



# NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

## IRELAND

This newsletter was published with financial assistance from



**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

## HDAl's Services

HDAl 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.

## Keeping Informed on COVID-19



COVID-19 continues to pose challenges for access to health and social services and for our day to day activities.

As public health restrictions ease, regular hand washing,

respiratory hygiene and social distancing are even more important. If we all follow HSE guidelines we can help to slow the spread of COVID-19 and keep our families and ourselves safe.

People in the 'very high risk group' (including people over 70 years and those with certain health conditions) are recommended to cocoon. People in the 'high risk group' (including people over 60 years and those with certain health conditions, such as neurological conditions) are asked to take extra care to follow the advice on keeping safe from Coronavirus.

The HSE provide reliable information on the virus including information on: Symptoms, How to Protect Yourself and Others, People at Higher Risk, Managing The Coronavirus at Home, Testing, Staying Well During the Epidemic, Services for People in Higher Risk Categories, Advice for Parents and Carers, Translated Information and a Regular Updates section <https://www2.hse.ie/coronavirus/>

## Making the most of your health phone consultation

Due to social distancing measures in hospitals and health clinics, phone consultations / telemedicine options are now being offered in place of out-patient appointments.

For some, a physical appointment may be the preferred option, but a remote appointment can work well if you have time to prepare in advance. Here are some tips to consider:

- In advance of the call, make a list of any changes to your health since your last appointment. Prepare a list of questions you would like to ask.
- Consider asking a family member to be at hand to take notes so you can focus on the conversation with your health professional.
- Have a pen and paper nearby.
- Try to keep your phone or iPad / Tablet charged.
- If your battery is low when the call comes in, let the caller know. Perhaps they can call back to another phone available to you.
- If possible, take the call wherever you have the best phone reception.
- Have a list to hand of all medications you are currently taking including frequency and dosage.
- If you need a prescription renewed be sure to let your healthcare provider know.
- If you or your family care giver are advised by your healthcare professional to remain at home as a precaution due to the COVID-19 pandemic and you need a letter for your / their employer, ask your neurologist for a letter.
- If you feel you have new or worsening symptoms such as weight loss or increased anxiety etc. it is important to let a member of your healthcare team know.
- Ask for advice on what you can do to keep as well as possible: maintaining weight, keeping active, managing stress etc.
- Ask if your next appointment is being scheduled or when you can expect another call from the clinic.
- At the end of your call, keep any notes you have made in a safe place so you can easily find them for follow-up.

## COVID Tracker App Launch



Stephen Donnelly TD, Minister for Health, Paul Reid, CEO, HSE, Dr Ronan Glynn, Acting Chief Medical Officer, Department of Health and Dr Sarah Doyle, Specialist in Public Health Medicine, HSE HPSC, launched a COVID Tracker App for Ireland

on July 7th. The app aims to enhance existing contact tracing measures, by enabling users to identify close contacts and to alert those who are using the app of the need for COVID-19 testing as quickly as possible. The COVID Tracker is a free app for your mobile phone, available to download from the App Store or Google Play. HDAI also provide information on the News section of our website at [www.huntingtons.ie](http://www.huntingtons.ie)

## HD Cognition Study Update

The Huntington's Disease Cognition Study is a research project taking place at Beaumont Hospital, under the supervision of Professor Niall Pender. It is understood that people with HD experience changes to their cognition (thinking) over time. The purpose of the study is to find out what kind of changes in cognitive ability take place in people with HD and their family members. By assessing each participant once a year, the team can then observe not only what kind of changes to cognition and emotion takes place but also how they develop over time. The study is also testing out a new tool designed to detect cognitive difficulties early in the course of the illness. This tool has been found effective when used with people with Motor Neuron Disease, and so the team believe that it may also prove useful in assessing people with HD.

The HD Cognition Study will be continuing for the foreseeable future, with appointments resuming in the coming weeks. So far 27 people have taken part, and while recruitment has slowed since March due to COVID-19 Prof. Pender's team are keen to get new people in for appointments as soon as possible. Participation is open to anybody from a family affected by HD, whether or not you have taken the genetic test and including people who tested negative. Spouses and partners are also welcome to attend with affected family members. If you are interested in taking part in this study, or in other HD research taking place in Beaumont Hospital, please email [enrollhd@beaumont.ie](mailto:enrollhd@beaumont.ie) or call 01 809 2223.

HDAI would like to thank **Donal Campbell** for his work on the HD Cognition study and with the Enroll-HD study. We wish Donal all the best as he moves to the next stage of his career.



## EHDN Newsletter

The European Huntington's Disease Network (EHDN) publish a newsletter three times per year (March, July, Nov). Their newsletter provides news on EHDN activities and other Huntington's disease news of interest to the HD

community, healthcare professionals and scientists. If you wish to receive EHDN newsletters you can visit their website and request to be added to their mailing list.

<http://www.ehdn.org/>

## Coping Resources

The Psychological Association of Ireland have posted a set of information videos on coping with social distancing and changes to your health services and routines.

Dr Fiadhnaid O'Keeffe, Clinical Neuropsychologist, discusses neurological conditions and COVID-19. Tips include:

- Don't delay seeking help from your health professionals if you experience a change in your health
- Get prescriptions in advance so you don't experience any delays
- Don't make changes to medication yourself - discuss concerns with your GP or Consultant
- Keep up to date with HSE guidelines on COVID-19
- If you need assistance with shopping / prescriptions ask for help - there is community help available or check with your patient organisation
- If you feel anxious try to do what has helped you previously
- Get a good night's sleep - avoid excess caffeine and looking at screens before bedtime, practice relaxation breathing e.g. breath in for 4 seconds and out for 8
- Limit your access to social media and news
- Try to keep structure to your day - maintain getting up and bed time hours and activities you enjoy - like music, reading, getting fresh air, gardening, speaking to friends and family
- Keep as active as possible - exercise helps reduce stress
- Keep in contact with your social connections
- Talk to someone about how you are feeling (you can call HDAI confidentially) If you feel stressed

For more info see: <https://www.youtube.com/watch?v=IKiffVs3obU&feature=youtu.be>

## HD Awareness



The annual #LightitUp4HD awareness week took place in Ireland from May 11th-15th. Despite the pandemic, Dublin's Mansion House, The Convention Centre Dublin and The Rock of Cashel generously supported our campaign.

We are very grateful to those living nearby who managed to get some photos and to all who supported us on social media. Unfortunately our planned family event with guest speakers from the Huntington's Association of Cyprus, had to be cancelled due to the pandemic, but we will endeavour to host the event when it is possible to do so.



## Fundraising - Thank You

### Hospital Saturday Fund



The Hospital Saturday Fund provided HDAI with a grant of €2,200 to assist in supporting people impacted by HD to cope with the impact of COVID-19. HDAI have used this funding to support people living with HD cope with the impact of cocooning and social isolation by providing communication aids, alarms and contributions towards emergency care hours etc.

### Monkstown Hospital Foundation



Sincere thanks to the Board of Monkstown Hospital Foundation for awarding HDAI a

generous grant of €2,000 towards the provision of assistive equipment for people living with HD in March 2020.



### 50th Birthday gifts

Congratulations and sincere thanks to Austin Mann who very generously nominated HDAI in lieu of Birthday gifts with €550 received.

### Recently Received Donations

- Seamus €1,000
- Brenda & Colm Flanagan €250 in lieu of Wedding Thank You Cards,
- Direct Debit donations from Fionna, Martina, Zil, Jacyntha and Ger,
- €600 received in donations via iDonate in recent months,
- €250 from Michael Moore, Leinster Cleaning,
- €120 from Máire's Handknits for HD,
- €1,000 received via Benevity.
- Thank you to all who sent *In Memory* donations.

Further donations received from HDAI's 2019 Fairyhouse event includes:

- €300 from the Foley Family,
- €100 from Mrs Noreen Foley.

### Membership

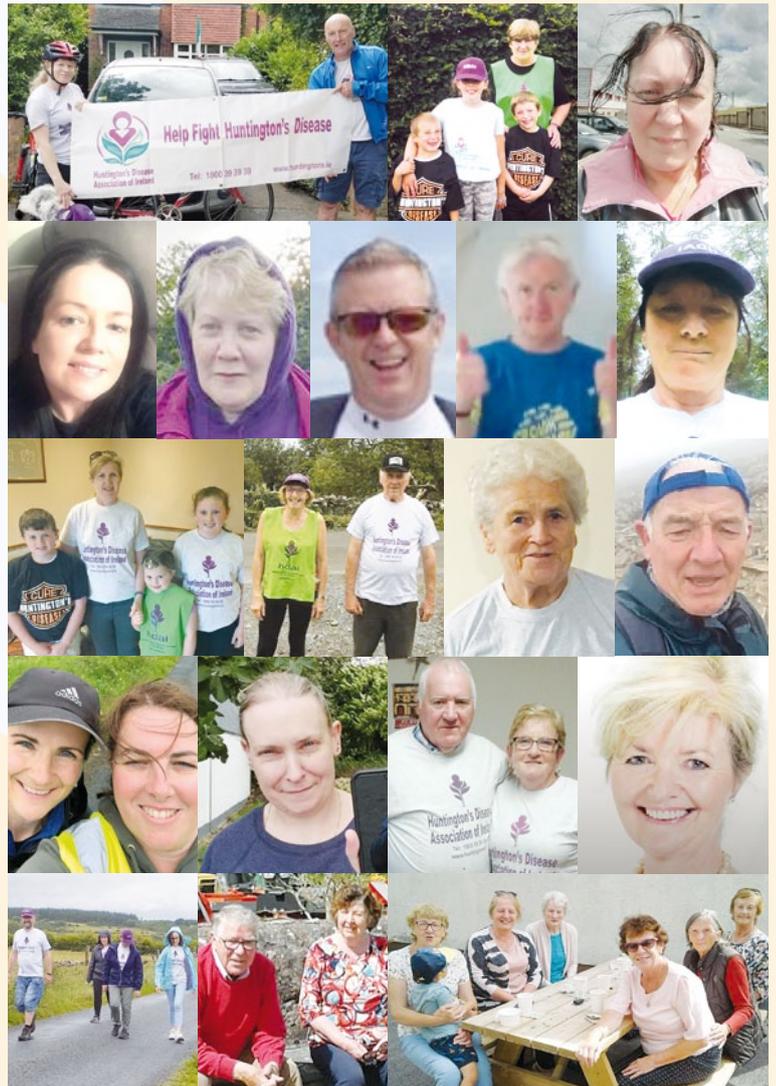
HDAI annual membership is open to all who have an interest in our work. Thanks to all who have renewed their 2020 membership and to our regular Direct Debit donors. Membership support enables HDAI to maintain services and supports to people impacted by Huntington's disease and helps to strengthen the voice of the HD Community in Ireland. It also provides an opportunity for those interested to help guide the work of HDAI.

**HDAI's services are available to anyone affected by Huntington's Disease regardless of membership status.**

## SunRise Up Croagh Patrick (SUCP)

**SUCP is held annually at Croagh Patrick, Westport, Co Mayo, to raise funds and awareness for people affected by Huntington's Disease, Parkinson's Disease and Motor Neurone Disease.**

The event was initially organised by John Kelly and supported by his University classmates and work colleagues from Hanson Regan. The event has grown and attracted wider support from people who have been affected by HD, PD and MND. Due to the COVID-19 pandemic, the 2020 event took place virtually on 27th June 2020. Instead of climbing the mountain, participants were asked to complete the equivalent challenge of 27,000 steps in adherence to social distancing guidelines, anytime during June 1st-27th 2020. Michael Kelly was the only hardy adventurer who climbed in very poor conditions on June 27th.



The SUCP organising committee worked extremely hard to organise participants and raise awareness on social media. A big thank you to all who raised funds for all three charities: John Kelly, Frank Fenn, Vincent Power (90 years young), Fergal O'Neill, Mary Kate Folan, Shannon Corr, Niall Bobbett, Justine Fenn, Eva Fenn, Laoise McKenna and Gary Fenn. The event was a great success and raised approximately €19,000 for the three charities.

We had remarkable support from the HD community and friends who participated: Ann & Joe Hannon & friends, Michael Connern & Family, Kathleen & Paddy Connern, Margaret Mangan & family, Anne O'Shea Clarke, Bridie O'Shea and the O'Shea family, Susan and Ger Breen, Ide Cussen & Paul, David & Sorcha Coyle, Breda, Tommy, Meadhb, Sorcha, Monica, Cathleen and Patricia. Sincere thanks to all who generously sponsored and contributed to the 2020 event.

## 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.**

## ID Card

A free Huntington's ID card is available if required. Please contact us at [info@huntingtons.ie](mailto:info@huntingtons.ie) or on our mobile no. **087 051 7772** and we will take it from there.

## HD Chair

Let us know if you need a HD Chair for a family member or if you have one that needs repair. Alternatively if you have one you don't need and would like someone else to make use of it we can arrange this. Please contact the office.

## HOPE Annual

The HOPE Annual 2020 is now available to view online at [www.huntingtons.ie](http://www.huntingtons.ie)



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## IN MEMORY

### Chloe Hayes



Chloe Hayes sadly passed away in May aged 19 years, having bravely lived with Juvenile Huntington's Disease for over ten years. Chloe is featured in the Rare Disease Guide which was launched last February: <http://rdi.ie/rdeasyguide-2020/>

HDAI, on behalf of the HD community, extend our heartfelt condolences to Chloe's family and friends. We are sincerely grateful to Chloe and her family for raising awareness of JHD and advocating for HD families. Thank you to Maureen Hearn for her kind donation in memory of Chloe.

### Paddy Carty



Paddy Carty passed away in June after living with HD for many years. Paddy, always cheerful and good humoured, will be lovingly remembered by his wife Eileen, his sisters, brothers and their families, friends, neighbours and carers.

Paddy, and his devoted wife Eileen, served on HDAI's Board in the past and together with their extended families have held many fundraisers (parachute jumps, line dancing events, beer bobble runs, coffee mornings etc.) on behalf of HDAI. Thank you to Triona O'Hanlon for her very generous donation in memory of Paddy.

### Ann Honor



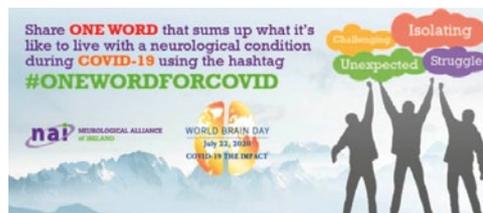
Ann Honor passed away in June. She defied HD and her other health conditions in her roles as a mother, grandmother, sibling, friend and neighbour. Ann was a regular attendee at HDAI's annual conference at Cuisle and very much enjoyed a song and a dance.

*"Our Ma, the legend, left this world on Friday the 5th of June. It was very peaceful. I hope she's rocking it up there with the spoons! She was the strongest woman I know. We were proud to be her children".* Christy, Tanya, Lynette, Gary and PJ

### Eugene Newman

HDAI have received donations of €1,200 in memory of the late Eugene Newman bringing total contributions to €1,400. Sincere thanks to Eugene's family, relatives and friends.

## Share One Word



The Neurological Alliance of Ireland are running a social media campaign for World Brain Day (JULY 22ND) which aims to raise awareness of what it's like to live with a neurological condition during COVID-19 in Ireland. You can support the campaign by sharing 'your' ONE WORD on social media using the hashtag **#ONEWORDFORCOVID**

## Congratulations Professor



Congratulations to soon-to-be Professor Ed Wild who is being promoted to Professor of Neurology at University College London (from October). Prof. Wild, a consultant neurologist, a researcher and a tireless advocate for the HD community is also a great friend to HDAI. (pictured in Dublin at HDAI's *Dancing At The Vatican* screening in May 2019).

## HDAI Online Support Group Meetings

Due to COVID-19 restrictions, Support Group Meetings will take place **ONLINE** until further notice. Please contact us at [info@huntingtons.ie](mailto:info@huntingtons.ie) if you are interested in joining an online chat on the dates below.



### Dublin Group

Aug. 8th  
Nov. 7th

### Cork Group

Jul. 25th  
Oct. 10th  
Nov. 28th

### West Group

Sept. 5th  
Dec. 5th

### Limerick Group

Oct. 24th

*Dates subject to change - contact HDAI for confirmation.*