



HDNL 2022 - Issue No 89, Q2 22

## CHECK OUT OUR WEB SITE

[www.huntingtons.ie](http://www.huntingtons.ie)

## GENETIC SERVICES

For information on Genetic testing, contact the Genetics Centre - Tel: 01 409 6902 and [www.genetics.ie](http://www.genetics.ie)

## SUPPORT MEETINGS

See information on page 4

## HDAI'S SERVICES

HDAI staff continue to work from home as much as possible. Our helpline remains open via mobile on 087 051 7772 and email: [info@huntingtons.ie](mailto:info@huntingtons.ie)



# NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

## IRELAND

## Members Meeting 2022

HDAI's 2022 Members Meeting & AGM will take place on Saturday 24th September at the Shearwater Hotel in Ballinasloe, Co Galway.

Rooms for an overnight stay on 24th September are limited so if you have not already booked please let us know as soon as possible if you wish to stay. Attendance on the day is free of charge but you must reserve your place in advance. Please contact us on [info@huntingtons.ie](mailto:info@huntingtons.ie) for further information.



Previous Members Meeting

## Our Call for a HD Specialist Service

HDAI, with support from clinicians with a specialist interest in HD, continue to focus on our campaign calling for a specialist service for Huntington's disease. Many HD family members have supported the campaign by corresponding with or visiting their local politicians to share their personal experience of Huntington's disease and their frustration with inadequate non-specialist services.

Professor Orla Hardiman, Consultant Neurologist at Beaumont Hospital, has been involved in developing a specialist multi-disciplinary service for people living with Motor Neurone Disease. As Clinical Lead for the Neurology Clinical Programme she recognises the need for a similar multi-disciplinary service for Huntington's disease with services integrated across acute and community services.

Professor Hardiman attended a meeting of the Oireachtas Committee on Health with the Neurological Alliance of Ireland on March 31st. At the meeting, Deputy John Lahart spoke about the need for improved care and awareness for Huntington's Disease and

asked Professor Hardiman her thoughts on the provision of specialist care for HD.

Professor Hardiman responded by saying that Huntington's is a good example of a rare neurological condition which is complex and where presentation of the illness is very difficult. People living with HD who experience behavioural and cognitive changes face a high risk of falling out of the system or of not being able to access services. She spoke about the need for the health service to train professionals to understand HD and discussed the need to identify how we can provide a meaningful service from the time of diagnosis through all stages of this complex illness.



During the discussion, Professor Hardiman (above), referred to evidence which shows that life expectancy and quality of life is enhanced by one third for people with MND who attend the specialist multi-disciplinary clinic. This is also borne out at an international level. In addition, there are value for money benefits to be gained from specialist health service provision because patients can manage their symptoms more effectively and require less hospital visits.

Services required for HD are cross-disciplinary and this can be challenging as funding is needed from various funding structures. To avoid challenges under current funding models Professor Hardiman called for the establishment of a working group across disciplines to map out the services that are needed, the cost of this service and where the funding may be sourced. Professor Hardiman asked the Health Committee to think about overarching strategic developments that require multiple stakeholders to determine a plan and a budget for an integrated cross-discipline service.

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Minister Mary Butler and Deputy John Lahart visited Bloomfield Health Services on May 23rd where they met members of Bloomfield's Clinical team along with Joe Kelly, CEO (left).

Bloomfield discussed their hope of developing and expanding their Huntington's disease service. Minister Butler is pictured holding HDAI's report *'Too many barriers, too little help'*.



Minister Anne Rabbitte met with HDAI representatives Anne Lennon Bird, John Eden and Patricia Towey on May 24th and had a positive discussion about the need for improved services for Huntington's Disease. Minister Rabbitte acknowledged that Huntington's disease is a unique illness which has implications for the person living with HD and their family.

As such, she said she recognised that services for people with HD and their families need to be improved upon.

## Family Voices

The Huntington's Disease Alliance have hosted two webinars to date in the 'Family Voices' series.

New webinar Brought to you by the HD Alliance

**Family Voices**  
In conversation with  
**Melanie Pearson**  
HD family member, carer and author

#HDAwarenessMonth

On May 16th Melanie Pearson in conversation with Roisin (SHA) and John (HDA) spoke about the impact of Huntington's disease on her family, her role as a caregiver to her mother and later her brother and about why her experience inspired her to write a book titled, 'Somebody Up There Likes Me: Living With The Shadow of Huntington's'

Melanie says

*"For all the agony and distress it can cause, it's amazing how Huntington's can bring people together - people in the same situation, who understand. This is a short talk from the personal point of view of a survivor. My mum and brother both had the illness and I grew up at risk so it's something that has deeply affected my life. I've written a memoir about my family and the impact HD has had on us all, and how we coped. I hope that sharing our experience might be helpful for other families."*



The recording is now available on our website and on YouTube [here](#).



For our second Family Voices webinar we were joined in June by Sarah Winckless, MBE, and Sean, a family member from Ireland.

Sarah is a British rower and former star of Team GB. She has a bronze medal from the 2004 Athens Olympics and was twice world champion (2005, 2006). In 2005 Sarah came to Ireland to share her Olympic joy with us and she met Sean who has been a huge fan ever since! Huntington's disease is in Sarah's family on her mother's side.

Sarah and her family supported her mum as she lived with the disease until she passed away in 2020. Sean and his family continue to support Sean's Dad. Sarah and Sean swap stories about growing up in families impacted by HD. They also share tips on how they coped.

Sarah is patron of the Scottish HD Association and actively raises awareness for Huntington's Disease across the UK and Ireland.

### UPCOMING WEBINARS - BOOK NOW!

Our third 'Family Voices' webinar is on **Wednesday, September 7th 2022** at 7.00am. We will be in conversation with Siobhan, a family member who will discuss her PGD journey and share her experience of finding out about her partner's risk. **To register, click [here](#).**

Registration is also open for our October Webinar: In Conversation with Charles Sabine on **Monday, 03 October 2022** at 7.00pm. **To register, click [here](#).**



## Mapping HD Care



The HSE Clinical Design and Innovation division, the HSE's Scheduled Care Transformation Programme and the National Clinical Programme for Neurology have been working to develop a Huntington's Disease Care Pathway.

The group hosted a Huntington's Disease Workshop on 1st July to look at the services required to continue the development of an integrated pathway for Huntington's Disease. HDAI representatives were invited to the meeting together with clinicians working with Huntington's disease from Beaumont Hospital and Bloomfield hospital. There were also clinicians representing a wide range of health services including: neurology, neuro-rehabilitation, mental health, genetic services, GPs and primary care.

Professor Hardiman and Professor Niall Pender provided an overview of Huntington's disease. HDAI representatives were invited to provide a summary of the patient experience. Selina, a HD family member then shared her family's experience of the impact of HD on three generations. Selina spoke about her struggle to be heard as a caregiver and the difficulties she faced in getting appropriate care for her loved one.

Selina was commended by attendees for her articulate and impactful contribution which helped increase their understanding of HD. Patricia provided some anonymous patient stories to highlight the common barriers families face in accessing appropriate services and the devastating impact the lack of specialist uncoordinated care can have on the entire family.



John Eden also attended the workshop and provided valuable feedback on the benefit and efficiency of HD specific services in Scotland. Dr Ian Daly and Dr Kieran O'Driscoll Bloomfield Hospital and Professor Jennifer Hoblyn provided feedback on the benefit of specialist multi-disciplinary services. Following the workshop Selina provided further feedback on a care pathway draft. HDAI are extremely grateful to Selina for her time and expertise.

## FUNDRAISING - THANK YOU

A big Thank You to Annemarie Murphy and extended members of the Porter family who suggested a Huntington's Disease awareness walk to remember their late family members Fran and Tony and deceased members of the HD community.

The extended Porter family were joined by other family members impacted by Huntington's Disease and their friends. The walk took place in Phoenix Park on Saturday April 30th and served as a marker for Huntington's Disease International Awareness Month in May.

Anne Marie and family members raised sponsorship on and off line, (thanks Amanda, Sonia and Taylor Lo for your online fundraising pages) and a big thanks to all who supported the HDAI online donation page. Fran's family donated a very generous €500 in her memory.



The walk has raised approx. €5,000 towards our work and provided participants with an opportunity to meet other families. Sincere thanks to everyone who walked on the day and raised funds.

### Mini Marathon

Josie Leavy took part in the Mini Marathon once again and raised a wonderful €750 for HDAI. Thanks to Josie's friend who gave a very generous donation of €300.



Aisling, Lisa and Marie participated in the Mini Marathon and raised a marvellous €930 for Huntington's disease. Thank you for your continuous support!



Thank You to Suzanne, Vanessa and Kelly (above) for taking part in the Mini Marathon and raising a fantastic €530 for Huntington's disease



Dee Jones raised €200 for HDAI from her Mini Marathon in June. Thank you Dee!

### Croagh Patrick Climb



Cliona, Colin Anna & Harry made the arduous Croagh Patrick climb in April and raised €558.37 for HDAI. Thank you!



Seodhna, John and daughter Éabha climbed Croagh Patrick in May in support of Seodhna's Mum Nuala and in memory of her late brother Karol who died suddenly in March. Thank you for raising €1,239.16 for HDAI.

### Donations

- Direct Debit donations from Fionna, Martina, Paul and Zil
- Monthly Donations via iDonate: David
- Benevity: Roseanne Evans

## Bequest

The late Bryan O'Hara made a bequest of €10,000 in his will to be donated towards Huntington's Disease research. The HDAI Board have agreed to allocate this contribution to the research led by Professor Niall Pender and Professor Orla Hardiman of Beaumont Hospital, Dublin. HDAI are sincerely grateful for this very generous bequest.

## ID Card

A free Huntington's ID card is available if required. Email [info@huntingtons.ie](mailto:info@huntingtons.ie) or mobile **087-051 7772**.

## Follow HDAI

 **Huntingtons Disease Association of Ireland**

  **@HDAI\_ie**

Thank you to our volunteers for their social media work.

## HD Chair



HDAI can provide a contribution towards specialist aids and appliances including seating. Please contact us at [info@huntingtons.ie](mailto:info@huntingtons.ie) if you or your loved one need assistance.



**Huntington's Disease Association of Ireland**

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[www.huntingtons.ie](http://www.huntingtons.ie)

## In Memory

Condolences to the family of Ellen Whooley, RIP. Ellen's family and friends donated an incredibly thoughtful contribution of €1,500 in her memory.

The All Saints Church Raheny Group, who are friends of family member Anna Porter, organised a recent Coffee Morning on behalf of HDAI contributing €593 towards our work.



Thank you to Dorothy and Gean (pictured) and to all who supported the fundraiser. Thanks also to the St. John's Coolock Tuesday Morning Badminton Club for a kind donation of €40.

## Support Meetings

HDAI were delighted to meet family members in person once again at our Dublin and West Support Meetings. Malika Lancaster, Psychotherapist and Body Work therapist provided a Mindfulness seminar for members following the Dublin Support Meeting. We hosted a lunch after both meetings to have a proper catch up!



## Monkstown Hospital Foundation



Monkstown Hospital Foundation

Sincere thanks to Monkstown Hospital Foundation

for awarding HDAI a very generous grant of €4,000 towards the provision of assistive equipment for people living with HD in 2022. Please let us know if you or your loved one needs specialist seating or aids and if you need information on getting an assessment.

## Recognition for Family Matters Campaign

Congratulations to M+F Health who won a Charitable Campaign of the Year Award at the Communiqué Awards 2022 for their work on the HD Family Matters campaign.

<https://hdfamilymatters.com>



M+F Health, a Communications and Public Affairs agency, devised the Family Matters campaign on behalf of the Huntington's disease Alliance with the aim of inspiring and supporting the Huntington's community,

celebrating the resilience of those affected by Huntington's disease (HD) and recognising every family's unique experience. As part of the campaign information was shared on multiple media channels and a dedicated microsite was developed to share powerful films, blogs, a supporters section and the #LivingHistory project with many contributions from the HD community.

Judges feedback included:

*"one campaign was head and shoulders above the rest"*

*"Family Matters was a strong, well put together campaign. It was really comprehensive, well-rounded and exceeded its target, with excellent results. The campaign was based on a clear understanding of the current position, prevalence and impact of Huntington's Disease and patient insight. It was well developed and executed".*



## HDAI Support Meetings

**Dublin:** 6th August

**Roscommon:** 3rd September

**Members Meeting (Ballinasloe):**

24th September

**Cork:** 8th October

**Limerick:** 22nd October

Please contact us at [info@huntingtons.ie](mailto:info@huntingtons.ie) if you are interested in joining a support meeting.

Dates subject to change - contact HDAI for confirmation