



HDNL 2024 - Issue No 96, Q1 24

NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

CHECK OUT OUR
WEB SITE

www.huntingtons.ie

HSE GENETIC SERVICES

For information on public Genetic testing, contact the Genetics Centre - Tel: 01 409 6739. Email: Clinical.genetics@olhc.ie

Genetic Counselling:
www.childrenshealthireland.ie

SUPPORT MEETINGS

See information on page 4

TRINITY COLLEGE DUBLIN'S

HD RESEARCH DAY

Tuesday, 21st May 2024
11.00am - 2.00pm

BOOK YOUR PLACE NOW!

Annual Members
Meeting



Saturday, 25th May 2024



Huntington's Disease
Association of Ireland

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WELFARE
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HD Research Day

Tuesday, 21st May, 2024 at Trinity College
Dublin from 11.00am-2.00pm



The HD research team at Trinity College Dublin and Beaumont Hospital are hosting a HD Research and Awareness event to mark HD Awareness month in May. This is an opportunity for family members to meet HD researchers and learn more about their ongoing work. This event is open to family members, researchers, students and anyone interested in HD. Places are limited so book now to ensure you can attend.

<https://forms.gle/etreEi3wNwtQnL59>

Annual Members Meeting

Saturday, 25th May, 2024 at The
Shearwater Hotel, Ballinasloe



HDAI's Members Meeting & AGM will take place on Saturday 25 May, 2024 at the Shearwater Hotel in Ballinasloe, Co Galway.

We are delighted to have Dr Timothy Counihan, Neurologist, Galway University Hospital as our guest speaker.

Attendance during the day is free of charge but you must reserve your place in advance. Contact us on info@huntingtons.ie for further information.

Meeting Minister Anne Rabbitte



HDAI meets Minister Rabbitte on December 13th

Minister Anne Rabbitte, together with representatives from the department of Disability and Mental Health, met with family members Derek and Joan, together with Patricia from HDAI, on December 13. HDAI thanked the Minister for her support in securing funding for specialist HD neurology nurses.

One Advanced Nurse Practitioner candidate post has been recruited for Beaumont hospital. Unfortunately the funded post for Galway University Hospital has been subject to the HSE staff embargo.

HD representatives highlighted the need for specialist and outreach services so that families are adequately supported. People living with HD may often find it difficult to engage with health and social services and this can have a huge impact on dependent children and family care givers.

RARE DISEASE NEWS

Rare Disease Day Conference

Stephen Donnelly, Minister for Health (below), was among the guest speakers at the Rare Disease Day conference Looking To The Future For Rare Diseases on February 29th.



The conference at Farnleigh House was attended by people living with rare diseases, advocates, care providers, clinicians, healthcare managers, policy makers and industry with the aim of discussing what the future holds for people living with rare diseases.

EU Action for Rare Diseases

The EU Commission has launched a new joint action (JARDIN) in early March to improve the diagnosis, treatment, and care of patients with rare diseases throughout the EU. This will include integrating European Reference Networks (ERNs) into national health systems: ERNs are virtual networks of highly specialised healthcare providers from across Europe, addressing complex or rare diseases and conditions that require highly specialised treatment or specific knowledge and resources.

Best Research Presentation Award



Congratulations to Eva Woods, HD Researcher for her best research presentation award from Dr. Arjumand Younus, Co-Director, Women in Research Ireland on March 21st. Women in Research Ireland (WIRI) is a volunteer-run charity which provides a platform for women and under-represented groups in Irish academia. Eva kindly supported HDAI on Rare Disease Day by wearing her HD t-shirt to work!

Brain Awareness



HDAI joined the 2024 Neurological Alliance of Ireland Brain Awareness campaign to promote greater awareness and understanding of the impact of living with a neurological condition as well as the need for investment in services, research and prevention.

The NAI also launched phase three of their Patients Deserve Better campaign, calling for regional neurology services.



The campaign calls for access to a Consultant Neurologist to be equally distributed across the country. The Neurology Model of Care recommends that Bantry General Hospital, Mayo University Hospital, Midland Regional Hospital, Portlaoise, Wexford General Hospital and Letterkenny University Hospital should have a Consultant Neurologist to support local neurology services. Prolonged travel and delayed diagnosis are associated with poorer outcomes and increased costs of care. See patientsdeservebetter.ie to support the campaign.

UCD School of Medicine Seminar



HDAI were invited to deliver a Huntington's disease talk to UCD School of Medicine, Rare Disease module students on January 25th. We are grateful to Dr Paula Byrne, Associate Professor, UCD School of Medicine for her invitation and kind feedback.

"I cannot thank you both enough for giving your time to the students on Thursday. What a powerful way to begin the module. The feedback has been amazing and we all felt it a real privilege to be in the room with you both."

Special thanks to Anne O'Shea Clarke for sharing her personal experience of supporting a loved one affected by HD.

FUNDRAISING - THANK YOU

Liffey Mills



Huge thanks to Liffey Mills, Ennis Co Clare for an exceptionally generous donation of €1,000 to support HDAI's work. Anne O'Shea Clarke, HDAI Treasurer met with Ciara Geoghegan and Zara Noone from Liffey Mills to accept their much appreciated donation.



Bank of Ireland Begin Together

HDAI received a generous donation of €500 from the Bank of Ireland Begin Together fund in December. A big thank you to Nicola for nominating HDAI.

Merative Healthcare Ireland Limited



Merative Healthcare Ireland Limited invited Bernie Spellman to speak at their staff event to mark St Patrick's Day. Staff members kindly donated to HDAI following Bernie's awareness talk. Huge thanks to Bernie and to her family friend Smit Jain for nominating HDAI and giving a very generous donation of €250. HDAI received donations of approximately €350 in total via IDonate. Bualadh bos!

Donations

- Direct Debit/regular donations from David, Fiona, Martina, Paul, Tarik and Zil
- Online donations included donations from David Purdom and CAF America matched funding,
- Thank you to the Staff of South Dublin County Council for a generous donation of €350
- And to South Dublin Libraries for €303 from their Christmas Raffle. Thanks to Alison and all the team for your support.
- Gerry and Kay generously donated €250 to HDAI in lieu of Christmas presents
- Mary K €150
- DF Byrne €500,
- Mick Scanlan Coin Collection €137
- UK Online Giving Foundation €300

Christmas Crib Donations



Valerie and Dave Moran very kindly created a Christmas Crib outside their house once again and received €1,000 in donations for HDAI from family, friends and neighbours. Thanks so much to all who donated.

Cobh Kindness

Huge thanks to the Cahill family in Cobh and to friends of the High Chapperal Bar for raising a massive €1,150 for HDAI at Christmas.

In Memory

The family of the late Sylvia O'Neill, who passed away on 14th February 2020, have donated €500 on her behalf.

"The charity was so good to her and made her feel like she was part of a community and wasn't alone. She loved the events she attended. Thank you from our family".

Further donations were received in memory of Tony, Yvonne & Jennifer Porter. Sincere thanks to John Scanlan, a family friend, who set up an online donation page in 2023 raising €1,057.94 in remembrance. Sarah also donated €100 in their memory.

The family of the late Tom Connern have donated generously in his memory. Sincere thanks to Michael, Paddy & Cathleen, Ann & Joe, Margaret & family, Ciaran & Sandra and Geraldine K for donations of €854.



Esther Murphy passed away in February having lived with Huntington's for twenty two years. Sincere condolences to Esther Murphy's husband Josh and her children and to her Dad, her siblings and extended family. Thanks to Esther's family and friends for online donations in her memory.



Kieran Hardiman died in January 2024. Sincere condolences to Kieran's siblings, extended family and friends. HDAI have received donations of €140 in his memory.



Sincere condolences to the O'Rourke family who lost their beloved brother Joe, in November 2023.

Membership


Thank you to those of you who have already subscribed for 2024.

2024 Membership can be completed online here: [www.huntingtons.ie/Membership](http://Huntington's Disease Association of Ireland - Membership (huntingtons.ie) www.huntingtons.ie/Membership)

ID Card

A free Huntington's ID card is available if required. Email 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 if you or your loved one need assistance.



Huntington's Disease Association of Ireland

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www.huntingtons.ie

Deputy John Lahart speaking at Bloomfield Hospital



HD Café

HDAI and Bloomfield Hospital held a HD Café evening at Bloomfield Hospital on March 27th.

Dr David Denton



Family members had an opportunity to meet Dr David Denton, recently appointed Clinical Director and other members of Bloomfield's multi-disciplinary team.

Guest speakers included Deputy John Lahart and Dr Francesco Ripanti. As a member of the Health Oireachtas Committee and the Cross Party Group for Rare Diseases, Deputy Lahart has provided great support to HDAI in advocating for specialist services. He shared his own experience of struggling to support a family member with a rare neurological disease at a time when specialist services were not available. Deputy Lahart spoke about the importance of co-ordinated care and encouraged family members to raise awareness by speaking with their public representatives.

Dr Francesco Ripanti, Department of Classics, School of Histories and Humanities, Trinity College Dublin, is interested in the concept of social prescribing and has included HD families in previous archaeology and wellbeing studies.



Dr Ripanti (above), held a workshop at the 2023 European Huntington Association (EHA) Conference in October together with his colleague at TCD, Dr Giorgos Papantoniou, who is a member of the EHA Board. Their workshop 'Abandonment - from Landscapes to Mindscapes' featured photographs to generate discussion with HD families. Dr Ripanti has also worked with families in relation to rare diseases and HD and on Archaeology and Wellbeing projects in Italy and Cyprus - <https://www.loggia-project.eu/>



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 July and 5th October

Dublin: 4th May and 10th August

Limerick: 13th April and 19th October

Roscommon: 7th September and 7th December

Please contact us at info@huntingtons.ie if you are interested in joining a support meeting.

Dates subject to change - contact HDAI for confirmation