



HDNL 2023 - Issue No 94, Q3 23

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@olchc.ie

Genetic Counselling: www.childrenshealthireland.ie

SUPPORT MEETINGS

See information on page 4

Annual Lunches

HDAI hosts a complementary annual member's lunch following our regional Support Meetings.



These events offer a chance to meet and chat to others in a relaxed atmosphere. Please let us know if you wish to join us for a lunch in your area:

Dublin: 4th November 2023

West: 9th December 2023

Cork: 25th November 2023

Limerick: 20th January 2024

Financial Wellbeing Service



HDAI are delighted to welcome **Sandra Porter** to HDAI's team as a Financial Wellbeing Officer. Sandra has previously worked in the voluntary sector in Ireland and abroad and

has also worked in financial retail services.

Sandra will work part-time, Monday to Wednesday, in order to provide information, advice, guidance, and support to people living with Huntington's disease on a range of income maximisation and debt advice issues. Sandra will mainly work remotely.

HDAI were successful with a grant application to the Rowan Trust Fund - Older Person's Fund at Community Foundation Ireland, which provides funding to groups working with people living with stroke, dementia and other neurodegenerative illnesses. Funding received enables HDAI to develop a pilot Financial Wellbeing Service for one year initially.

Please contact us to avail of free and confidential advice and support with:

- Access to benefits and entitlements
- Information on house adaptations, education grants etc.
- Financial health checks
- Household budgeting
- Completing complex applications and forms
- Managing household bills
- Managing debt

You can contact Sandra via email: sandra@huntingtons.ie or phone 086 191 0361.

HDAI's survey on the experience of families, which we conducted earlier this year, included a question on financial issues.

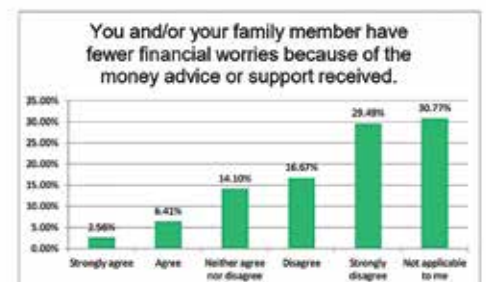
Common themes that emerged included:

- the complexities and bureaucracy of the benefits system and the need for timely advice in order to get the correct entitlement,
- having to battle with yet another system,
- difficulties obtaining a medical card,
- difficulties finding help with financial or benefit issues.

"My sister cannot get a disability allowance and a medical card....She tells the doctor she is well and in good form. The Doctor takes her at her word and doesn't see the dysfunction at home"

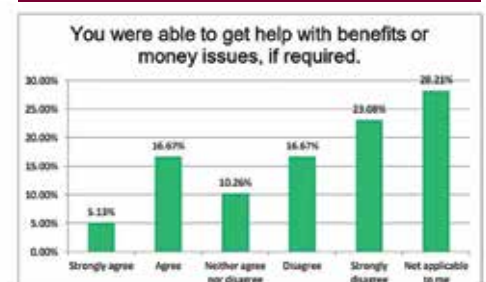


Survey Finding: Financial Worries



As a result of limited access to financial advice, very few respondents (9%) said that their financial worries had been alleviated. 8 people made additional comments.

Survey Finding: Benefits Advice



22% respondents said they had been able to get help with money issues with the remainder being equivocal or disagreed/strongly disagreed.

Postcard from Dubrovnik

CHDI Foundation is a privately-funded, not-for-profit biomedical research organisation devoted to developing Huntington's Disease therapeutics. <http://chdifoundation.org/>



CHDI's 18th Annual Therapeutic Conference took place in April 2023 in Croatia. Charles Sabine, OBE, Emmy award winning television journalist and HD advocate, provides an annual video of highlights from CHDI's annual conference. The 2023 Postcard from Dubrovnik can be viewed at Postcard from Dubrovnik 2023 on Vimeo ([link via www.huntingtons.ie/CHDI-Foundation](http://www.huntingtons.ie/CHDI-Foundation))

TedxBath



Ever the advocate, Charles joined the panel of Speakers at TEDxBath on Saturday 14 October 2023 where he talked about de-

stigmatising Huntington's disease, his life and family life, clinical trials and the work of HD researchers. Professor Ed Wild also joined Charles at the event.

The talk was streamed and you can look back on social media @tedxbath2023 and on Instagram at ted_bath.

Family Voices Webinar Series



A recording of the Family Voices Webinar in conversation with Astri Arnesen is now available via our website at: [Huntington's Disease Association of Ireland - Family Voices Webinar Series \(huntingtons.ie\)](http://www.huntingtons.ie). Astri, who is from Norway, shares her own experiences of living in a family where there is Huntington's disease. She discusses how she and her family coped with her being at risk. Astri also talks about her role with the European Huntington's Association and the Association's work advocating for Huntington's families and building bridges with the scientists researching potential Huntington's treatments.

Rare Diseases Ireland Get Rare Aware Event

Rare Diseases Ireland coordinated a **Get Rare Aware** awareness event in Leinster House on 28th June 2023, with the support of Deputy John Lahart and Deputy Padraig O'Sullivan. Professor Sally Anne Lynch, Geneticist and Vicky McGrath, CEO Rare Diseases Ireland, spoke about the vital need to invest in genetic services now to build foundations for an efficient health service.

Patient representatives from approximately twenty-five rare disease groups attended and Patricia Towey, represented HDAl. Twenty one political representatives attended.

People living with rare diseases are often mis-diagnosed, provided inappropriate and potentially harmful treatment, and their health continues to deteriorate. An accessible and adequately resourced genetics service would help increase awareness among health professionals and help the 300,000 people in Ireland living with a rare disease.



Media coverage included interviews on RTE's Drive Time and Virgin Media's Ireland AM. Patricia was interviewed by Ocean FM and The Sligo Champion in July and gave examples of people living with HD being mis-diagnosed or waiting years for a confirmed diagnosis.

Budget 2024

The Government has announced that Budget 2024 will see an investment of €195m into Disability Services. Minister Rabbitte confirmed that this includes two additional community neuro-rehabilitation teams. HDAl await further detail to see whether specific funding for Huntington's specialist services will be allocated.

Care Alliance Ireland

Care Alliance Ireland provides a summary of budget changes of interest to family caregivers.

Key Payment Increases (January 2024)	Taxation & Means test Changes
<ul style="list-style-type: none">All weekly payments (Carer's Allowance/Benefit; Disability Payments) increase by €12; proportional increases for those on 1/2 rateDomiciliary Care Allowance increase by €10 per monthQualified Child Increase raised by €4	<ul style="list-style-type: none">Home Carer Tax Credit increase by €100Incapacitated Child Tax Credit increase by €200Carer's Allowance Means Test: Income disregards increase to €450 per week for a single person and to €900 per week for a couple (from June 2024)

Source: CAI Budget 2024 Infographic (carealliance.ie)

FUNDRAISING - THANK YOU

Croagh Patrick Barefoot Climb



Martin Byrne and his son climbed Croagh Patrick BAREFOOT in July on behalf of Martin's friend who is affected by HD. Their challenging endurance test has raised a marvellous €2,034 (net of fees) via iDonate.

"Myself and my son completed it bare foot up and down and our feet are cut to shreds - not an easy challenge but so, so worth it for this great cause".

Snookering a World Champion



Aaron Cahill (inset) took on the challenge of playing Denis Taylor, former Snooker World Champion, on August 7th at The Rock, Cloyne. They raised a whopping €1,355 for HDAl. A big thank you to Aaron and the Cahill family for this wonderful support.

Hackney Marathon

Sincere thanks and congratulations to Aisling McQuaid who participated in the Hackney marathon and raised €1,081.83 (net of fees) for HDAl.

UCD Karate Club

Thank you to all at UCD Karate Club who raised €1,060 for HDAl.



Donations

- Direct Debit/regular donations from David, Fionna, Martina, Paul, Tarik and Zil.
- Val and Margaret €500.
- Donations via iDonate: Pat €100 • Anonymous €275.
- Huge thanks to LCS Cleaning Service who chose HDAl as a charity partner for 2023. They have contributed €1,500 in total during 2023.



Joe Doran HD Awareness Walk

The Joe Doran HD Awareness walk took place in July at Lough Key Forest and Activity Park. The tremendous efforts of Joe's family ensured that it was a phenomenal success raising a brilliant €15,470 for HDAl.



Huge thanks to Pauline, Anne, Tadgh and Jessica, Peggy Fogarty, Joseph, Berni and Susan Doran, Tommy, Johnny and their families and all the extended family. Jessica very kindly made her own bracelets to support her Uncle's walk.



Joe's family greatly appreciated all the support from Longford and Galway including Joe's friends, Mark and gang, Sinead Mallon and Alan Folan and friends from Galway. Family friend Ming Flanagan (MEP) and his family also supported the walk. Thanks also to members of the HD community who supported the event.

It was a pleasure to welcome the team from Bluebird Care Longford, Roscommon and Westmeath who participated in the walk and raised €385. Pictured below are Therese, Michael, Carlos, Ronel, Ollie and Kaia.



Pauline spoke to regional newspapers and radio stations to help increase awareness. We very much appreciate the support from everyone who joined the walk, online donors and those who raised sponsorship. We received very generous contributions from J Coffey Construction Ltd, Joseph Doran and family, Eddie Barrett, Tom & Geraldine Mitchell and the Gibson family to name but a few.

Thanks also to Louise and the team at Lough Key for their fantastic support. Lough Key is a wonderful location and we hope to walk again next year!

Family Planning Support

Pre-implantation genetic testing helps people at risk of certain genetic conditions such as HD to avoid passing the condition on to a future child.


Yvonne Porter generously left a bequest in her will which allows HDAI to provide €2,000 towards the cost of this procedure for those wishing to avail of it.

Contact us on info@huntingtons.ie for further information.

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.



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Email: info@huntingtons.ie
www.huntingtons.ie

In Memory

Paul Whelan



"Sadly, my husband Paul Whelan passed away on August 1st, 2023 having lived with HD for many years. Paul was lovingly supported by his son and three

daughters and by the extended family. Thanks to the HDAI staff for all their care and support."

Denise

Paul's family and friends generously donated €937 to HDAI in Paul's memory. Sincere condolences to Paul's wife Denise and to his children and extended family.

Jennifer Porter



Jennifer Porter, much loved daughter of Anna and the late Tony, and twin sister of the late Yvonne, died on October 1st. Jennifer will

be forever loved and deeply missed by her mother Anna, her best friend Sarah & family, her aunts, uncles, cousins, extended family, neighbours and friends.

"Jennifer was warm, friendly and kind, with a sharp wit. She was a dedicated volunteer and Board member of HDAI when in good health. She supported the Association in so many ways, even shaving off her beautiful hair to raise funds! Rest in peace Jennifer, we were honoured to have known you and we will remember you fondly".

HDAI

Jennifer's family and friends have donated €1,300 to HDAI in her memory. Thank you to family friend John Scanlon for creating an online donation page.

Diet Tips

Dietary Intake, Mediterranean Diet Adherence and Caloric Intake in Huntington's Disease: A Review, Christodoulou et al., 2020.

Christodoulou et al. conducted a review of studies that have investigated Mediterranean Diet adherence, micro-and macronutrients, supplementation and caloric intake in people with HD, in order to identify if dietary exposures resulted in improvement of disease symptoms, a delay in age of onset or if they contributed to an earlier age of onset in people with HD.

The results of their review suggest an improvement in the cognitive and motor scores and a better quality of life in people with HD who had high Mediterranean Diet adherence.

The authors acknowledge limitations to their study including timeframe and sample size and propose that 'Good quality evidence from better designed studies can offer invaluable research insights into the relationship between diet and HD onset and progression and can be used in both non-pharmacological and pharmacological interventions to modify onset and/or progression of HD'.

The European Huntington Association have recently shared some Mediterranean Diet Tips on Social Media:

MEDITERRANEAN DIET TIPS

- Eat more fruits and vegetables
- Choose whole grains
- Use unsaturated fats from plants
- Eat more seafood
- Get nuts
- Enjoy some dairy
- Spice it up - use spices instead of salt
- Reduce red and processed ^{eat} meat
- Reduce sugar intake
- Eat fresh fruit instead of sweets



(Mayo Clinic, 2023; World Health Organisation, 2018)



HDAI Support Meetings

Dublin: 4th November 2023

West: 9th December 2023

Cork: 25th November 2023

Limerick: 20th January 2024

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

Dates subject to change - contact HDAI for confirmation