



HDNL 2018 - Issue No 72, Q1 18

# NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

This newsletter has been published with financial assistance from **The Hospital Saturday Fund**

## SUPPORT MEETINGS

See dates on page 4

## GENETICS

For information on Genetic testing, contact the Genetics Centre. Tel: **01 409 6902** and **www.genetics.ie**

## ENROLL HD

You can express your interest in participating by emailing [enrollhd@beaumont.ie](mailto:enrollhd@beaumont.ie)



## MEMBERS MEETING & RESPITE WEEKEND - CUISLE

8th-10th June, 2018



**HDAI's annual members meeting, respite weekend and AGM** will take place in Cuisle Holiday Centre, Donammon, Co. Roscommon.

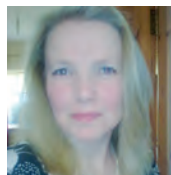
**Genetic Counsellor Marie Duff**, Department of Clinical Genetics, Our Lady's Hospital, Dublin, will provide information on the HD Predictive Counselling Service.

**Enroll-HD:** An update on the progress of the project will also feature.

## Invest in Neurology Campaign



The Neurological Alliance of Ireland (NAI) with the support of eleven of its member groups (including HDAI) launched a campaign 'Invest in Neurology' on March 7th to call for improved services for the 800,000 people living with neurological conditions in Ireland.



Caroline who has the HD gene, inspirationally shared her personal story in support of the campaign. Caroline has been interviewed by local

radio stations, regional newspapers and The Sun newspaper. She spoke about the long waiting lists, the need for research and specialised services in Ireland and the lack of support for people:

*"A lot of people don't know what to do, where to go, who to talk to - they need reassurance, they need support"*.

The main asks of the campaign are:

1. Immediate investment to address critical deficits in neurology staffing, including neurologists, specialist nurses and allied health professionals nationwide
2. Targeted long term investment in neurology services to support implementation of the Neurology & Epilepsy Models of Care
3. Dedicated resources to support the development of clinical pathways for headache, multiple sclerosis, Parkinson's disease and rare and genetic neurological conditions.

The campaign leaflet and manifesto is available on NAI's website: [http://www.nai.ie/go/neurology\\_campaign](http://www.nai.ie/go/neurology_campaign)

There is also a web tool available, via the above address or from HDAI's Facebook page, for people to email their local elected representatives. Please consider emailing your local TDs to call for their support for the campaign.



Members of NAI at Leinster House

Senator John Dolan raised this issue in the Seanad during Brain Awareness week. He spoke about the lack of neurologists and specialist nurses in the health care system in Ireland and the fact that some people have to wait up to two years to see a neurologist.

## Brain Awareness Week Conference

The Irish Brain Council and the Neurological Alliance of Ireland held a joint conference 'Research and Healthcare Responses to the Challenge of Brain Conditions in Ireland' to mark Brain Awareness Week.



Professor Mark Ferguson, Director General of Science Foundation Ireland delivered the opening address. Professor David Henshall, Royal College of Surgeons Ireland discussed his research on cell and molecular mechanisms of epilepsy.

Professor Henshall is also the Director of the Science Foundation Ireland Research Centre 'FutureNeuro' which is recently established to focus on the diagnosis and treatment of chronic and rare neurological conditions.

(continued on page 2)

## Brain Awareness Week Conference - continued from page 1

Professor Ian Robertson, Trinity College and Co-director at Global Brain Health Institute spoke about the importance of research into brain conditions and depression and commended Atlantic Philanthropies for their contribution to neuroscience research. Professor Cora O'Neill University College Cork is Deputy Head of the School of Biochemistry and Cell Biology and Director of Cork Neuroscience Centre of Excellence in Neurodegeneration. She discussed the work of over 40 Principal Investigators

collaborating on neurodegeneration research. Professor Tim Lynch, Clinical Lead of the National Neurology Clinical Programme was joined by Mags Rogers, NAI to present preliminary findings from the first patient experience survey of neurology services. Prof Lynch outlined the need for more neurologists and multi-disciplinary staff to cater for demands on the service.

He also referred to exciting advances in research for neurological conditions including Huntington's Disease. Videos from the conference are available on HDAI's facebook page.

## Living with a Neurological Illness

### Planning for the Future - Booklet Launch

The Neurological Alliance of Ireland and The Irish Hospice Foundation have launched a booklet for people who have an advancing neurological illness, and who want to make plans for their future. It may also be useful for family members, friends, carers and healthcare professionals. HDAI was a member of the working group that contributed to the development of the booklet. It is available on HDAI's website and hard copies are also available on request - email: [info@huntingtons.ie](mailto:info@huntingtons.ie) Professor Orla Hardiman launched the booklet

and commended the authors for its quality. She discussed the importance of people with advancing neurological conditions having the power to make decisions about what they may and may not want to happen in their future. Ideally palliative care should be available to assist people at the different milestones that might occur. Professor Hardiman emphasised that palliative care should not be considered to be about dying but about assisting people to have a good quality of life for as long as possible.

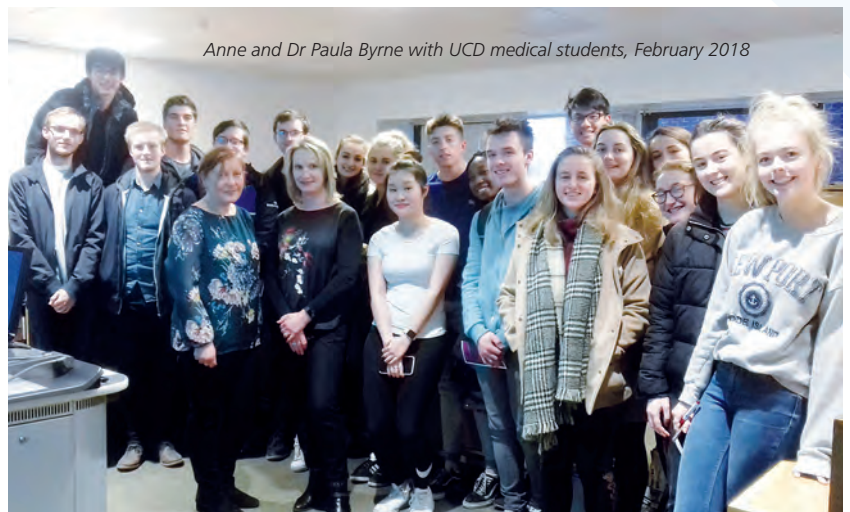


## HD Seminars

**UCD** - Following an invitation from Dr Paula Byrne, Associate Professor, UCD School of Medicine Anne O'Shea Clarke and Patricia (Information & services Coordinator) gave a talk on Huntington's Disease to medical students taking a module on rare genetic disorders in February. Anne and her late husband Christy gave talks to medical students previously and Dr Byrne acknowledged their contribution,

*"Christy and Anne have contributed enormously to the education of UCD medical students in so many ways and they have left a lasting impact".*

**Nursing Homes** - Liz (Family Support Officer) has given talks on 'Understanding HD' to staff in care facilities in Co. Waterford and Co. Tipperary.



## Thank You

## The Hospital Saturday Fund



Paul Jackson, Chief Executive, HSF, Ardmhéara Mícheál Mac Donncha, Patricia (HDAI) and Ms Lesley Garrett, HSF Patron

Twenty-nine Irish charities including HDAI received donations from the Hospital Saturday Fund at a special reception in Dublin recently. In total, €134,500 was donated to the medical charities and organisations at the event, which was hosted by Ardmhéara/Lord Mayor of Dublin, Mícheál Mac Donncha. HDAI was awarded a generous grant of €4,000 towards our newsletter and Hope Annual publications. Speaking at the reception, The Lord Mayor celebrated the extraordinary work of all the charities receiving donations from the Hospital Saturday Fund.

Paul Jackson, Chief Executive, Hospital Saturday Fund said:

*"We are delighted to continue the tradition of supporting many charities in Ireland, many of which are less well-known. The Hospital Saturday Fund is honoured to support the efforts of such deserving charities and help in some way towards the exceptional, tireless work that they do".*

In 2018 the Hospital Saturday Fund will give €1.4m in donations and grants to medical charities for care and research, hospices and hospitals across the UK and Ireland. Assistance will also be given to individuals whose illness or disability has caused financial difficulties.

## The Ireland Funds France

HDAI is sincerely grateful to the Ireland Fund of France for their recent extraordinary contribution of €30,000 towards our work. Special thanks to the IFF Board and President Helen Lambert (*below right pictured with Ambassador Byrne Nason*). This funding will be used to provide HD information seminars, increase awareness of HD, and collaborate with health professionals to improve services and promote research.



The Ireland Funds France held a dinner and auction in 2017 in support of research and treatment to aid those affected by HD. The event which benefited the HDAI and its partner organisation in France, l'Association Médicale Hendayaise pour les Maladies Rares (AMHMR) was held at the Cercle de l'Union Interalliée, a private club in Paris. Her Excellency Geraldine Bryne Nason, Ambassador of Ireland, Nicolas Levy, Professor of Human and Medicinal Genetics, and Dr. Brigitte Soudrie, Specialist in Rare Neurological Diseases spoke at the event. The auction, led by Pierre Mothes, Vice President of Sotheby's France, included a golf trip to Ireland and a painting donated by Eduardo Guelfenbein. Donations were also received from Louis Vuitton, Valentino, Dior, Christian Louboutin and many others.

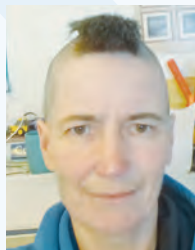
### Celbridge Craft Fair



Sincere thanks once again to Máire and Ido Cussen for creating and selling beautiful wollen handknits at the Celbridge Craft Fair.

Proceeds from the fair and the sale of their very cheerful HD snowmen raised a marvellous €1,045 for HDAI. They also sold €65 worth of HDAI Christmas cards. We are very grateful for your exceptional commitment and hard work.

### Mohawk for HD



A big Thank you to you Gail for raising €235 for HDAI.

*"Just a quick note about why I decided to fundraise for HD. I thought about ways to say thank you to a friend for the support and help that she had given me through a time of serious illness.*

*To say thanks for the times that she held on to me, and for the times that we laughed with each other. I also did it because I wanted to highlight Huntington's and that was simply it. As for the Mohawk well it was fun, cold because I picked the wrong time of year to do this. And while some did laugh at it and others gave out to me for it, it did allow me to highlight the seriousness of this illness. By the time this note is printed my hair will have grown back, my own regret is that I didn't raise more".*

### Beauty Salon Fundraiser



A big thank you to Yvonne and her colleagues and customers at Inner Beauty Salon in Gorey who raised

a marvellous €350 for HDAI last year.

### Christmas Cards

HDAI received wonderful support from members and friends supporting and selling cards.

These included: Ann Maher €408, Deirdre McInerney and colleagues at Mary Immaculate college €270, Ann Hannon and her friends at Maxol, Ballindine €152, Gurteen Post Office €160, Bernie Spellman €145, Angelina & Pat €152. If you have Christmas themed photos or paintings for our 2018 card designs we would be delighted to receive them.

### Recently Received Donations

- In memory of Antoinette Berridge - €100
- Pearse College, Clogher Road - €200
- DITA Eyewear Europe staff - €100
- Martina, Finnola and Zil monthly Direct Debit donations.
- Ger and Jacyntha - online donation
- Lock 13 Flanagan's Mill - thanks to Barry, Orla and Sergio for their HD collection of €93.
- John Kelly, Sunrise up Croagh Patrick €400

## MEMBERSHIP

2018 membership forms are enclosed and available online.

## Upcoming Events

### Light It Up 4HD

On May 14th to 18th buildings in Ireland including; Kerry County Council County Buildings, Killarney Municipal District Office, Town Hall, The Mansion House, Dublin City Council Civic Offices and Arás Chill Dara, Kildare Co Council will light up to raise awareness for HD. You can support this international #LightItUp4HD campaign by taking a photo or a selfie with a lit up building or by sharing images on social media. Contact [info@huntingtons.ie](mailto:info@huntingtons.ie) for more information.



### Dublin's VHI Women's Mini Marathon takes

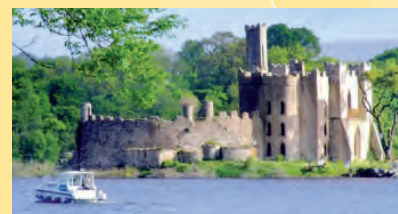
place on Sunday 3rd June at 2pm. Entries are now open <https://www.vhiwomensminimarathon.ie/>

If you would like to participate on behalf of HDAI we can provide t-shirts and sponsorship forms.

### Sunrise Up Croagh Patrick

This is an annual get-together of friends who climb Croagh Patrick to raise funds for charities supporting people affected by HD, Parkinson's Disease and MND. The event was initially organised by John Kelly and supported by his University classmates and work colleagues from Hanson Regan. This year's climb is on **30th June 2018** - for more information contact us on [info@huntingtons.ie](mailto:info@huntingtons.ie) and see <https://www.sunriseupcroaghpatrick.com/>

### Joe Doran's HD Awareness Walk, Lough Key - Sat 28th July



Enjoy the beautiful Lough Key Forest Park, Roscommon, while raising awareness and funds for HD. Suggested donation €5 per person or sponsorship cards available.

## HD ID Card

A free Huntington's ID card is available. Please send your photograph, address, phone number and an emergency contact person's phone number to the HDAI office and we will take it from there.

## Follow HDAI on Social Media

**Facebook:** [https://www.facebook.com/pages/Huntingtons-Disease-Association-of-Ireland/121707387897701?ref=br\\_tf](https://www.facebook.com/pages/Huntingtons-Disease-Association-of-Ireland/121707387897701?ref=br_tf)

Please Like our page.

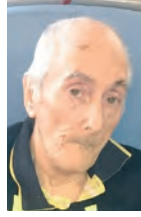
**Twitter:** @HDAI\_ie

**Thank you to our volunteers for their social media work.**

## Acknowledge Kindness

Do you know someone who deserves a special Thank You for their kindness and support? If so, please let us know.

## In Memory



**Tony Porter** died on 14th December 2017. He will be lovingly remembered by his wife Anna, daughters'

Jennifer and Yvonne and by his siblings and extended family. HDAI received €1,170 in memory of Tony. Our gratitude to Anna, Yvonne, Jennifer, family members, friends and neighbours.

**Tom Connern** died on 14th December 2017. Tom will be lovingly remembered by his wife Imelda, children Michael and Sharon, sisters Ann and Margaret and brother Paddy. HDAI received €110 in Tom's memory.

**Darren O'Reilly** - Our condolences and gratitude to Darren's parents Violet and Cecil, the extended O'Reilly family and their friends for donations of €230 in Darren's memory following his untimely death.

## HDAI and HDANI Joint Conference - September 29th - Save the Date



HDAI and HDANI, the HD Associations of Ireland and Northern Ireland plan to host a joint meeting in September in Newry.

The programme hasn't yet been finalised but we are delighted that Dr David Craufurd, Consultant in Neuropsychiatric Genetics at the Manchester Centre for Genomic Medicine (MCGM) and Professor Åsa Petersén, Professor in Neuroscience and Senior Consultant in Psychiatry, Lund University, Sweden have agreed to speak.

There will be dinner and entertainment on the night so if you are interested in staying at the hotel, please let us know.

## HD Cope

The European Huntington Association (EHA), Huntington's Disease Society of America (HDSA) and Huntington Society of Canada (HSC) have formed a Huntington's Disease Coalition for Patient Engagement (HD-COPE), a new global coalition to give families who are affected by HD a direct voice in HD clinical research.

Astri Arnesen, President EHA said,

*"Our voice matters and by uniting in a global coalition, we will make our voice stronger. I am convinced that contribution from HD-COPE will add value to all aspects of clinical research because we have a unique perspective and knowledge about HD".*



West Support Meeting Annual Lunch



Anne with Dr Ed Wild and Professor Sarah Tabrizi

HDAI are delighted that Anne Lennon Bird has joined as a representative from Ireland on the European patient advocacy team. Anne attended the first meeting in London in February where the group visited the HD Centre at UCL.



**Huntington's Disease Association of Ireland**

Carmichael Centre  
North Brunswick Street  
Dublin 7

Tel: 01 872 1303

FreeFone: 1800 393939

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

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



## HDAI Support Meetings

All those impacted by HD are welcome to join us at our Support Meetings in Cork, Dublin, Roscommon and Limerick. Our Family Support Officer or a HDAI representative will host the meetings. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information.

**DUBLIN**

May 5th  
Aug. 11th

**CORK**

July 30th  
Oct. 7th

**ROSCOMMON**

**Cuisle June 9th**  
(Carers Meeting)

**LIMERICK**

April 14th  
Oct. 13th