



HDNL 2024 - Issue No 97, Q2 24

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

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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

COME ALONG AND SUPPORT

## Joe Doran's Huntington's Walk



Saturday, July 13th 2024

For further details or to donate see: [www.idonate.ie/fundraiser/JoeHDWalk24](http://www.idonate.ie/fundraiser/JoeHDWalk24)



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WELFARE ENTITLEMENTS

## Members Meeting May 2024

HDAl's 2024 Members Meeting and AGM took place at the Shearwater Hotel, Ballinasloe once again. Dr Timothy J. Counihan, Department of Neurology, and Dr Tom Burke Principal Specialist Clinical Neuropsychologist at Galway University Hospital Galway were Guest speakers for the event.



Earlier in his career, **Dr Timothy Counihan** (above), spent five years working in the Massachusetts General Hospital, Boston, where he gained specific knowledge of Huntington's disease. He worked there at the time when Nancy Wexler, James Gusella and other collaborators including Galway born scientist Mike Conneally, were collecting and analysing blood samples from HD families in Venezuela.



Their research contributed to the identification of the HD Gene, a significant milestone for clinical research and more in-depth observational studies. Professor Bernhard Landwehrmeyer also worked in the neurology clinic at that time. On returning to work in Germany he became one of the founders of the European Huntington's Disease Network (EHDN) and a principal investigator in numerous HD clinical trials and observational studies, including the Enroll-HD observational study.

Since his return to Ireland, Dr Counihan has worked with numerous people living with HD at his University Hospital Galway neurology clinic. The lack of resources for neurology services in Ireland has made it very difficult to develop specific HD multi-disciplinary services.

Dr Counihan is hopeful that together with Dr Tom Burke and other interested professionals, the ongoing work to bring an Enroll-HD study site to Galway and with the allocation of funding for a HD nurse specialist, the HD service can be advanced.

He spoke about the importance of Research developments, including the availability of family planning options such as PGT (preimplantation genetic testing), provides greater optimism for the future. PGT allows couples with a known risk to have children without passing on the HD gene or having a genetic test themselves.



Dr Counihan reminded families of the importance of attending appointments and of providing feedback on the service. He discussed the benefit of planning ahead with regard to health so that we can all express our wishes. This is often more important for people with neurological conditions such as Huntington's disease where communication difficulties may occur.

**Dr Tom Burke** provided an overview of his research work at University of Galway and Galway Neuroscience Centre. He has worked with Huntington's disease for over 10 years.

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## Members Meeting May 2024

Dr Burke discussed progress to date on establishing an Enroll-HD site at Galway and the positive impact this can bring to encourage further research and collaboration for the west of Ireland. He highlighted the importance of neuropsychology in supporting people with cognitive changes and also discussed the benefit of blood biomarkers, and genetic modifiers in HD in measuring potential treatment.

Dr Burke has met with prominent researchers in the UK over the last year to pursue collaboration in HD research studies.

Attendees had a choice of workshops, both of which were well attended:



### In This Together:

**Workshop on Future Planning**, a discussion for all family members, facilitated by Anne O'Shea Clarke, Sage Advocacy and Sandra Porter, Financial Wellbeing Officer, HDAI

### Carers Workshop:

**A workshop for Family Care Givers** facilitated by Liz O'Sullivan, Family Support Officer.

Following the meeting, family members had a chance to socialise and chat over dinner and enjoy some music and dancing afterwards.



*"Just a quick note to thank you for the great experience last weekend. 24/5 May. All speakers were very informative and a lot of information was learned. Thanks again".  
Martin*

*"Thank you for last week's AGM. It was very informative and interesting - a lot of work was put in to get everything running so smoothly. Great to have all the support that you offer, always the lifeline people can reach for. Thank you.  
Debbie*

## HD Research Day

Trinity College Dublin hosted a Huntington's Disease Research Day on Tuesday, May 21, to mark HD Awareness month.

HD Researchers at Trinity College Dublin and Beaumont Hospital spoke about their work.

HDAI representatives highlighted the need for collaboration and the development of services and Prilenia provided an update on their HD clinical trial.



**Professor Niall Pender**, in his opening address, 'HD Research: Where We Have Come From and Where We are Heading', stated that:

*"We need timely, inclusive, comprehensive, accessible and responsive services which are delivered with compassion and grounded in local and international research evidence."*



**Colm Peelo's** talk entitled, 'HD-Cognition: The Neuropsychology of Huntington's Disease', discussed the importance of neuropsychological supports.

**Kimberly Kiyui** provided an update on 'Enroll-HD: A Global Effort Towards Understanding HD'



**Eva Woods**, (above) discussed her research work: "Understanding Pre-Manifest HD: Combining Neuroimaging and Electrophysiology to Identify Novel Biomarkers"

**Patricia Towey**, HDAI in her talk: "HD in HD: Bringing Focus and Shaping the Future" gave an overview of HDAI's work and discussed the need for specialist multi-disciplinary HD services and research in Ireland.



**Dr Roisin McMackin**, in her talk "What is PPI?-Bringing Your Perspective to HD Research" spoke about the importance of public and patient involvement in research in order to ensure that the views, needs and interests of those affected by research are heard and considered in how research is designed, performed, and reported on. She invited attendees to support research work by participating in PPI. For further information see [www.mcmackinlab.com/work-with-us/public-and-patient-involvement](http://www.mcmackinlab.com/work-with-us/public-and-patient-involvement)

**Dr. Cruz-Herranz**, Director of Clinical Development at Prilenia provided an update on Pridopidine, an oral investigational drug currently in development for the treatment of HD symptoms. The company is planning to submit a Marketing Authorisation Application to the European Medicines Agency this year. If approved, Pridopidine could potentially be commercially available to patients in Europe as early as 2025.

HD volunteers **Amanda** and **Brian**, gave a very compelling overview of their advocacy and awareness work which has included producing the 'Dancing at the Vatican' film and promoting HD research. They highlighted the importance of collaboration.



**Orla Russell**, recently appointed advanced nurse practitioner candidate for HD at Beaumont Hospital, gave an overview of her role.

Huge thanks to everyone who organised, participated and attended this very positive HD Research event. Special thanks to Eva Woods for her organisational skills!



Dr Tom Burke, Professor Jennifer Hoblyn, Anne Lennon Bird and Giorgos Papantoniou pictured at the TCD event.

## Joint Oireachtas Committee Meeting



HDAI were invited to join the Disability Federation of Ireland to address the Joint Oireachtas Committee on Social Protection, Community and Rural Development, and the Islands with regard to the impact of means testing on Disability Allowance, Disablement Pension and other social welfare schemes on 29 May 2024.



Fleachta Phelan, Policy Advocacy Manager with DFI gave an opening address and was joined by Sandra Porter, Financial Wellbeing Officer, HDAI and Pdraig Hannafin, Rehab Public

Affairs Research Administrator. HDAI is a member of the DFI and welcomed the opportunity to join in the meeting address. Sandra highlighted the increased cost of disability for people living with neurodegenerative illness and the burden associated with a hereditary disease. A recording of the address is available to view from the Oireachtas committees video archive: [oireachtas.ie/en/oireachtas-tv/video-archive/committees](https://oireachtas.ie/en/oireachtas-tv/video-archive/committees).

## NAI Oireachtas Committee on Health Meeting



Richelle Flanagan, NAI patient advocate

Representatives from the Neurological Alliance of Ireland presented to the Oireachtas Committee on Health on May 15th, to provide an update on the implementation of key healthcare strategies for neurology and neuro-rehabilitation. NAI representatives also discussed the continued wait for specialist neurological nurses due to the HSE staff embargo and highlighted the crucial need for a second HD specialist nurse in Galway. Deputy Roisin Shorthall

said it was a 'no brainer' that having specialist nurses makes a huge impact on the lives of people with neurological conditions. Senator Frances Black highlighted the need for neuropsychologists.



Senator Frances Black

## NAI Briefing to Oireachtas Members, April 2024

NAI representatives reminded Oireachtas members that neurological conditions now represent the leading cause of disability worldwide and affect over 860,000 people across Ireland.



AV room attendees on April 24th



HD advocate Gavin pictured with Deputy Johnny Guirke and Patricia, HDAI

Patient advocates, clinical healthcare leaders and patient organisations joined in the call for the implementation of key healthcare strategies in neurology, neuro-rehabilitation, stroke and dementia services. They highlighted that emerging treatments and recent investment in services provide new hope for people but warned that the current recruitment moratorium as well as delays in implementing key policy recommendations risk undermining this Government's legacy. Government must prioritise investment in healthcare for people with neurological conditions in order to meet Ireland's commitments under international frameworks.

## THANK YOU

### Membership

Thanks to all who renewed their 2024 membership. Your engagement supports HDAI's work and helps to keep the HD community connected.

### Mini Marathon

A big thanks to everyone who participated in the Mini Marathon on behalf of HDAI. Marie, Lisa and Aisling participated and raised €325 for HDAI. Rohanna and Shauna Rahman (photo 1) participated and raised €280.



1



2



3

Josie Leavy rallied her supporters once again and raised €800 which included a generous €300 donation from her friend. A big thank you to Sinead (photo 2) who also participated and raised approx. €500 in sponsorship.

Stephanie O'Reilly, who had never ran before, set herself a challenge of running in 1hr 10 minutes in memory of her aunt and other family members. She and her supporters (photo 3), Dave, Erica and Warren completed the challenge and raised a fantastic €936 via iDonate.

### Birthday Gifts

Cliona Mead who celebrated a significant birthday very kindly suggested donations to HDAI in lieu of birthday gifts. A big thank you to Cliona and to her family and friends who raised a marvellous €429.

### Donations

Thanks to our donors for their generous support including:

- Direct Debit/regular donations received from David, Fionna, Martina, Paul, Tarik and Zil.
- Other donations included: Bernadette €500, Catherine €120 (membership and donation), David Purdom €300, Debbie & Martin €700, John Moore €294. Marion O'Hanlon €120, Mick Scanlon coin collection €180, Sylvia Ayling €150 and S Goggin €1,000.

Note: Membership, sponsorship and donations via online fundraising platforms are subject to bank and platform fees.

### In Memory



Catherine Pearson donated €500 in memory of her late husband Alan

O'Dwyer who died in January.

*"Thank you for your help over the years. Without the support of HDAI and local voluntary care organisations, our lives would be very different".*

HDAI extend condolences to the family and friends of Carol Roache who died earlier this year. HDAI have received €1,929 in memory of Carol. Sincere thanks to Nancy and to Carol's family and friends who donated so generously to HDAI in Carol's memory.



Allan Gapper passed away on 4th May in his sons arms at home. He bore his illness bravely

over many years. Condolences to Allan's loving wife and family who supported him in his heart breaking challenge.

*"I cannot thank you all at HDAI enough for all the help, support and advice you have given us over many years - it has been invaluable".*

Denise

## Grants - Thank You



**Monkstown Hospital Foundation** - HDAI were successful in a grant application to Monkstown Hospital Foundation who have provided a generous grant of €5,000 towards the provision of specialist seating and equipment for people impacted by HD.




**TUSLA Family Support Agency** have

provided a grant of €2,710 towards HDAI's counselling service.

## 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)

## Minister visits Carmichael Centre



Minister Joe O'Brien, Minister of State at the Department of Rural and Community Development, the Department of Social Protection and the Department of Children, Equality, Disability, Integration and Youth visited Carmichael Centre on April 24th and spoke to resident member groups including HDAI.

## Postcard from Palm Springs



2024 research update at [chdifoundation.org](http://chdifoundation.org)

## Light It Up for HD

Lord Mayor of Dublin Daithí de Róiste lit up the Mansion House in purple in support of #LightItUp4HD, an international campaign to raise awareness.



HDAI Chairperson, Thomas Lillis, is pictured with the Lord Mayor above.

## Connecting Threads Event



Dr Giorgos Papantoniou, Dr Francesco Ripanti and colleagues held a 'Connecting Threads: Collaborative Approaches to Archaeology, Heritage and Community Wellbeing' event in Trinity College Dublin on May 24 which included a presentation from Filipa Julio, European HD Association on their Moving Forward project (to educate and support young people impacted by HD). For further info see <https://www.loggia-project.eu/>

## Free Travel Scheme Changes

Recent changes to the State's Free Travel scheme allows people who are medically unfit to drive for at least a year or who have never been able to drive due to a disability or long-term health condition apply to avail of Free Travel. Thanks to Epilepsy Ireland who campaigned for this change.



## HDAI Support Meetings

HDAI hosts regional Support Meetings which offer people impacted by HD a chance to meet and chat to others in a relaxed atmosphere. Please let us know if you wish to join us for a meeting in your area. Dates for future support meetings in 2024 include:

**Cork:** 20th Jul. & 5th Oct.

**Dublin:** 10th Aug. & 9th Nov.

**Limerick:** 19th Oct.

**Roscommon:** 7th Sept. & 7th Dec.

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