



# NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

## IRELAND

### 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 6739** and [www.genetics.ie](http://www.genetics.ie)

### SUPPORT MEETINGS

See information on page 4

### DANCING AT THE VATICAN



Now free on YouTube

### 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@huntington.ie](mailto:info@huntington.ie)



Our regional support group meetings have moved online during the current Stay at Home guidelines. Please get in touch if you would like to join an online support group chat.

## Contribute to our 'Living History' project for Huntington's Disease Awareness Month



Huntington's Disease Association of Ireland, together with our colleagues in the Huntington's Disease Alliance UK and Ireland, are working on a unique project, **#FamilyMatters** to mark Huntington's Disease Awareness Month in May. Throughout May, we will be campaigning together, sharing the stories of people living with HD and working hard to raise awareness. We need your help!

*We are building a digital space for the Huntington's community to contribute (named or anonymously) pictures, words and thoughts on how you feel about the way Huntington's affects you and your family.*

By creating this space and allowing everybody within our community to post a message or a visual image, we will be able to create a wonderful 'living history' project that will help the wider world understand the impact of Huntington's disease.

See [www.huntingtons.ie/News](http://www.huntingtons.ie/News) to get involved and support the campaign on social media. Huntington's Disease Association of Ireland - Facebook, Twitter: @HDAI\_ie and Instagram: @HDAI\_ie

## HDBuzz Vaccines and HD

Many HD families have questions about vaccination for the coronavirus. HDBuzz have written a very helpful article on the subject and their short answer to the question:

Should HD patients get the vaccine? is - **absolutely, yes!** Read their article here: <https://en.hdbuzz.net/299>

## HDYO Young Adult Virtual Congress

Huntington's Disease Youth Organisation (HDYO)'s International Young Adult Virtual Congress took place from March 13-14 2021.



The HDYO team delivered an outstanding event with two days of insightful talks, peer support, research updates, input from HD family members contributing to research and hope for the future! There was a world-wide participation and attendance.

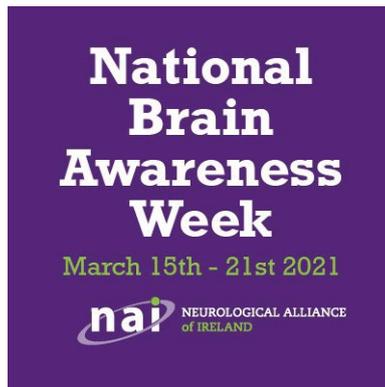


HDYO is an international non-profit supporting, educating, and empowering young people up to 35 years, impacted by Huntington's Disease around the world. They also provide resources for parents. If you missed the Congress check out their website [hdyo.org](http://hdyo.org) and You Tube site for access to sessions.

*"I found the HDYO Conference to be not only educational but truly inspirational, Thank you".*

Joan, Ireland

## Brain Awareness



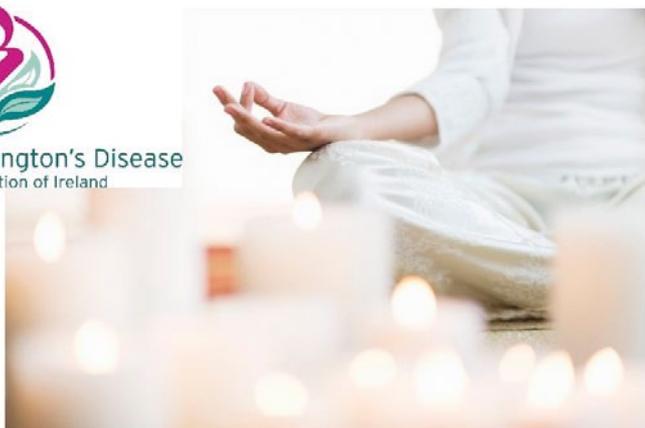
*Love your Brain* is an awareness campaign led by the Neurological Alliance of Ireland to coincide with National Brain Awareness Week March 15th to 21st 2021. The campaign aims to promote greater awareness and understanding of the brain and

brain conditions as well as the need for more investment in services, research and prevention. *Love your Brain* is supported by research groups and patient organisations including Huntington's Association.

There are 4 parts to the Campaign:

- Understand your Brain
- Keeping Your Brain Healthy
- Living with a Neurological Condition
- Promoting Brain Research

See [www.loveyourbrain.ie](http://www.loveyourbrain.ie)



## MINDFULNESS & WELL BEING Celebrating Brain Awareness Week

Saturday 20<sup>th</sup> March  
11am -12pm

VIRTUAL EVENT  
CONTACT [INFO@HUNTINGTONS.IE](mailto:info@huntingtons.ie)

We are holding a Mindfulness and Wellbeing event on March 20th to mark Brain Awareness Week.

To register please email: [info@huntingtons.ie](mailto:info@huntingtons.ie)

## Physiotherapy Clinical Guidelines

Physiotherapy is important for treating people with Huntington's Disease. To help physiotherapists, the European Huntington's Disease Network (EHDN) Physiotherapy Working Group has put together and published Clinical Guidelines.

See [huntingtons.ie](http://huntingtons.ie) / Exercise and Physiotherapy for information.

## Brain Health Webinars



Dementia Research Network Ireland are hosting a series of weekly webinars from March - May on the topic of Brain Health. The webinars are free to attend and people can register through Eventbrite.

<https://www.eventbrite.ie/e/brain-health-online-webinar-series-tickets-139933796753>

Each talk will be followed by a Q&A with the audience.

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

## Rare Disease Day

Huntington's Disease Association of Ireland is a member of Rare Diseases Ireland which is a national alliance for voluntary groups representing the views and concerns of people affected by, or at risk of developing, genetic or other rare diseases.

Rare Diseases Ireland joined with other rare disease groups around the world to mark Rare Disease Day on 28th February 2021.

Rare Disease Ireland asked people to *Raise A Toastie* to raise awareness for those living with a rare disease. Huntington's Disease Association of Ireland supported the campaign and asked people to raise a toastie. We received some great toastie snaps (see below) which we shared on social media using [#RareDiseaseDay](https://twitter.com/RareDiseaseDay) and [#RaiseAToastie](https://twitter.com/RaiseAToastie)



As Huntington's is a rare disease, The Huntington's Alliance UK and Ireland launched our [#FamilyMatters](https://twitter.com/FamilyMatters) campaign on February 28th. See [www.huntingtons.ie/News](http://www.huntingtons.ie/News) for information.

## THANK YOU

### 2021 Membership

Thank you to members who have already paid their 2021 contributions. Annual membership is open to all who have an interest in our work. Membership support enables us to maintain services and supports to people impacted by Huntington's disease and helps to strengthen the voice of the HD Community in Ireland. It also provides an opportunity for those interested to help guide the work of HDAI.

A 2021 membership form is available online via our website and contributions can be made online. Due to the current restrictions, we ask members not to send membership by post at this time. HDAI's services are available to anyone affected by Huntington's Disease regardless of membership status.

### Ongoing Marvellous Support

We are so grateful for all the marvellous support in what has been a very challenging time. A big Thank You to recent donors and to those who renewed membership including:

- Direct Debit donations from Fionna, Martina, Zil and Jacyntha & Ger
- The Rahman family via Your Cause - €511.14
- Seamus - €1,000
- The GPO Union Room Dublin Mail Centre - €500. (George and colleagues were friends of the late Christy Clarke)
- On behalf of Triona Hanley - €200
- Donation on behalf of "my beautiful friend Triona" from Marian, David and Rachel
- Alain - €250
- Mary S - €100
- Sorcha - €100 "for continuous support over the years"
- Margaret & Val - €100
- Mick Scanlon Coin Collection - €131
- Mark and the team at D8 Fitness Store, Dublin 8 - €1,000
- Patrick and Teresa O'Sullivan - €1000
- Professor Niall Pender and the Medical Independent (article fee) - €150
- Roseanne Evans donations via Benevity - €60

### In Memory Donations

- John O'Donovan very kindly donated €100 as a New Year gift for his Aunt Ann who is living with Huntington's and in memory of his Grandmother Julanne, Aunts Margaret (Peggy), Theresa, and Uncle Gerry who have passed because of the disease.
- Thank you to Catriona, Patricia, Richard and Pdraig for their contribution of €570 from the New Year's Day Swim in memory of Eugene Newman.
- The B Shift at Bausch & Lomb very generously donated €280 in memory of Martina Grant.
- Thanks also to June who donated €60 in memory of Martina.
- Geraldine Keane kindly donated €50 in memory of deceased relatives from the Connern and Mullahy families

## In Memory



Gaye Kennedy died peacefully in TLC Nursing Home on 14th February having bravely lived with HD for many years. Gaye will be lovingly remembered by her sisters and brothers, nieces and nephews, Godchildren and her friends.

A HD chair has been donated to HDAI in keeping with Gaye's compassionate and generous nature. Rest in Peace Gaye.

### Covid-19 Stability Scheme for Community and Voluntary, Charity and Social Enterprise Organisations

HDAI received a very welcome additional grant of €10,508 from the Department of Rural and Community Development to counteract the impact of the pandemic on charity fundraising in the first six months of 2021 and the increased demand for supports.

### Malahide Golf Club

Sincere thanks to Pauline Duddy (Ladies' Captain) and her associates at Malahide Golf Club for their very kind contribution of €730 to support Huntington's families.

### Frank's Head Shave



Frank Cunningham has raised over €2,000 with his *Head Shave for Huntington's*. A huge thanks to Frank and his family and friends including John Griffin owner of *Addicted Coffee Shop* in Cobh who held a collection box at the café and collected €700 towards Frank's fundraiser.

### Crafts



Nancy Shannon created beautiful crochet baby blankets and received donations of €145 for HDAI. Thank you Nancy!

## Follow HDAI on Social Media

**Facebook:** See: **Huntingtons Disease Association of Ireland**

**Twitter:** @HDAI\_ie

Thank you to our volunteers for their social media work.

## Instagram

HDAI has joined Instagram - all follows and likes appreciated @HDAI\_ie

## Meet Aoibh



Aoibh Boyle Brennan has been working with HDAI since February as part of her BSc degree in psychology in Maynooth University, where 3rd year students take one semester on work placement. Aoibh has been attending virtual support meetings and training seminars, reviewing the website and publications and supporting our Family Matters awareness campaign. We are delighted to participate in this placement programme and are grateful to Dr Richard Roche, Senior Lecturer / Associate Professor at the Department of Psychology, Maynooth University, for including HDAI in this beneficial project.



**Huntington's Disease Association of Ireland**

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FreeFone: 1800 393939

Email: [info@huntingtons.ie](mailto:info@huntingtons.ie)

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

## UPCOMING EVENTS

### Sunrise for Brain Conditions

"SunriseForBrainConditions" is a 'not for profit' Partnership organising events to raise funds for chosen Brain Condition Registered Charities in a fully transparent and compliant manner. The team are greatly assisted by a community of friends who get together to organise these events, have a super time and raise funds for worthwhile charities fighting Brain Conditions / Neurological Diseases. Funds raised go towards providing increased Specialist Care.



The initial impetus came from John Kelly who was greatly moved by seeing the impact of brain conditions at first hand by way of his mother-in-law, father and mother. From personal experience, John understood the need for funding and was determined to do something about it. This took the form of a fundraising climb, "Sunrise up Croagh Patrick" an event supported by his University (UCD) classmates and work colleagues from Hanson Regan.

The event has grown and attracted wider support from many great people who have been affected by Huntington's Disease, Parkinson's, Motor Neurone Disease and Multiple Sclerosis. Traditionally our main event of the year has been a climb up Croagh Patrick, which is challenging but also great "craic" with most people staying overnight in Westport.

Last year, because of Covid-19, the group organised a successful Virtual Climb which raised over €20,000 for Brain Conditions' charities (almost €9,000 going to HDAI), bringing the total amount raised since 2016 to over €85,000. This year, 2021 will be busier & better with more fundraising events planned.

[www.sunriseforbrainconditions.org](http://www.sunriseforbrainconditions.org)

Events include:

- **100K Cycle on 20th/21st March** (Spring Solstice Weekend).
- **Croagh Patrick Climb - Virtual event - June 2021**  
**Actual event - June 26th, Croagh Patrick** (if restrictions allow)

### The Henley Mermaids

Following a successful swim relay of the English Channel in July 2020 (raising £35,000 for Henley Music School) their next ambitious challenge is a swim relay of The Bristol Channel from Illfracombe in North Devon to Swansea in Wales in **July 2021**.

[www.idonate.ie/TeamHenleyMermaids](http://www.idonate.ie/TeamHenleyMermaids)

The Mermaids are also actively advocating for Brain Awareness - check out their blog and social media posts.

[www.henleymermaids.com/my-blog](http://www.henleymermaids.com/my-blog)



*The Henley Mermaids: Laura Reineke, Fiona Print, Joan Fennelly, Susan Barry and Jo Robb swim with the Henley Open Water Swimming Club.*

### A Song for HD



Denise is sharing her beautiful voice to sing a song each day of St Patrick's week for Huntington's disease.

Check out [www.idonate.ie/ASongforHD](http://www.idonate.ie/ASongforHD)

## HDAI Online Support Group Meetings

The online support group aims to provide a safe meeting space for participants to build support and share their lived experiences with others with similar experiences. The family support officer facilitates meetings and can provide further information on relevant community resources. Please contact us at [info@huntingtons.ie](mailto:info@huntingtons.ie) if you are interested in joining an online chat.

Limerick Group

April 10th  
Oct. 24th

Dublin Group

May 8th  
Aug. 7th

Cork Group

Mar. 27th  
July 24th

West Group

Sept. 4th  
Dec. 4th

Dates subject to change - contact HDAI for confirmation.