



2018

HDNL 2018 - Issue No 75, Q4 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**

## GENETICS

For information on Genetic testing, contact the Genetics Centre - Tel: **01 409 6739** and <http://www.olch.ie>

## SUPPORT MEETINGS

See dates on page 4

## ENROLL HD

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



## SAVE THE DATE



We are excited to announce that **Professor Sarah Tabrizi** will speak in Dublin on the evening of **Saturday April 13th** more information to follow.

Photo Courtesy of UCL

## THANK YOU

**Sincere thanks** to all who have volunteered, fundraised, donated, given grant assistance or participated in training or information seminars in 2018 to improve quality of life for people with HD. **We are very grateful.**



## HDAI and HDANI Joint Conference

HDAI and HDANI held a two day joint conference in September. Day 1 was dedicated to information and workshops for health and social care professionals working with people with HD. Professor Asa Petersén and Lauren Byrne spoke at the conference. Later they were joined by health professionals with HD expertise including: Muthu Thangaramanujam, Senior Physiotherapist, Dr Jennifer Hoblyn from Bloomfield Health Services, Dublin, Dr Seamus Kearney and Dr Peter Trimble, Belfast City Hospital for a panel discussion. Thanks to family members North and South who shared their expertise in afternoon workshops.

### Feedback included:

*"Liked link-up of neurology and psychiatry as it can be difficult to get psychiatric engagement with HD patients".*

*"I've a better understanding of HD and feel I could cope with managing the different aspects much better."*

The second day of the conference was dedicated to HD families and included presentations from HD professionals:



**Dr David Craufurd**, University of Manchester, Centre for Genomic Medicine, discussed **'Treatment for HD: where we are now, and where we might be going'**

Dr Craufurd is a senior lecturer and honorary consultant in neuropsychiatric genetics. He set up the UK's first multidisciplinary management clinic for HD. He is actively involved in a number of European and world-wide research projects and clinical trials.

Dr Craufurd mentioned the motor, cognitive and behavioural aspects of HD and noted that behavioural symptoms are often more distressing, and have greater impact on Quality of Life for both patients and carers.

He discussed factors which can influence irritability for instance:

- hunger
- fatigue

- frustration (e.g. clumsiness, communication)
- cognitive overload
- anxiety and depression
- impaired ability to defer gratification
- inability to anticipate consequences
- emotional blunting
- loss of inhibitory input

Dr Craufurd discussed the benefit of psychological support including education for family members and caregivers and a structured routine for the person with HD. He also discussed medication to treat irritability and depression in HD.

**Dr Niall Pender**, Principal Clinical Neuropsychologist and Head of Department of Psychology at Beaumont Hospital, Dublin discussed **'Coping with the emotional and cognitive challenges of HD'**



Dr Pender discussed the complexities of the human brain and reminded us that any normal human brain is susceptible to mistakes and forgetfulness. He cautioned against people

at risk mistaking everyday memory lapses for the onset of HD symptoms as this causes unnecessary anxiety. If you continue to be concerned and anxious, talk to your GP or to people you trust.

Dr Pender referred to *'the vicious cycle of neurological illness'* where a combination of movement, thinking and mood changes can cause a person to withdraw from activities thus increasing stress and disability. Cognitive skills affected by HD can have a significant impact on education, occupation and day to day life. The most commonly reported changes are in attention, concentration and memory. People may also experience difficulties with planning, problem solving, mental flexibility and thinking speed. Chronic illness management models use disease modifying measures to minimise the effects of the condition allowing a person to maintain their quality of life for as long as possible.

How we manage our memory, daily routine, our sleep and anxiety can all help to keep us well and independent for as long as possible.

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### Important factors to consider when working with cognitive difficulties:

- Avoid overload and reduce distractions - one task at a time
- Little and Often - small amounts done frequently rather than lots done at once
- Routine - space tasks into a regular routine
- Slow down - don't jump in - wait for a person to respond
- People with HD fatigue easily - take rests
- Use memory aids: calendars, diaries, smart phones and making paper lists to assist memory (this doesn't make your brain lazy)
- Everyone is different- symptoms can vary a lot between people - each person needs an individualised plan.

Concentrating and spending a little more time doing something can help a lot. Self-management involves taking control of the way you think and feel about HD and how you cope in everyday life. It's about taking an active, rather than a passive, role in the management of your condition. Relaxation and mindfulness helps to reduce stress and anxiety. Linking-in with a multi-disciplinary team to help manage symptoms is very important.

- Seek Information - Understanding your condition;
- Identify stress, anxiety and fatigue and learn strategies to cope - Mindfulness, relaxation, (abdominal breathing, progressive muscle relaxation);
- Cognitive assessment;
- Medication review;
- Self care: Healthy diet, minimise alcohol (it can magnify cognitive difficulties and irritability), avoid smoking, exercise for fitness and well-being, sleep well and adopt good sleep practices;
- Psychotherapy to address adjustment issues such as low self-esteem, social isolation, grief and lack of independence.

### Helpful resources online include:

The Mindfulness and Relaxation Centre at Beaumont Hospital: <http://www.beaumont.ie/marc>

Mental Health Ireland: <https://www.mentalhealthireland.ie/what-we-do/>

The NHS also has useful resources such as Sheffield Improving Access to Psychological Therapies: <http://iapt.sheffield.shsc.nhs.uk/>

The physical and emotional burden of coping with a loved one's illness can be a significant challenge for caregivers. It is important to have systems in place to protect and support caregivers. Dr Pender hopes to work with HDAI and colleagues at Beaumont to develop projects which focus on supporting caregivers. He urged care givers who are struggling to reach out and seek support.

### Enroll-HD

Dr Pender established an Enroll-HD site in Beaumont Hospital in 2015 which is the only site in Ireland. The Enroll-HD team at Beaumont is expanding slowly and 37 people have now registered (Sept 18) with some participants having completed four annual visits. People from NI can also participate in the Beaumont site. See: <https://www.enroll-hd.org>

Lauren Byrne gave a very informative talk on **'Fighting Public Enemies #1 and #2'**. Lauren is a research fellow and PhD student to Dr Ed Wild at UCL Institute of Neurology in London. She is working on developing biomarkers that can be used to track disease onset and progression in the blood and spinal fluid of patients with HD. Her recent work on a blood test known as neurofilament light (NFL) was published in 2017 in the prestigious journal, *The Lancet Neurology*. Lauren is also a member of a HD family in Northern Ireland.



Lauren referred to the HD gene as public enemy #1 and gave a summary of the advances in HD research to date. Over 12,000 family members and 58 scientists contributed to finding the HD gene and the ethos of collaboration continues to this day. Mouse models have shown that interventions work in slowing the disease. The Huntington's Disease Clinical Trials Corner in the *Journal of Huntington's Disease* <https://www.ncbi.nlm.nih.gov/pmc/articles> provides a summary.

She discussed the ASO gene lowering Ionis HTRx drug designed to bind to the huntingtin message to change the disease progression. Following the success of the initial trial, Roche Pharmaceuticals are planning a study (GENERATION-HD1) to test the long term efficacy and safety of the drug now called RG6042. During her talk, Lauren shared a short video clip from Dr Ed Wild, who outlined the importance of this trial to show that the progression of HD can be altered. Using the *'if it bleeds we can kill it'* line from the film *Predator* he stresses the huge victory of knowing the disease can be altered.

Lauren considers public enemy #2 to be the silence around HD. She spoke about the secrecy and stigma surrounding HD historically and the current day difficulties in talking about the illness and seeking support. The last 25 years have seen positive developments in research and awareness with the establishment of networks such as CHDI, EHDN and the development of HD studies such as Enroll-HD, Track HD etc. Technological advances in brain scans, blood tests, lumbar punctures, thinking tests and genetic studies can help to detect changes earlier so that people can potentially have access to treatments before the onset of symptoms. HD Buzz is an excellent research news resource and HDYO is of huge benefit to young people from HD families. Lauren attended the **HDddenNoMore** Papal audience for HD last year and found it an amazing experience. To conclude, Lauren thanked all the HD Research Heroes who have taken part in trials.

**Professor Asa Petersén** discussed Research on non-motor aspects of Huntington disease.

Professor Petersén is Professor of Neuroscience and runs a HD research Laboratory at Lund University, Sweden. She is also Senior Consultant in Psychiatry and leads a weekly HD multi-disciplinary clinic at the University Hospital in Lund, with psychiatry, neurology, neuropsychology, nurse, social worker,

occupational therapist, physiotherapist, speech therapist, dietician, clinical geneticist and genetic counsellor input. Professor Petersén has been involved in HD research for over 20 years and has worked as a HD clinician for 10 years. She is now working with colleagues to develop a HD centre of expertise to progress research, run clinical trials and become a national reference centre.



Professor Petersén (left), with Mary and Anne

By understanding neurobiological mechanisms, new targets for therapeutic interventions may be found. Depression, apathy, irritability and anxiety are common and difficult symptoms in HD. Sleep problems and changes to circadian rhythm can be a feature of HD; causing anxiety, lack of concentration, irritability and forgetfulness. Studies in HD mice have revealed that a good sleep can slow disease progression. This demonstrates the benefit of treating sleep problems for people with, or at risk, of HD. Changes to certain areas of the brain cause physical and cognitive symptoms but less is known about what causes psychiatric symptoms and sleep and metabolic disturbances. The hypothalamus controls emotion, sleep and metabolism and this is the area of the brain Professor Petersén's laboratory is interested in studying further.

One study in the Lund lab used HD mice models to study depression by comparing the mice to their siblings who do not have the gene. Studies show a lack of Oxytocin in the hypothalamus causes depression but when the HD mice are given Oxytocin it ameliorates their symptoms. These studies can potentially reveal targets for novel therapies. Professor Petersén joined family members for dinner on Saturday evening. We are very grateful to her for her time and expertise over the weekend.

**Recordings of all the presentations are available on HDAI's YouTube Channel (Huntington's Ireland)**

In the late afternoon, **Deirdre Shanagher**, Irish Hospice Foundation, delivered a workshop on *'Planning ahead with a neurological condition'* and Siobhan Harding Lester, Genetic Counsellor, Belfast, delivered a workshop on Genetic Testing. Family members had a chance to meet or catch up over dinner on Saturday night. It was a pleasure to work with our colleagues at HDANI in putting this conference together and we look forward to hosting joint events in the future.

**Meeting with Minister Daly**

HDAI are very grateful to Jim Daly, Minister of State at the Department of Health with special responsibility for Mental Health and Older People, who met representatives of HDAI together with Dr Niall Pender in November. Issues discussed included the need for a dedicated HD multi-disciplinary clinic, improved access to psychiatric and psychological services, home care supports and access to appropriate MDT care services.

## Fundraising - Thank You

### Wild Atlantic Mizen Cycle

HDAI was one of 6 charities chosen to benefit from the 2018 Wild Atlantic Mizen Cycle held on July 14th, with over 500 cyclists taking part. The Cycle, now in its 16th year, is organised by the West Cork Emergency Services & Friends, primarily made up of members of An Garda Síochána, Cork County Fire Service, HSE Ambulance Service, West Cork Civil Defence, The Red Cross and The Irish Coastguard. HDAI received €3,000 towards supporting families impacted by Huntington's Disease in Cork.



Nuala O'Brien very kindly attended the event presentation in The Bantry Bay hotel in September on behalf of HDAI. Thanks you to Cormac Daly and all the organisation team, to the event sponsors and to all those who volunteered to make this spectacular event a great success.

### Crookhaven Pub Quiz

Thanks so much to Dawn Little, Claire Barrett and to all who helped organise a very successful Pub Quiz in the Crookhaven Inn in West Cork recently. The event raised a marvellous €1610 for HDAI.

### Mount Joy Garda Station

Colleagues and friends of the late Sergeant Padraig Moran at Mount Joy Garda Station held a coffee morning in his memory. The event, held in the Station canteen in October, was very well supported by Garda from all over Dublin who knew and worked with Padraig during his service.



Thank you to Inspector Mick Mulligan, Sergeant Catherine Curtin, Garda Sonya Deane and Inspector John Egan for organising this event which raised €1,110. A huge thank you also to Padraig's wife Fiona (centre) for all her help in raising awareness & funds in support of families with HD.

### Casual Day, Raffle and Cake Sale at Dunnes Stores

A very big Thank You to everyone at Dunnes Stores Head Office who baked cakes, organised a raffle and supported the Casual Friday on October 19th to raise €2,975 for HDAI. The association is indebted to Martina O'Reilly and her family, friends and colleagues for all the wonderful support given in recent years.

## Celbridge Craft Fair



Íde, Máire, Oisín and friends once again held a very successful 'Handknits for Huntington's Disease' stall at the Celbridge Craft Fair on 24th and 25th November. Their highly sought after HD Snowmen are also on sale in shops in Celbridge (Walsh's Pharmacy) and Maynooth (The Elite Bakery).

### Charity Tea Dance

Della's Benefit Tea Dance for HD took place on Monday 29th October at the Ard Ri House Hotel, Tuam. The event raised a fantastic €1,920 for HDAI thanks to the wonderful support of Ann Hannon and her family, friends and neighbours.



Della and her brother Val (front right and left) presented a cheque to Ann, Margaret, Cathleen and their family and friends in November.

### Half Marathon



Huge thanks to Josie Leavy who participated in yet another marathon to raise €695 for Huntington's Disease. Josie is pictured with her friend Kathleen Keogh.

### Christmas Cards

A big Thank You to all who have bought and helped to sell HDAI's cards this year. So far proceeds from our sellers include: Angelina and Pat €65, Mary at Gurteen Post Office €160, Cecil €48, Mark €50, Cork Support Meeting €146, Dublin Support Meeting €175, Íde €56, Deirdre, Mary Immaculate College €184.

### Recently received donations

- Ger & Jacyntha, Martina, Finnola and Zil's monthly Direct Debit donations.
- Communications Workers Union Dublin Postal Amalgamated Branch - Donation of €250 from the late Christy Clarke's former colleagues
- Patrick & Teresa O'Sullivan €1,000.
- Pearse College Porter's Cabin €23.46
- John Moore €500
- Flanagan's Mill €83
- Myles O'Toole Boys Club €500
- Seamus €1,000
- Sylvia Vincent €50 - In memory of Tony

## UPCOMING EVENTS

### Fairyhouse Race Day



HDAI in collaboration with Fairyhouse Racecourse, will hold a fundraising event on **Sunday 7th April, 2019**. A table for ten people will include:

- Admission Tickets and a Race card for each guest
- 4 Course Meal
- Pre-race celebrity tipster
- Designated area with access to the Stand

If you know any racing fans, or if you have contacts in companies who may like to sponsor a table, please contact us for further information.

### HD Charity Walk - Clare

**Toonagh, Co. Clare.  
Sunday 13th January 2019.**

Registration 11am at Toonagh Hall situated 8km from Ennis on Corofin Road near The Burren. Adults €10, children free. Refreshments and treats afterwards.



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## In Memory



**Margaret O'Brien** was born on the 12th of July 1945 and sadly passed away on the 7th of July 2018 at home with her loving husband Paddy and six kids Patrick, Micheal, James, Lisa, Daniel and Nuala. Love and miss you always mom xxx



**Jacinta Grant** died 13th Sept. at the age of 39 years. Jacinta was a funny, unique and brave young girl who was strong and coped with her illness so courageously. She will be sadly missed. Jacinta's family and friends donated €300 to HDAI in her memory.



**Theresa Kelly** died on 17th September surrounded by her loving family. She was a great wife, mother and grandmother and will be sadly missed. Theresa's family and friends donated €300 to HDAI in her memory.



**Acknowledge Kindness** - Please send a bouquet of flowers to **Helena, the Activities Coordinator at the Fairview Community Unit** where Michael is a patient. Helena is totally dedicated to all her patients and is a pure angel with all the love and attention she shows to all. May her energy be endless. Many thanks to Helena from **Bernie, Michael, Kevin and Oisin**.

Some photos below from our Annual Support Meeting Lunches in Dublin, Cork and Roscommon. The Limerick lunch will take place on 12th January 2019. Joint Conference in Newry (bottom).



## HDAI Support Meetings



### DUBLIN

Feb. 2nd  
May 4th

### CORK

Mar. 23rd  
Jul. 27th

### WEST

Feb. 16th  
Jun. 8th (Cuisle)

### LIMERICK

Jan. 12th  
Apr. 13th

*Dates subject to change - contact HDAI for confirmation and location*