all and there is no 'right' way. Family members will be at different stages in a process of change. You can avoid conflict by accepting that not everyone will be able to offer as much as you can.

What can people do to avoid or reduce Role Strain?

- Talk to others who have been in similar circumstances - the HD Family
- Agree roles - get help to do this if needed
- Periodically take a look at your role demands to determine if there is over-commitment - review what your own needs are.

Capacity and Planning Ahead

The Assisted Decision-Making (Capacity) Act 2015 provides a statutory framework for individuals to make legally-binding agreements to be assisted and supported in making decisions about their welfare and their property and affairs. This assistance and support is particularly required where the person lacks, or may lack, the capacity to make the decision unaided.

A number of new arrangements are covered by the Act, including Assisted Decision-Making and Co-Decision-Making. A process is also set out for the court to appoint a Decision-Making Representative for an individual. Advance Healthcare Directives are introduced into law for the first time.

Citizens Information website www.citizensinformation.ie

The Citizens Information website provides updated information.

Benefits and Allowances

- Illness benefit is based on PRSI contributions and is not means tested.
- Disability Allowance is means tested. You may also be eligible for Free travel and a medical card
- Carers Allowance is means tested. The max weekly rate is €204, caring for one person, €304 if caring two or more.
- You can apply for Supplementary Welfare Allowance if you have no other income or are waiting for a claim to be processed.

Aine also provided a list of the specialists necessary to support people with HD.

Primary Care Services

www.hse.ie/eng/services/list/2/PrimaryCare

- **GP** - provides referrals to specialist services including services at Bloomfield Health Services
- **PHN** - access to home help service, refers on to services, advice on health etc.
- **OT** - assessment for home adaptations, aids, e.g. toilet seats, bed alarms, wheelchairs etc. Advice on activities to enhance quality of life
- **Physiotherapy** - very important for people with HD
- **Speech and Language Therapy** - assessment for swallowing and communication
- **Psychology** - cognitive assessments, therapeutic services
- **Dietician** - advice on grading of diet and maintenance of Body Mass Index

Bloomfield Health Services

www.bloomfield.ie

- Specialist unit for the care of people with HD
- Assessment services for people with HD, inpatient and out patient
- Neuro Cognitive and Memory Clinics
- Education and training - workshops for carers and professionals and outreach services for other facilities caring for people with HD
- Neuropsychology and Neuropsychiatry
- Specialist Nursing care, Physiotherapy and Occupational Therapy Services
- Social Work - psychosocial assessment and support for the person with HD and their carers/families
- Access to specialist Dietetics and Speech and Language Services

Caroline Gallagher shared her experience of being impacted by HD. She inspiringly stated.



"I have never been afraid of Huntington's disease"... I know not everyone will share my view, but I feel I can live with Huntington's. If I was diagnosed

with any other terminal illness, then my chances with life are not so fortunate".

Caroline lost her grandfather and aunt to HD but she has also tragically lost her mother and her brother prematurely to terminal cancer and a brain tumour. *"I love my family no matter what gene we may inherit. The focus should never be on the disease it should be about the people you love".*

Caroline suffered a head injury some years ago as a result of a car accident. Her GP had no experience of HD but has since done a lot of research on HD. Caroline pointed out that she will be a patient with this GP for many years and is grateful for her interest in researching the condition. Counselling has helped Caroline in the past and she feels that it is an important support for carers as well as for people living with HD. She has now returned to college to study Holistic Counselling and Psychotherapy and enjoys related workshops in Mindfulness & Mindful Living.

Caroline talked about how important it was to her to educate her children about HD and to ensure that they understand their own risk. She feels strongly that as a gene carrier she is responsible for finding out as much as she can about the condition to enable her to live well and to contribute to research when possible. *"Huntington's is not by choice, however you are in control of how you react and that has an impact on your life and that of your family".*

Caroline has always been an advocate of fitness and exercise. She successfully worked with Roscommon GAA ladies teams at an all-Ireland level and now coaches minor teams. Caroline believes in maintaining a proper diet and in keeping her brain active. She spoke of the benefit of reading, doing crosswords, keeping a daily journal and practising mindfulness. She includes simple acts of mindfulness in her daily routine such as having a cup of tea in the garden, taking a walk and admiring nature, listening to the birds and even the crows!

Caroline ended her inspirational talk by expressing her hope that others living with HD would share their experience at future meetings. To conclude she reminded us once again that she *"Can live with HD"*

HDAI received many positive comments from attendees on the afternoons' presentations and on the weekend including *"Thank you so very much for a really beautiful weekend... It was inspirational to see the very powerful HDdenommore video and to hear everyone's talk of their journey with HD. I was especially moved by Caroline who shows amazing strength and holds a very strong positive view on how to cope with living with Huntington's"*

Fundraising - Thank You

Dunnes Stores Bag Packing

Mary O'Reilly organised a bag packing slot at Dunnes Stores, Donaghmede from 22-24 June and together with her family, friends and HDAI volunteers raised a magnificent €3,110. Thank you to all who worked hard packing bags on behalf of HDAI. Special thanks to Mary for co-ordinating this event and for the long hours given over the 3 days. HDAI are also very grateful to management and staff at Dunnes Stores, Donaghmede for their help.

Dublin Mini-Marathon

HDAI appreciate the wonderful women who took part in this year's Dublin mini-marathon to raise funds and awareness for HDAI: Grainne Allen has participated frequently for HDAI and has raised almost €400 in 2017.



Jade O'Reilly (left) has raised a magnificent €520.

Shannon Hayes (above left) also supported HDAI in 2017.

Viking Marathon



Caroline Lamb (left) completed the Viking Quarter Marathon in Waterford on behalf of HDAI.

Recently Received Donations

- Martina, Finnola and Zil monthly Direct Debit donations.
- Stephen Gorman €500
- Austin & Pat €200
- Wedding Favours: Clodagh & Martin €120, Nichola & Wesley €70
- Danny Murphy held a collection at Flanagans Mill, Sallins and raised €345 for HDAI

SATURDAY JULY 15th



Lough Key, Boyle, Co. Roscommon

Joe Doran will once again lead the **HD Awareness Walk** in Lough Key, Forest Park on Saturday 15th July (suggested donation €5.00 or sponsorship cards available). We will gather from 10.00am to start walking by 10.45am. Lough Key Forest Park is just off the N4 between Carrick on Shannon and Boyle, Co. Roscommon.

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.

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.

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 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.

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.



Huntington's Disease Association of Ireland

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www.huntingtons.ie

HD Awareness Week

Huntington's Disease Awareness week took place on May 15th -19th, 2017.

Associations of the HD Alliance (England & Wales, Scotland, Northern Ireland and Ireland) held various events and joined HD support groups around the world for the Light It Up campaign.

Family members who talked to media during the week included Anne Lennon Bird (*Pat Kenny Show Newstalk FM*), Anne McErlean (*Highland Radio Donegal*) and Pauline Doran (*Irish Times and The Journal*). Dr Niall Pender was also interviewed by Jonathan Healy on the Newstalk Pat Kenny show. He spoke about the HDdenmore campaign's aim to increase awareness for HD and stimulate research. He also highlighted the need for HD multi-disciplinary clinics in Ireland.

HD Information Video

HDAI produced an information video on HD with the assistance of Shannen Friel, Emma Rooney, Jenny Rosie Fitzsimons and Lorcan Henry, final year Advertising and Marketing Communications Students at the Institute of Technology Tallaght. HDAI would also like to acknowledge the assistance of Patricia Medcalf, Lecturer in Marketing at IT Tallaght.



In the Video Dr Sinead Murphy, Consultant Neurologist outlines the symptoms of HD and the need for early neurorehabilitation referrals to

manage the physical, cognitive and emotional changes and improve quality of life. Sean



Lennon (left) shares his experience of HD as a family member. HDAI are extremely grateful to Dr Murphy and to Sean Lennon for their contribution. The video is available via HDAI's website and You Tube channel.



Senator John Dolan spoke at the video launch in Buswells Hotel on May 15th. Senator Dolan represents the disability community as a member of Seanad Éireann and is CEO of the Disability Federation of Ireland.

He reminded us of the critical work of support organisations and stressed that 'no organisation should consider themselves small when they are providing vital national support to people impacted by a rare condition and their family carers'. HDAI were also honoured to have Comhaltas musicians John and Daragh Kelleher, Sean and Ciara Murphy, Alan Morrisroe and Cillian O'Flanagan perform at the event.

Light It Up



Many prominent buildings in Ireland supported the international **LightItUp4HD** campaign, these included:

The Mansion House; Christ Church Cathedral; The Convention Centre Dublin; County Buildings in Tralee and Killarney; Donegal Council Buildings in Lifford, Millford and Donegal Town; Dublin City Council Civic Offices; Bloomfield Health Services; Irish Life Fountain; and Malahide Castle.



Paddy Byrne from Life Pharmacy, Ballsbridge kindly organised a number of buildings in Ballsbridge, Dublin to light up these included: *the RDS; City of Dublin Education and Training Board Curriculum Development Unit, The Poor Clares and Life Pharmacy.*

Yvonne and her team at Inner Beauty, Gorey, Co. Wexford also supported the campaign by wearing purple, decorating the salon and very generously sponsoring beauty treatments for a person with HD. We hope to continue with this campaign next year. You can get involved by contacting prominent buildings in your area or by organising an imaginative purple event.

Contact info@huntingtons.ie with any suggestions you may have.



HDAI Coffee Mornings/Support Meetings

DUBLIN

Aug. 12th

CORK

Jul. 1st
Oct. 7th

LONGFORD

Sept. 9th

LIMERICK

Oct. 14th