



HDNL 2015 - Issue No 63, Q3 15

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

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.



Christmas Cards 2015

HDAI are selling HDAI Charity Christmas Cards again this year. A pack of 15 cards (175mm x 125mm) of 15 individual designs costs €8.00 per pack which includes postage. To order you can post a cheque to the office, including your name & address or check out our website, www.huntingtons.ie

Hope

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

IRELAND

Hope and Music for HD

HDAI hosted an Information Seminar in Limerick on 14th September "Hope and Music for HD". The seminar included information on the global research study on HD "Enroll-HD" and a very uplifting talk by Brian Schrag, a HD Activist from USA.

Enroll-HD



David Flood, Huntington's Disease Youth Organisation

(HDYO) Ireland Representative and HDAI Board member gave a presentation on Enroll-HD. The presentation included information on how Enroll-HD aims to help the HD research community by:

- Developing better, smarter clinical trials
- Promoting and facilitating the recruitment of clinical trial participants
- Providing clinical data and biologic samples to help better understand HD
- Determining what interventions work to improve the care of people with HD

See www.enroll-hd.org for further information.

An Enroll-HD information video featuring Dr. Niall Pender and Charles Sabine was launched on the night and is available to view on HDAI's website (see research page). Dr Pender stresses the importance of developing HD research in Ireland. International activist Charles Sabine discusses his own participation in the study and states that, **"We can all be a part of overcoming this disease"**. HDAI are indebted to Brain Moore who voluntarily produced this very informative Enroll-HD information video, thereby contributing to the global HD research effort.



Ellie Moran, Assistant psychologist, who helped Dr Pender set up the ENROLL-HD programme at Beaumont, kindly attended the seminar and answered family members questions on the Enroll study. It was a pleasure to collaborate with Ellie during her time at Beaumont and we wish her every success in her future studies. Brian Schrag informed us that he and his wife are participants of Enroll-HD in USA and that from a personal perspective he is always eager to contribute to HD research.

"No sir, officer, I am not drunk ..."

Brian Schrag, PhD, Director of SIL Ethnomusicology and Arts Group (based in Dallas, USA) gave an inspirational talk *"No sir, officer, I am not drunk"*

to HD family members and interested music therapy students. Brian is a HD activist who uses his professional experience as an Ethnomusicologist to create awareness for Huntington's disease.



Brian has HD himself and positively shares his family story while demonstrating the benefit of art and humour as a way of creating a loving, supportive environment for people living with HD. His talk was very well received and feedback included:

"Brian gave us great hope and showed us the healing that can be felt through the use of art. [My Husband] who has advanced stage HD was noticeably moved and got very involved in the session. For [him], Brian showed the power and strength a person with HD can have within and also spread to others ..." Anne

"Brian's presentation was inspiring, the idea of using creative talent to help those affected with Huntington's. It's a lovely way to gift someone, whether it be with a painting, sketch, short story or piece of music especially composed. ...It was nice to include participation and audience involvement" Deirdre



Brian, Christy & Anne

HDAI are sincerely grateful to Brian who generously offered to meet family members in Ireland, while here to participate at a professional conference at the

University of Limerick. Brian very kindly brought along his eye catching awareness t-shirts for those in attendance.



Brian, Dee & Dave

You can find more information on Brian's HD awareness work at www.HDBlues.org and www.MakeLifeHD.org. The awareness

t-shirts can be purchased online at www.hdblues.org We wish Brian every success in his vital HD advocacy work.



Ireland AM Awareness

Michelle (left), a HD family care giver, outlined the complexity of HD and highlighted the need for better home care supports and access to respite for people with disabilities on the TV3 Ireland AM breakfast show on 07/10/2015. Alongside Michelle, John Dolan, CEO Disability Federation of Ireland, referred to a recent survey commissioned by

The Wheel, which found that 42 per cent of charities experienced a fall in income in the year up to May 2015, while at the same time 72 per cent of organisations dealt with increasing demand for their services.

If you are interested in creating awareness or advocating for people impacted by HD please let us know.



HD Awareness Walk

HDAI was very pleased with the response to our Awareness walk in Lough Key on July 18th. Joe Doran (and Nanook) led the "refreshing" walk which was enjoyed and well supported by many of Joe's family and friends despite a few too many raindrops! People taking part in the walk generously contributed €210 on the day and another €1,475 was raised through donations and sponsorship

giving a grand total of €1,685. Thank you to everyone involved in supporting the walk. Specific thanks to Joe, Pauline and Anne Doran, Christina and Bob Dempsey, Mary Dennany, Clare O'Toole and family and to Clare and Farrell-Coy Ltd for their help with the posters. Local radio and newspaper coverage helped to generate awareness. A flyer for the walk was produced and distributed in local retail

outlets and medical centres generating advance publicity. It was a great effort from everyone involved. Lough Key was an ideal setting for the walk and we hope to host it again in July next year - you are welcome to join us!

If you are considering an awareness walk for HD in your area, let us know as we can provide advice and support.

HDANI Information Seminar

Understanding and Managing Behaviour in HD

Professor Jane Paulsen, Director of Huntington's Disease Society America Centre of Excellence at University of Iowa and co-author of the Physicians Guide to the management of HD spoke at a HDA Northern Ireland seminar in Belfast on September 19th. World renowned HD clinician and researcher, Prof. Paulsen is committed to strengthening the relationship between clinical treatment and research for people with HD. She discussed the innovative approach taken at the HDSA Centre to integrating clinical services, education, outreach, and research opportunities. Combining these elements has proven an efficient way to benefit individuals with HD in a personal way as well as advance scientific efforts in the field of HD research.

Errol Walsh, HDANI Member Services

& Development, gave a very informative presentation on "Living with HD: A family perspective". He discussed the impact HD can have on individuals and families but in particular on young people who live with a symptomatic parent. Errol highlighted the benefit of Huntington's Disease Youth Organisation as an international resource for young people and their parents.

Dr Seamus Kearney, Neurologist discussed the limitations of treating Huntington's Disease from a purely neurological perspective. He spoke of the need for a multi-disciplinary approach and the benefit of HD Specialist nurses in coordinating the range of services required including neurology, psychiatry, psychology, carer support and rehabilitative services.

Dee (Board Member) and Patricia represented HDANI at the seminar in Belfast on September 19th.

HDANI Information Seminars

HDAI was invited to give information seminars in care facilities in Dublin City, Co. Dublin and in Co Mayo in July and August.

Feedback included: "It was very useful for us and gave us a better insight into the challenges faced by people with HD and the level of care that they require"

UCD Seminar

HDAI was once again invited to speak to UCD graduate entry medical students on September, 10th. Anne and Christy Clarke, together with Liz HDANI family support officer, discussed the impact of HD and answered questions from students in attendance.

Thank you to Dr Paula Byrne, Senior Lecturer, UCD School of Medicine and Medical Science, for giving us the opportunity to increase awareness of HD. Anne and Christy are tireless advocates and we would like to extend our heartfelt thanks on behalf of the HD community in Ireland.

Fundraising Thank You

Huntingtons Disease Charity Cycle

Caroline Wallace and Will Whelan organised a very successful charity cycle for Huntington's Disease in Limerick on Sunday 13th September which raised a fantastic €1,250. Despite flood alerts in the days preceding, and persistent rain on the day, a great number of cycling enthusiasts, family and friends came along to support the event. There was a wonderful atmosphere on the day and at the after cycle celebrations at Deebert House Hotel, Killmallock, Limerick.

Caroline, a cousin of Anne O'Shea and her partner Will, put a huge amount of work into coordinating the cycle event, advertising the cycle, setting the routes which were unfortunately shortened to one 60km route due to the poor weather conditions, adhering to health and safety guidelines and organising signage and refreshments. HDAI are very grateful for their tremendous effort and to all who contributed to this remarkable event.

Caroline and Will would like to acknowledge the support they received from the following:

- Margaret O'Sullivan of Deebert House Hotel who provided the function room and facilities for all participants and very generously provided complementary soup to warm up all the cyclists on their return. This was very welcome indeed.
- Lidl Supermarket in Charleville for sponsoring the food.
- Killmallock Cycling Club for the insurance to cover the cycle and sponsorship of bottled water for refreshment stops.
- Dave Dwane of Exact Signs for sponsoring the direction signs to clearly mark the route. This was a huge investment to the event and will be available for the future.
- To all their family and friends who helped mark and marshal roads, take great photos (*Jack O'Shea photography*), make sandwiches and cycle on the day.
- To Anne, Christy and Jackie for being there on the day. This reminded every cyclist that they went out in the constant rain to support a very good cause.

Mini Marathon

HDAI is very grateful to Colette Kelly who participated in the 2015 Dublin Mini Marathon and raised an excellent €250 for HDAI. Thanks to those family members and friends who sponsored Colette.

Hand Knits

Pat Davis has consistently supported HDAI for many years by selling her beautiful hand knits in aid of Huntington's and has recently sent us another €150.

Hell & Back Challenge

Muireann O'Miachain (wearing a HD T-shirt) together with 24 friends from her local Lucan gym completed the grueling Hell and Back challenge in Wicklow in June.



Muireann works with people affected by HD and kindly nominated HDAI as one of the beneficiary charities for this event. Thank you to Andy Grehan, personal trainer at Lucan Gym, for coordinating the sponsorship contributions. The event raised a magnificent €1,305 for HDAI which included a generous donation from the O'Reilly family.

C&C Cellular

A big Thank You to Brendan Chambers at C&C Cellular for once again recycling old mobiles on our behalf. We received a welcome cheque of €134.16. Thanks to all who sent in old phones and in particular to Anne Hannon who is a very impressive collector!

Bank of Ireland Online

Sincere thanks to Stephanie O'Reilly and her colleagues at Bank of Ireland Online for their very generous charity contribution of €450. Stephanie chose HDAI as their charity recipient for funds raised this quarter. A further donation of €250 was given from Bank of Ireland *Give Together*. Thanks to all involved.

Donations & Membership

HDAI is very grateful to members and friends for their very generous support in Quarter 3 2015, including: Martina and Finnola for their monthly Direct Debit donations, Susan Maher, Sr. Marie Feeley, Marie Cosgrave, Robert Cosgrave, Cecile Greneche Glynn and Audrey Craven for their donations. Thank you to all who have returned their 2015 membership forms.



Group photo in Deebert House after the cycle.

Jack O'Shea Photography



Jack O'Shea Photography

HD Café at Bloomfield

Family members are invited to attend a HD Café event at Bloomfield Health Services, Rathfarnham on Tuesday 17th of November at 7.00pm.



Susan O'Neill, Senior Physiotherapist, will give a talk and refreshments will be served. Contact us on **1800393939** for further information.

Thank You



Alysha Brizzell from Brockport College New York joined HDAI for four weeks

this summer as part of her summer internship programme in Ireland. Alysha showed a keen interest in learning about Huntington's Disease and helped out with a variety of administration tasks. We wish Alysha every success in completing her degree and in her search for fruitful employment.

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



Huntington's Disease Association of Ireland

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In Memory



Tony McKeown died on 20th September aged 58 years. He was a caring husband and father who courageously lived with HD for many years. He will be lovingly remembered by his wife Kay, his children Jay and Rebecca and his wider family and friends.

Kay asked us to mention the great care Tony received recently at the Park Nursing Home in Limerick. Tony loved the warm care and attention from the staff there who were also very kind to Tony's family.

Kay also wished to acknowledge the support received from HDAI over the years and through the Limerick support group

Sincere condolences to Tony's family.
May he Rest in Peace.

Acknowledge Kindness



I am nominating my sister-in-law Anna P for flowers. Everyone who knows her admires her for her strength and her faith. She courageously looks after three loved ones affected by HD. She is one-in-a-million.

Love, Betty and family



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.

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>

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 hardworking volunteers for their social media work.

European HD Conference



HDAI Board members Anne and Dave represented the Association at the European Huntington Association Conference in Warsaw, Poland in September. Dave also attended a HDYO meeting held prior to the EHA conference. Anne, a HD care giver was invited to join a panel of speakers for the conference seminar on predictive testing. She gave a very poignant description of what it's like when those you love go through the HD predictive testing process. A more detailed report on the conference will be available in our next newsletter.

HDAI Support Meetings



You are very welcome to join us at our Support Meetings from 11.00am to 1.00pm on a Saturday in Cork, Mayo, Dublin and Longford and in Limerick from 10.30am. 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

Nov 7th

CORK

Dec 5th

LONGFORD

Oct 17th

LIMERICK

Nov 21st

MAYO

Dec 12th

This is your Newsletter - Please contact us if you wish to contribute.