



HDNL 2023 - Issue No 93, Q2 23

NEWSLETTER OF THE HUNTINGTON'S  
DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

CHECK OUT OUR  
WEB SITE

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

HSE GENETIC SERVICES

For information on public Genetic testing, contact the Genetics Centre - Tel: 01 409 6739. Email: [Clinical.genetics@olchc.ie](mailto:Clinical.genetics@olchc.ie)

Genetic Counselling:  
[www.childrenshealthireland.ie](http://www.childrenshealthireland.ie)

SUPPORT MEETINGS

See information on page 4



Cathy Coughlan, S&LT

## Members Meeting 2023

HDAI welcomed new and regular attendees to our 2023 Members Meeting and AGM at the Shearwater Hotel, Ballinasloe on 20th May. Guest speakers included Cathy Coughlan, Senior Speech & Language Therapist, HSE Cork Kerry Community Healthcare, Dr Tom Burke, Senior Clinical Neuropsychologist, Dr Ian Daly Clinical Director, and Dr Kieran O'Driscoll, Consultant Psychiatrist, Bloomfield Hospital.

Cathy Coughlan gave a talk on Speech and Language Therapy for Huntington's disease. Cathy has a special interest in HD, and she has worked with a number of people living with HD in Cork and Kerry. Some of the many useful tips Cathy discussed included:

### Tips for Voice Care

- Water is the most important!
- Pace speech - try a pacing board or tap out words
- Take more frequent breaths
- Try reducing throat clearing
- Be aware of voice fatigue
- Modify the environment
- Monitor any changes.

### Tips to Manage Swallowing Problems

- Contact your local Speech & Language Therapist via your GP, PHN or Consultant
- A Speech & Language Therapist will organise an appointment to assess swallowing and give specific recommendations based on the assessment
- Some people may require their food and/or fluid to be modified to ensure they can swallow safely
- There are alternative means of nutrition e.g. PEG, this is a medical and personal decision

- It is very important to have a discussion on food/fluid modification, safety and quality of life.



Dr Kieran O'Driscoll, Dr Tom Burke and Dr Ian Daly

### Evaluation comment from family carer:

*"My partner worked with Cathy Coughlan and she was brilliant. It informed me as to how a good speech therapy session is done".*

Cathy's presentation slides are available on request by emailing [info@huntingtons.ie](mailto:info@huntingtons.ie)

Dr Ian Daly and Dr Kieran O'Driscoll, spoke about managing mental health mood and Psychosis in HD.

Family members had a choice of attending workshops including:

- **In This Together:** A Workshop for People Living with HD facilitated by Anne O'Shea Clarke, Sage Advocacy
- **Carers Workshop:** A workshop for Family Care Givers with Liz O'Sullivan, Family Support Officer
- **Practical wellbeing strategies** from ACT for HD with Dr Tom Burke, Senior Clinical Neuropsychologist.

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## Enroll-HD Information Stand



Rebecca Mason and Gulten Geneci, EHDN Language Area Coordinators for the UK and Ireland hosted an information stand at our meeting to speak with family members interested in finding out more about the Enroll-HD study.

## Funding agreed for Two Nurse Specialist Posts for HD

Professor Orla Hardiman, Clinical Lead for the National Neurology Programme, together with The Neurological Alliance of Ireland (NAI), has confirmed that among the 23 neurology nurse posts secured in budget 2023, two have been assigned to Huntington's disease. Both Galway University Hospital and Beaumont Hospital, Dublin have received funding confirmation to begin recruiting for a Huntington's disease specialist nurse.

The Patients Deserve Better nationwide campaign led by the NAI and supported by its member organisations, including HDAI, saw funding for 23 specialist nurses announced by Minister of State for Disability Anne Rabbitte in Budget 2023.

Speaking at an Oireachtas Committee on Health meeting on May 17th, NAI Executive Director Magdalen Rogers stated.

*"The priority in the immediate term is to recruit these nurses and establish appropriate training here in Ireland. The Irish Neurology Nursing Forum (INNFF) which formed last October are working together with the National Clinical Programme in Neurology towards an education pathway for nurses entering into or currently working in neurology nursing roles. The NAI want to warmly thank both our members and the outstanding individual patient advocates who took part in this campaign and all those who supported the campaign around the country".*

Sincere thanks to families impacted by HD who have spoken with Minister Rabbitte or who have contacted their local public representatives to highlight the need for improved services for Huntington's disease.

## Update on Patients Deserve Better Campaign



This year's 'Patients Deserve Better' campaign, calling for community neuro-rehabilitation teams to be established around the country, has seen some success to date. Funding for teams in CHOs 4 (Cork/ Kerry) and CHO 2 (Galway/Roscommon/Mayo) was announced by Minister for Disability, Anne Rabbitte, on May 10th. Funding is also secured for full teams to be recruited in CHOs 6 and 7.

Mary, a HDAI family member, spoke at the Cork/ Kerry launch in February and Derek, a family member from Galway, joined the panel of speakers for the Galway/Roscommon/Mayo campaign launch on May 30th.

They gave compelling arguments for the need for neuro-rehabilitation and coordinated specialist care for people living with neurological illness. Recordings of the launches are available on the Neurological Alliance of Ireland - YouTube channel. You can take action to support the 'Patients Deserve Better' campaign by visiting [www.patientsdeservebetter.ie](http://www.patientsdeservebetter.ie) where you can contact your local politicians directly.

## Enroll-HD, the Global Observational Study of HD is 10 years strong!



HDAI had the pleasure of joining Professor Niall Pender (above), Enroll-HD Principal Investigator at Beaumont Hospital, and his team to mark the occasion. Ruth Fullam, Enroll-HD Study Director provided an overview of the study and reminded us of the importance of gathering data to: Enhance understanding of HD, Support clinical trials and Improve clinical care.

If you are a member of a family impacted by HD and wish to know more about this study see: <https://enroll-hd.org/for-hd-families/about-this-study/>

## HD Café



To mark Brain Awareness Week Bloomfield Health Services and HDAI hosted a HD Café on March 22nd giving family members the opportunity to meet Bloomfield's HD Specialist team over coffee and treats. We were delighted to catch up with so many family members.

## FUNDRAISING - THANK YOU

### Mini Marathon

Josie Leavy (below left), 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.



Sincere thanks to Suzanne and Darren Meehan (above right), who supported HDAI in the Mini Marathon again this year raising €500 online.

### Donations

- Direct Debit donations from Fionna, Martina, Paul and Zil.
- Regular donations from Darren and David.
- Newman family donation €350.
- Sincere thanks to Leinster Cleaning Services who donated a further €500 to HDAI in May. The company very generously chose HDAI as a charity partner for 2023.
- Thank you to all who have renewed their membership and to those who donated at our Members Meeting.



### In Memory Donations

- Thank you to Margaret and Val who donated €2,000 in memory of the late Josephine Ui Mhordha.
- HDAI received a bequest of €3,000 from the estate of the late Catherine Mahony. Condolences to Catherine's family and friends.

### Monkstown Hospital Foundation



Monkstown Hospital Foundation provided a very generous grant of €4,000 in April 2023 to contribute towards the cost of specialist and equipment for people living with HD.

### Nancy's Handknits and Bridge Club Support

A big thank you to Nancy Shannon who donated €150 to HDAI from the proceeds of her knitwear. HDAI also received €200 donations from Nancy's friends and Bridge Club members. In addition the Kiltimagh Thursday Bridge Club donated €481.81 to HDAI with the Tuesday Club donating €325. We are very grateful for this very generous support.

### Upcoming Events

The **Joe Doran Annual Awareness Walk for HD** takes place in Lough Key Forest Park on **Saturday, July 22nd** at 10.45. We look forward to catching up with those of you who can come along.

**For info see: [iDonate.ie](https://www.idonate.ie) | Support Joe Doran Huntington's Walk July 22nd**



### Mizen to Malin Challenge Cycle

A team of 14 cyclists ( Pat Whelan Vinny O' Hollaran, Niall O' Connor, Pat Griffin, Declan O' Regan, Lorraine Whelan, Peter Courtney, Fintan Mac Coitir, Mortimer O' Sullivan, PJ Talty, Mikey Whelan, Brian Keane, Al Meaney, Joe Collins) completed an extraordinary 640km cycle from Mizen in Co. Cork to Malin in Co. Donegal over the May bank holiday weekend. Pat received a very loud cheer from family members attending our annual members meeting. The team defied all expectations raising a jaw dropping contribution circa €32,000. This was a huge effort from the cyclists and their logistics team!

We greatly appreciate this remarkable work. Thank you also to their family, friends, colleagues and sponsors for this wonderful support.





## In Memory

David Carty (pictured left), passed away in May aged 69 years. We send condolences to the Carty family, David's friends and caregivers. The Carty family donated €1,000 to HDAI in David's memory.

*"It was David's wish and that of the family that we make a donation to the association for all the help and support given to us over the years"*

## NAI Pre-budget Submission

The Neurological Alliance of Ireland launched their pre-budget submission on May 27th which seeks investment for neurology services in Budget 2024. The event held in Buswell's hotel was supported by NAI's member groups including HDAI (pictured below).

Over thirty Oireachtas members from across all political parties attended the launch. They were also thanked for their support for the 2022 NAI campaign to tackle the shortage of nurse specialists in neurology.

Representatives from the newly established Irish Neurology Nursing Forum, who worked together with the NAI on the campaign, highlighted the new neurology nursing posts funded in hospitals all around the country thanks to their support.

## Rare Talks at South Dublin Libraries




South Dublin Libraries (SDL) hosted eight different talks throughout May and June with a focus on rare diseases. HDAI were invited to participate and delivered a talk on *The Diagnostic Journey: A Patient's Perspective*, on 11th May. Sinead shared her family member's long and difficult journey to receive a diagnosis of HD.

She discussed the escalation of symptoms, the impact of the mis-diagnosis and the struggle to receive care for her loved one. Sinead also discussed the impact on the family and the lack of a coordinated service following the diagnosis. Patricia Towey, HDAI provided an overview of HD and of the research undertaken to provide a definitive test for HD. Despite the availability of predictive and diagnostic tests some people experience misdiagnosis and difficult diagnostic journeys. HDAI believe that the development of a specialist HD service will increase awareness among health professionals and improve understanding and awareness.

## 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.



## HDAI Support Meetings

**Dublin:** 12th August

**West:** 2nd September

**Cork:** 22nd July

**Limerick:** 21st 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*



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