



HDNL 2015 - Issue No 62, Q2 15

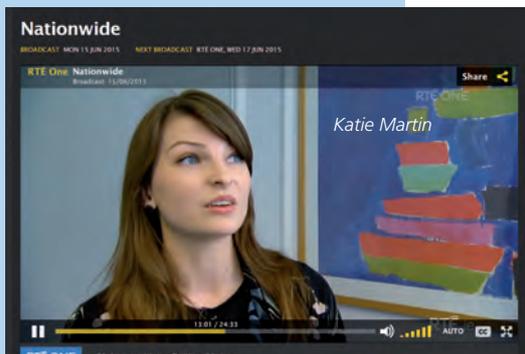
NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

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## Enroll-HD featured on RTE's Nationwide

Reporter Valerie Waters interviewed Dr. Niall Pender, Principal Clinical Neuropsychologist and Head of Department of Psychology, Beaumont Hospital, together with family members Christy Clarke and Anne O'Shea Clarke, Katie Martin and Sean Lennon, as part of Nationwide's Enroll-HD feature on June 15th 2015.

Dr. Pender gave a brief overview of HD and the symptoms it causes. He explained that Enroll-HD is a worldwide observational research study that aims to involve as many people from HD families as possible with a view to making better treatments available. During study visits participants will undergo a neurological assessment and simple tests on thinking and questions on mood, methods of coping and family history. A participant has the option of donating a blood sample for genetic analysis (the sample is for research purposes only and is NEVER reported back to the site or to the participant).

Christy and Anne portrayed the impact of HD on their lives. Christy was diagnosed with HD in 2004. Anne pointed out the range of rehabilitation services necessary and the importance of accessing services when symptoms first start. She mentioned the benefit of having a reliable home care service and a very supportive family.

Katie discussed the significance of HDAI's support in assisting her to connect with other young people. Katie's mother has been living with HD since Katie was very young and she is now in nursing home care. Although many people in her family have had HD, Katie stressed that it can be very different from one family member to another and therefore she relies on HDAI's Information and Support service.

Sean spoke about the difficulty in seeing his Dad's health slowly decline throughout his childhood and teenage years. Family and friends remind Sean of the strong capable man his Dad was and that he never complained despite his illness. Sean and his

family use this as their inspiration to remain as positive as possible when coping with the impact of HD on their lives.

You can email [enrollhd@beaumont.ie](mailto:enrollhd@beaumont.ie) to register your interest or seek further information. Information is also available on HDAI's website [www.huntingtons.ie](http://www.huntingtons.ie)

HDAI rely on family members vital advocacy work to raise awareness and greater understanding of HD. If you are interested in advocating for the HD community please let us know.

## Members Meeting and Respite Weekend

HDAI's Annual General Meeting took place on June 6th at the Irish Wheelchair Association Respite Centre, Cuisle, Co Roscommon. HDAI's 2014 Annual Report and Financial Statements were presented to members. The AGM was held in conjunction with an annual Members Information Meeting and respite weekend (5th-7th June).

### Dr. Jennifer Hoblyn - HD research

Dr. Jennifer Hoblyn, Clinical Director of Bloomfield Health Services, and Clinical Senior Lecturer at the Department of Psychiatry, Trinity College Dublin, delivered a very interesting seminar on the clinical features of Huntington's Disease, current treatments available and an update on research developments.



HD is caused by the presence of the huntingtin gene that codes for Huntingtin protein both wild type (normal) and mutant type. The mutation is caused by an expanded CAG repeat on exon 1 on the HTT gene. The accumulation of abnormal mutated protein interferes with normal production of other proteins causing these nerve cells to malfunction.

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## 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](http://www.genetics.ie)

## OLD MOBILES?

Have you any old mobile phones? If so, please send them to us. If we recycle them we will get much needed funds. Please email [info@huntingtons.ie](mailto:info@huntingtons.ie) or phone 1800 393939 for more information.

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The loss of these neurons (particularly medium spiny nerves), leads to the development of the symptoms of HD.

Potential therapies under investigation include various gene therapies to: reduce the amount of mutated huntingtin protein; to target and degrade mutant protein; to prevent misfolding, to identify gene protein interaction networks that may lead to the discovery of disease modifiers and points of intervention; identify other potential genetic modifiers and identify neuroprotective molecules. Gene Silencing refers to the shutting off of the instructions for a specific protein being made in the cell. Other research of interest includes investigating stem cells as a delivery agent for potential treatments and studies to address dopamine imbalance in neurodegenerative conditions. Dr Hoblyn also discussed environmental modifiers and referred to animal studies suggesting that an enriched environment and active lifestyle can delay the onset of Huntington's disease. Rehabilitation can also improve motor function and quality of life for people with HD. (Frich et al, 2014)

Dr Hoblyn and some of her colleagues at Bloomfield Health Services attended the 2014 European Huntington's Disease Network (EHDN) Conference in Barcelona last September and were impressed to see that there were over 900 delegates at the conference interested in collaborating on HD research and developing standards of care. Members of the Bloomfield Health Service team have joined EHDN working groups.

Bloomfield Health Services is an independent not for profit healthcare provider in Rathfarnham Dublin 16. Bloomfield Hospital's approved psychiatric centre has 114 continuing care beds. Their multidisciplinary care team includes: Psychiatry, Medicine, Psychology, Pharmacy, Physiotherapy, Social Work, Occupational therapy, Nursing Staff, Nutrition, Optician, Chiropodist and access to SALT and Palliative Medicine. Their HD service includes a Nurse Specialist for HD, a HD Assessment Clinic, a 16 week MDT assessment program and caregiver support and educational workshops.

Dr Hoblyn reminded attendees that there are significant reasons for hope for the HD community because: the cause of HD is known; targets for interventions have been identified; a predictive test can identify presymptomatic individuals; there is intense scientific activity and insights gained from other neurodegenerative conditions and there is an active organised receptive HD community. Dr Hoblyn also mentioned the advantage of having Enroll-HD sites in Ireland and encouraged those present to participate in research if possible. She reminded people of the need to "Speak up and Be Heard" to advocate for services and fundraise if possible to help develop better services.

## David Flood - Enroll-HD

David Flood, Huntington's Disease Youth Organisation (HDYO) Ireland Representative gave a presentation on Enroll-HD. The presentation included information on:

### How will Enroll-HD help the HD research community

- Develop better, smarter clinical trials,
- Promote and facilitate the recruitment of clinical trial participants,
- Provide clinical data and biologic samples to help better understand the human biology of HD,
- Determine what interventions work to improve the care of people with HD.

### What happens to Data

- All data and bio-samples will be available to researchers for research purposes,
- All data is coded - your name and no other information that can identify you is associated with the data,
- You get a nine digit number (HDID),
- All data that is shared (including bio-samples) are re-coded and cannot be traced to you,
- Computer systems and data storage are protected.

for further information see [www.enroll-hd.org](http://www.enroll-hd.org)

Liz, HDAl family Support Officer, facilitated a Carers workshop on Saturday morning which was attended by 19 people.

*"The feedback I receive from facilitating these meetings is always so positive, people feel understood and most importantly not alone. Thanks to all of you who make this such a special space" - Liz*



Reflexology, chiropody and massage therapies were available on Saturday. Sixty four people attended on Saturday with the majority staying over. Attendees enjoyed dinner together on Saturday evening and lively music later. Later again, David and Frederike encouraged a very enjoyable singsong. As always the Cuisle team were brilliant.

*"I really enjoyed the weekend and hope to be there next year also" - Joe*

*"I was very nervous coming along for the first time but from the moment I met other people I felt relaxed and at ease. Everyone is so welcoming and kind and it is so great to meet others who understand your story. I never felt alone. Thank you." - Susan*

## SSNO Funding

HDAI welcomes the recent government decision to extend Scheme to Support National Organisations (SSNO) funding to June 2016 for HDAI and other neurological and disability charities who faced funding cuts from July 2015.



As part of The Claire Byrne Show's feature on equality on 25th May 2015, the reliance of disability support groups on the SSNO funding was discussed.

Audience member Michelle O'Reilly outlined the difficulty her family faced when her husband Dirk was diagnosed with HD. Due to symptom onset he could no longer continue in employment and Michelle eventually had to leave her own career to care for Dirk and their two children. She referred to the importance of HDAI's information and support service which relies on SSNO funding to assist families such as hers.

Member of the Show's panel, Minister for Equality Aodhan O'Riordain announced that the SSNO scheme would continue for the 23 disability groups impacted until June 2016. Also on the panel, Journalist Fintan O'Toole highlighted the stress caused to those in need of support and stated that a long term solution was necessary.

The Disability Federation of Ireland (DFI) and the Neurological Alliance of Ireland (NAL) have called for an extension of the bridging scheme to the end of December 2016, along with a commitment to implement a disability inclusion funding scheme commencing January 2017. Commenting on the lack of security for the groups Mags Rogers, Development Manager, NAL stated,

*"Charities have been sidelined into spending significant time and effort in seeking to have the funding extended, time that should have been available to concentrate on supporting people with neurological conditions and their families".*

The funding has only been extended to June 2016 which means that the charities concerned once again face an uncertain future with no guarantee of support for people with neurological conditions after June 2016.

## Fundraising

### Dublin Women's Mini Marathon

A big Thank you to Yvette and friends who participated in the 2015 Dublin Mini Marathon on behalf of HDAI and have raised over €360.



left to right: Lynne Mayo, Amy Cramer, Yvette Murphy and Vanessa Clarke



Carol Lee raised a phenomenal €1,250 and great awareness for Huntington's Disease among family and friends and on social media. Sincere thanks to Carol and to all those who supported her. Carol would like to

specifically thank her mother Christine Lee and her cousin Pauline Doran for their assistance.

*"This charity is extremely close to my heart. Huntington's has impacted the lives of the most amazing family I know. Together they have endured so much but they have remained strong and close. ... Their strength is unbelievable."*

### Hell & Back Challenge

Muireann O'Miachain and 24 friends from her local gym completed the The Hell and Back challenge in Wicklow in June. Muireann works with people impacted by HD and suggested HDAI as one of the beneficiary charities for this event.



Bridget Colgan Dempsey and Muireann O'Miachain (right)

### Sandy Cove Vintage & Classics

Thank you to Sandy Cove Vintage & Classics Charity Shop, Sandy Cove, Co. Dublin for their contribution of €300 to HDAI. The shop nominated HDAI as their chosen charity in March and April 2015. Thanks to Ita, and Monica and to Catherine Paradise for her support. We are very grateful to all who donated items to the shop.

### Birthday Fundraiser

Bridie O'Shea (right) is presented with flowers from her daughter Anne (left) for her 60th birthday.



Bridie very generously organised a fundraising event in Bulgadden Castle, Kilmallock, Co Limerick for HDAI on her birthday weekend. She was joined by family and friends on the night. Thanks to Bridie and all the O'Shea family for their support in raising a marvellous €1,314 for HDAI.

### Hand Knits

Thank you to Mary and Ide Cussen for their ongoing support and awareness raising. Mary continues to knit for HDAI throughout the year and recently sent HDAI €120 from contributions received.

### Tuam Tea Dance

Ann Hannon and friends organised their 2015 Charity Tea Dance in the Ard Ri hotel, Tuam on St Patrick's Day. HDAI are very grateful to Ann and her family and friends for their great support and commitment. Thanks to everyone who sold tickets and donated prizes and to those who attended. Thanks also to Della and her team for their support in organising this event.



(Back, L to R): Tom McHugh proprietor Ard Ri Hotel, Paddy Connern, Joe Hannon, Della Dolan. (Front): Joe Mangan, Ann Hannon, Margaret Mangan and Cathleen Connern.

### Kilmallock, Limerick Charity Cycle

Limerick cycling enthusiasts Caroline Wallace and Will Whelan, have very generously volunteered to organise a charity cycle in aid of HDAI on **13th September 2015**. Contact HDAI for more information.

### Joe's Walk

Last year Joe Doran climbed Croagh Patrick to raise awareness and funds for HDAI.



This year Joe has chosen another scenic location and has planned a HDAI Charity Walk in Lough Key, Forest Park, Boyle, Co Roscommon. On July 18th Joe and friends will walk 5km starting at 11.00am from the Visitor Centre. Please come along and show your support. <http://www.loughkey.ie/>



**Please consider raising funds for HDAI if you are taking part in the 2015 Dublin City Marathon on October 26th.**

### Dublin Rotary Club

Dublin Rotary Club raised a marvellous €2,250 for HDAI. Pictured (l to r): Geraldine Grant, Patricia, HDAI, Dublin Rotary Club President Tom O'Neill and his wife Maura.



Firhouse Community College Rotary Interact Club also raised €136.96 for HDAI. This support and awareness raising is very much appreciated by HDAI.

### Donations & Membership

HDAI is very grateful to members and friends for their very generous support in Quarter 2 2015, they include: Martina and Finnola for their monthly Direct Debit donations; George, Pauline, Christina, Susan, Vera and Josie for their recent donations. HDAI have received €2,485 for 2015 membership contributions. Thank you to all who have returned their membership forms.

### Respite Weekend Raffle & Donations

HDAI received donations of €300 at Cuisle and €412 was generated from the raffle. Thank you to Marks & Spencers for their very generous €80 gift voucher. Thanks also to those attendees at Cuisle who contributed great raffle prizes.

## In Memory



**Elish O'Connell** passed away on 7th June at 56 years old. She was surrounded by her family and loved ones.

Sincere condolences to her daughter Beccy, partner Darren and their son Jack; Elish's son Duncan and her sister Sue and family. Elish lived in a nursing home in Bedfordshire for the past 8 years.



**Nessa McInerney** Nessa McInerney died on 7th May 2015, aged 55. She will be lovingly

remembered by her sister Deirdre, brother Brian, sister-in-law Diane, nephew Ian, niece Ciara and her aunts and uncles. The family are grateful to Nessa's neighbours, friends and carers for their kindness, friendship and support and especially to the staff at the Irish Wheelchair Association who looked after Nessa with such love and friendship. 'Sleep well our princess'



**Jimmy Maher** died suddenly of cancer on April 12. He had courageously lived with HD in recent years. He

was a much loved husband, father, grandfather and great grandfather. He is sadly missed by his family and friends.

The articles which appear in this newsletter may not necessarily represent the views of HDAI.



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## Better Health, Better Living at Beaumont Hospital

Beaumont Hospital (Department of Psychology and Gastroenterology) has launched a staff and patient led Chronic Disease Self-Management Programme (CDSMP) called Better Health, Better Living. The CDSMP was originally developed at Stanford University in California, USA, and has international research to show it works for people around the world. The Better Health, Better Living programme is designed to help people learn ways of managing many of the symptoms that are common to on-going health conditions. It can help you develop the skills you need to become an active self manager of your condition.

*Topics covered include:*

Managing pain, fatigue and difficult emotions, nutrition and exercise, communicating effectively with your family, friends and health care team, problem solving and decision making, how to set manageable goals, and managing your medications. The programme is facilitated by two trained supervised leaders, one of whom has a chronic condition themselves; the other being a health care practitioner. All of the leaders understand the challenges of living with on-going conditions and many use the very same health management techniques you'll learn during this programme to cope with on-going health conditions.



Any patient of Beaumont Hospital with a chronic health condition is welcome to attend this programme. During six 2.5 hour weekly sessions you will meet with 10-12 other patients, and have the opportunity to share your experiences with each other if you feel comfortable doing so.

*Previous participants of the programme have reported the following benefits:*

Increased knowledge about self-managing their condition, increased self confidence, decreased pain and decreased depression. The Better Health Better Living programme is a practical series of classes that teaches new skills -many people find it supportive but it is not therapy.

Beaumont Hospital has been running this programme for a number of different health conditions with a great deal of success. People worldwide have found it helpful for the following conditions: Epilepsy, Depression, Parkinson's disease, Cancer, Arthritis, Stroke and many other conditions.

*"The most important thing that I have accomplished in the group is learning to speak more openly about my condition. Previously I would not have spoken openly about the level of pain or discomfort that I suffer...The other thing I learned was to set achievable targets or goals for the week ahead...Once you have reached your target there is a great sense of accomplishment and pride"*

### Post programme participant

Beaumont Hospital Better Health, Better Living team plans to continue to run groups in Beaumont Hospital and have also begun running groups in community centres in the greater Beaumont area.

For further information regarding the CDSMP please contact Ms. Mary Forry at [maryforry@beaumont.ie](mailto:maryforry@beaumont.ie) or Dr. Jennifer Wilson O'Raghallaigh at [jenniferwilsonoraghallaigh@beaumont.ie](mailto:jenniferwilsonoraghallaigh@beaumont.ie) or check out the research at [www.patienteducation.stanford.edu](http://www.patienteducation.stanford.edu).



## Hope Annual Launch

This year Frankie (featured on page 8 of Hope Annual), launched the 2015 Hope Annual and encouraged others to get writing for next years edition.

## Information on HD



The HDAI Booklet, *Facing Huntington's Disease: A handbook for families and friends*, together with the handbooks: *The Caregivers Handbook*, *Physicians Guide* and *Understanding Behaviour* Information booklets are

available on our website or you can contact the office for a hard copy.

## Standards of Care for HD

The Euro HD Network working groups, are working on guidelines for Standards of Care for HD. These are available from our website <http://www.huntingtons.ie/content/information-0>

## 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)

**Twitter:** @HDAI\_ie

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

## HDAI Coffee Mornings/Support Meetings

**DUBLIN**

Aug 8th  
Nov 7th

**CORK**

Jul 4th  
Oct 3rd

**LONGFORD**

Oct 17th

**LIMERICK**

Nov 21st

**MAYO**

Dec 12th