



HDNL 2011 - Issue No 46, Q2 11

NEWSLETTER OF THE HUNTINGTON'S  
DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

CHECK OUT OUR  
UPDATED WEB SITE

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

SUPPORT MEETINGS

See dates on page 4

GENETICS

The National Centre for Medical Genetics holds genetic clinics in Dublin, Cork, Galway and Limerick. Contact details - 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 [hdai@indigo.ie](mailto:hdai@indigo.ie) or phone 1800 393939 for more information.

YOUR NEWSLETTER

Please send us your views

SHARE YOUR SKILLS

If you have time and energy to contribute, or if you know of a friend or family member who has, please consider joining our committee. All queries welcome.

## CYCLE FOR HD

HD Alliance are organising a

### LONDON TO PARIS FUNDRAISING CYCLE

for 26th - 30th September 2012

If you are a keen cyclist wanting to have a Tour de France adventure while raising funds for HDAI please contact us for more information.

## Huntington's Disease featured on Primetime Investigates



Primetime Investigates 30th May 2011 featured the effects of health cuts on a number of people waiting for treatment and / or care. Rosemary and Michael courageously told their story to help create awareness for HD. Rosemary is determined to secure adequate home care so that Michael can remain at home despite the progression of his condition. HDAI received positive feedback as a result of this feature including:

*I just want to complement you on the prime time programme last night. Rosemary & Michael were brilliant & very brave to tell their story - Ann*



Denis thanking Rosemary at our Members meeting in Cuisle

*Thank you to you and all at HDAI for the excellent contribution to the Prime Time Investigates programme aired last night. Please say thank you to the Higgins family for their brave contribution too - Elizabeth*

*Families affected by motor neurone disease, acquired brain injury and Huntingtons Disease who appeared on the programme were outstanding in their dignity, their ability to communicate their issues and their perseverance in the face of incredibly difficult circumstances - Mags*

*Just want to say I think you did a great job on the programme last night. It was great to get the publicity for the association - Niall*

*So glad to see the issue of HD get a platform. It is utterly heartbreaking and we know it's only the tip of the iceberg - Avril*

*A really good programme, very well put together - Anne*

*Primetime programme last night was powerful, well done - Pat*

## Members Meeting & AGM - June 12th 2011

Our AGM, Members Meeting and Respite weekend took place on weekend of June 10th - 12th in Cuisle Respite Centre, Co. Roscommon. 55 people attended with the majority enjoying the weekend at Cuisle Respite Centre.

The AGM took place at 1pm on Saturday. Denis Ryan, HDAI Chairperson welcomed all in attendance and reported on HDAI's activities over the year. HDAI's 2010 Review and Financial Statements were distributed to members. Pat Griffin our Treasurer presented HDAI's financial statements and outlined cuts from statutory funding. He thanked those who fundraised throughout the year for their vital support. Pat mentioned the marvellous contribution from Corporal John Carroll and also thanked our regular fundraisers: Ann, Phil, Geraldine, Josie and others who are outstanding in their support.

Our 2010 annual audited accounts were approved and D.F. Byrne was appointed as Auditor for the coming year. The existing board members resigned and were re-elected for 2011 in addition to Bernie from Tipperary. Denis reminded members that if they wished to find out more about the work of the committee they are welcome to contact the office for more information. Copies of our annual accounts and Chairpersons report are available from the office.

Complementary relaxation, chiropody, reflexology and massage therapies were enjoyed by members again this year. Some attendees very eagerly tested the recently added Jacuzzi facilities at Cuisle. Many people with HD and their family members availed of a relaxing neck and shoulder massage from Eileen and Alice.

Jenny once again very kindly provided chiropody to people free of charge. Lots of "massage was fabulous" comments from grateful participants.

Liz held a carers workshop which was very well attended. She asked those present to contact her through the office if they felt in need of individual support.

Our raffle raised €206 towards the cost of the weekend. HDAI are grateful to all who bought tickets and to all who provided prizes for the raffle.



Ann (right) wins 1st prize in our raffle

Thanks to Josie who volunteered her expert photography services in between her love of the dance floor. Jacinta very generously entertained many members at Cuisle by reading Tarot cards on Saturday evening. There was a long queue of mostly ladies wanting to have their cards read. Anne nominated Jacinta for an Acknowledging Kindness bunch of flowers.

Most of our members enjoyed a dance or two while PJ and Margaret Reid provided us with lively tunes and great entertainment. As usual the socialising lasted until the early hours!

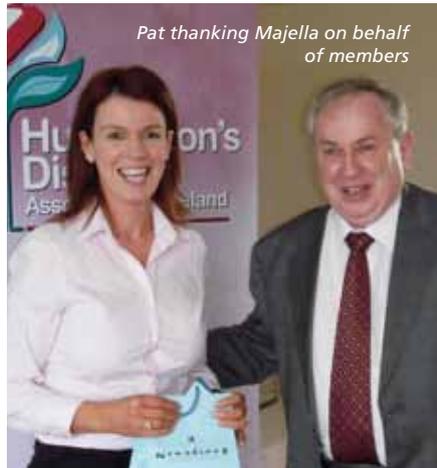


The team at Cuisle provided us with an excellent service again this year and we are always grateful for their kindness, flexibility and help. In particular thanks to Ailish, Duty Care Managers Mary and Geraldine and Drivers Clive, Bill and Tony.

One member summed up the weekend by saying "It's a great **freedom** weekend. My husband (who has HD) loves to come as it is the only place he can truly enjoy a dance. Thank you to the Association"

**Majella McConville**, Huntington's Disease Specialist Nurse, Northern Ireland gave an inspirational account of her work at our Members Meeting. Majella has worked for over 5 years with people with HD and their families across Northern Ireland. Majella complemented Dr Patrick Morrison Consultant Geneticist who

saw the need for HD Nurse specialists in Northern Ireland and undertook a needs assessment in 2004 to highlight this need. Majella is based at Belfast City Hospital and works with various multi-disciplinary teams across Northern Ireland.



Majella spoke about her work and the need to overcome barriers in accessing services for people with HD. She gave some examples of people living in denial who are afraid to seek medical or social services for fear of losing control of their own lives. Sometimes it may be because they have had a bad experience when dealing with other health professionals.

With the correct approach from health professionals people can have greater control over their own lives and have a good quality of life despite HD. Majella acts as an advocate for many people affected by HD who may be unable to initiate access to the services they need. She also works with other health professionals to ensure people get the assessments and services they need

She provides educational talks to staff in nursing homes and offers tips on overcoming behavioural problems related to HD but in particular she supports family carers who need support. Majella emphasised the need to talk to the person with HD and ask them what their needs are. Good communication can overcome problems and encourage people with HD to engage in making choices about their future.

Currently Majella has 128 people with HD registered for her service but she knows there are many more living with HD in Northern Ireland. Greater awareness of HD helps to overcome stigma and encourage people to avail of services. Another HD Specialist nurse will be in post shortly and Majella looks forward to extending their service.

HDAI are very grateful to Majella for travelling to Roscommon to address our meeting. One of our members present suggested we should clone her - we certainly need the service here!

## HDAI Family Support

This space enables family carers to have a chat about their experiences as a carer living with HD. Because HD is such a rare and complex condition, peer support is vital for those caring to know they are not alone facing this challenge. There are support meetings held frequently all year round and the dates are published on page 4 of this newsletter.

## Carers Week

Carers Week took place from June 13th - 19th, 2011. Tom Hopkins (aka Christy Phelan, Fair City) spoke about the generosity of carers and the magnificent contribution they make. He reminded carers to keep in touch with friends and to maintain hobbies and interests as much as possible to avoid the isolation many carers experience.



Bernie Spellman (wearing a HDAI T shirt) pictured with Tom Hopkins and other family carers

## Acknowledge Kindness

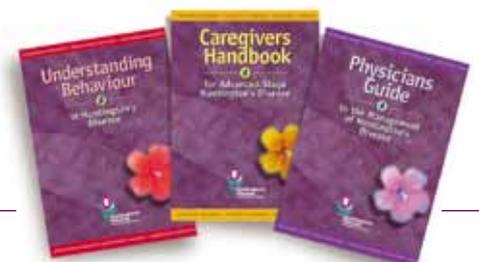
Thank you to the management and staff at **ABBEYLANDS NURSING HOME** for looking after Tom so well.

You are always friendly and helpful when family members visit. Although Tom can no longer speak, staff take the time to understand his own special sign language and to wait for his answers. He appreciates been offered choices and being given extra time to communicate. We are grateful for the extra efforts taken to cater for his tastes and needs. It was good to have the opportunity to chat to Michael and Monica on a recent visit. Thank you all for your flexibility and kindness from all Tom's family.

**Do you have a friend or neighbour who deserves a bunch of flowers or a Thank you voucher? If so please let us know.**

## Information on HD

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



## Renowned Vancouver geneticist wins prestigious 2011 Canada Gairdner Wightman Award



**Michael Hayden**, an ABC researcher whose dogged pursuit of a treatment and cure for Huntington's disease has ignited hope

around the world is being honoured for his efforts with Canada's top medical award. He is a physician and geneticist who is the world's most cited author on Huntington's disease and has won the **2011 Canada Gairdner Wightman Award** for his ground-breaking contributions to medical science.

The Canada Gairdner Wightman Award, worth \$100,000, is given annually to a Canadian for leadership in medical science throughout their career. Hayden, a professor in the Faculty of Medicine at the University of British Columbia and director and senior scientist at the Centre for Molecular Medicine and Therapeutics at the Child & Family Research Institute, was selected for his leadership in medical genetics, entrepreneurship and humanitarianism.

*"This is totally thrilling, and in particular, the award actually becomes even more significant when I think about those who preceded me and the heritage that they left,"* Dr. Hayden, who is based in Vancouver, said in an interview. *"As a physician scientist, to whom chance has given unusual opportunities, I am deeply aware of the degree to which my own success today is built upon the work, cooperation and struggles of others."*

*"We are extremely proud of Dr. Hayden and his enormous achievements and contributions to bettering the lives of people around the world through medical research,"* says UBC President Stephen Toope. *"His tenacity, resourcefulness and generosity of spirit are well known to those who have the good fortune of working with him, and will now be further celebrated through the Wightman Award."*

Dr. Hayden has made important discoveries about how Huntington's disease develops and created the world's first predictive test for it – the first such test for any genetic disorder.

## Fundraising

### Women's Mini Marathons

Thanks to all of you who sent in proceeds from your fundraising in the 2011 Women's Mini Marathon.



Amanda, Maria, Martina and Katherine

Amanda and her friends have raised a magnificent €1000+ so a huge thanks to you all.

Thanks to Mary and her friends from Limerick for taking part in the Dublin Mini Marathon and raising a super €400 for HDAI.

Cathorina, Diane and Regina (below) raised a marvelous €350 for HDAI by participating in the Castlebar Mini Marathon on a sunny May day.



As Tina always sings "You're the Best" **Thanks Ladies!!**

### Tuam Tea Dance

Ann's fundraising Tea Dance and raffle in the Spring was a great success and raised a marvellous €2,577 for HDAI. Once again we would like to thank Ann and her family and friends for their continuous support and energy. Thanks to Della and her team for their support in organising this event.



(Left front): Bridge Mullen, Margaret, Paddy Connern, Ann, Della Dolan. (Back row): Tony O'Toole, Olive O'Toole, Helen Egan, Joe Hannon.

### Dancing

Thanks once again to Geraldine, Phil and all her line dancing friends in Wicklow for the very generous monthly contributions to HDAI from your dance classes.

### Direct Debit Contributions

Thanks to Finnola for her monthly Direct Debit contributions and to all who have sent in donations.

### Mobile Recycling - C&C Cellular



Thanks to Brendan Chambers and C&C Cellular for €684 for old mobiles. If you have any old mobiles, we would be happy to receive them. Thanks to all who sent in old mobiles recently with a special thanks to Joan and Joe.

**Balla Walk, Mayo** takes place on Saturday **23rd July 2011**. Contact the office for more information.

### Malahide Golf Club

A sincere thank you to Lady Captain Pauline Duddy, the committee and ladies at Malahide Golf Club for organising a charity fashion show and raising an excellent €1010 towards our work.



Malahide Golf Club Lady Captain Pauline Duddy (right) with Jackie (centre) and friend Mary Oakes.

We would like to extend our thanks to all who contributed. Thank you also for helping to raise awareness of Huntington's Disease.

### Morning Fitness Gym

A big Thank You to Mark and friends at Morning Fitness Gym for organising a charity collection which raised an excellent €251 for HDAI. Thank you to all who contributed.

### Cake Sale

Thank you Michelle for organising another cake sale and raising a marvellous €655 for HDAI. We are very grateful to you and all at BOI REIM and BOI PB and to all those who supported this event.

### Membership

**A big Thank You to everyone who sent in their 2011 membership subscriptions. Your support is very much appreciated.**

## Donations

### In Memory

Thanks to Anne McLoughlin's family for their very kind donations of €370 in her memory.

## 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.

## Leisure Day

Would you like to attend a therapeutic leisure day in the Phoenix Park? This one day service allows a patient to use therapeutic facilities such as a Jacuzzi, massage, or music therapy etc. St Mary's run an enjoyable leisure day at their therapeutic centre which is located in a very scenic area of the Phoenix Park. Contact the office for more information.

## HD Chair

Please let us know if you need a HD Chair for a family member or if you have one that is in need of repair. Alternatively if you have one you do not need and would like someone else to make use of it we can arrange this. Please contact the office.

DO YOU HAVE ANY ARTICLES TO CONTRIBUTE OR TOPICS YOU WOULD LIKE DISCUSSED? THIS IS YOUR NEWSLETTER

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



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## HDAI Strategic Objectives

Strategic aims for 2012 - 2017 were discussed at our 2011 Members Meeting, providing an overview of the feedback received from the questionnaires sent to members in March 2011, and seeking the opinion of those present on the areas of priority identified for our future Development / Strategic plan.

1. Encourage people at risk of HD to live full lives. 2. Enable people with HD to improve/maintain physical and emotional wellbeing. 3. Enhance carers access to information and support. 4. Increase awareness and understanding of HD. 5. Develop and sustain Huntington's Disease Association of Ireland.

We received 26 responses to the 70 questionnaires sent to members. All agreed with the aims listed above. If you would like more information, or would like to contribute to the process, please contact us on 1800393939 or send an email to [hdai@indigo.ie](mailto:hdai@indigo.ie) **Denis Ryan**

## Lost in Transition

**Lost in Transition** is the collaborative work of 23 students from Kevin's school, Scoil Chaitriona with writers Roddy Doyle and Anne Enright. This book is available at Easons and all proceeds go to the voluntary organisation **Fighting Words**.

Fighting Words is a creative writing centre, established by Roddy Doyle and Sean Love. Fighting Words helps students of all ages to develop their writing skills and to explore their love of writing. More information available at [www.fightingwords.ie](http://www.fightingwords.ie)



Kevin pictured with his parents and Roddy Doyle at the book launch of "Lost in Transition"

## Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Caregivers



**The Dementia Services Information and Development Centre** based at St. James's Hospital, Dublin recently launched a new booklet for family caregivers of people with dementia. The booklet has been written to provide

practical information to family care-givers of people living at home with a cognitive impairment or a dementia and to help them better cope with the day-to-day choices and dilemmas they may confront. To download the booklet go to: [http://www.cardi.ie/userfiles/PracticalGuide191110\(final\)\[1\]\[1\].pdf](http://www.cardi.ie/userfiles/PracticalGuide191110(final)[1][1].pdf)

## NHI Care Awards - Celebrating Excellence in Care

The aim of Nursing Home Ireland Awards (in Association with Homecare Medical Supplies), is to promote best practice within the sector and pay tribute to those individuals who have demonstrated outstanding excellence and dedication within their field of work.

Nominations can come from a member of the care team, resident or relative. This is to ensure that everyone who is involved in the sector can have their say.

The award categories have been chosen to reflect not just on the professionals delivering services but also on the achievements of residents, part time staff as well as how well the nursing home integrates into its surrounding community.

If you want to make a nomination, application forms are available to download at [www.nhicareawards.ie](http://www.nhicareawards.ie)

All application forms and 500 word submissions should be returned by **5.00pm on or before Friday 29th July 2011**.



## HDAI Coffee Mornings/Support Meetings

You are very welcome to join us at our Coffee Mornings/Support Meetings in Cork from 11am to 1pm on the first Saturday of each month. The West of Ireland meeting is held on a quarterly basis. A Limerick support meeting is also available. In Dublin, meetings have relocated to a city-centre hotel. We will also

host carers workshops in Dublin and Cork. Our Family Support Officer or a committee member will host the meetings. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information.

**DUBLIN**

Aug. 13th  
Nov. 12th

**CORK**

Oct. 1st  
Dec. 3rd

**WEST - Castlebar:**

September 10th  
December 10th

**LIMERICK**

Oct. 15th