

## Donations

A number of companies kindly donated to HDAI since our last newsletter. Thanks to Integritas Ltd for €250, Heineken Ireland €250, Vodafone €400 and DCC for €250.

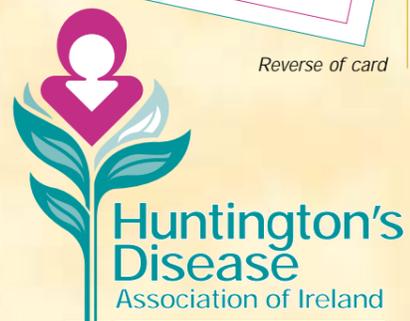
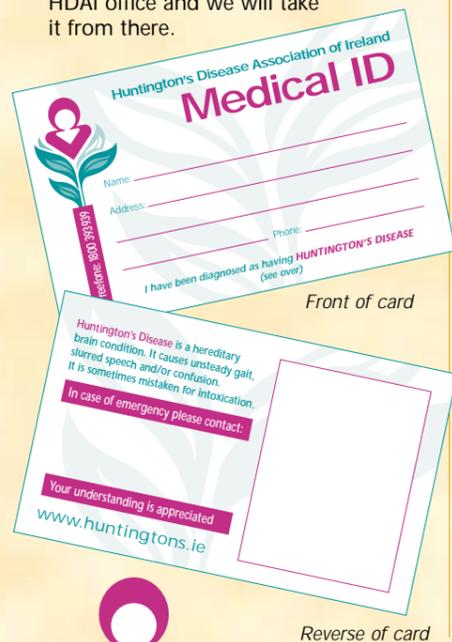
We would also like to express our sincere thanks to Jennifer, Doreen, Stan and Sandra for their recent donations. Thank you to all those members and friends who have donated recently and to those who sent in their membership contributions. Your support is a great source of encouragement to the committee and staff of HDAI.

### 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.

### Medical 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.



## Support Meetings

### THE WEST OF IRELAND SUPPORT MEETING

The last meeting was held in Castlebar on December 10th. Members met for a lively chat over tea, coffee and fresh scones. Catherine our Family Support Officer hosted the meeting. Two new members attended this meeting and met up with our regulars there.

The next West of Ireland support meeting takes place in Castlebar on March 11th.

### CORK SUPPORT MEETING

Monthly meetings are also well attended in Cork. The meeting is usually hosted by a member of the committee or by Catherine and takes place on the first Saturday of the month.

### DUBLIN SUPPORT MEETING

Our Dublin support meetings are not well attended over the last while with no attendance in some months. This may be because

Catherine is available to meet with people who have issues they need advice and support with and they prefer to contact her directly. The committee feel that unless this situation changes it may be best to change the meetings to every second month or once per quarter.

We are also considering changing the venue to a city centre location depending on costs. Please let us know if you have any suggestions on improving this meeting. Future Dublin meetings take place on February 18th, March 25th, April 22nd and May 20th.

Support meetings give members the opportunity to meet other people in similar situations and exchange information on many issues including:- the care of HD patients, coping with the illness within the family and support available for carers. The support meetings are valuable and we will continue them as long as you find them useful.

## HDAI Library

We have a stock of relevant books in our library. These are available to our members on request. Is there a book you know off that you would like us to add to the library? If so please let us know.



## Coffee Mornings

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 and Dublin from 11.00am to 1pm on the THIRD/ FOURTH Saturday of the month (Fourth to avoid bank holiday weekend). The West of Ireland meeting is held on a quarterly basis. The support meetings offer our members the opportunity to meet in a relaxed atmosphere to swap stories and avail of peer support. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information

### DUBLIN

Feb 18th • March 25th  
April 22nd • May 20th

### CORK

March 4th • April 1st  
May 6th • June 3rd

### CASTLEBAR

March 11th • June 10th  
Cuisle Roscommon

Carmichael Centre,  
North Brunswick Street, Dublin 7.  
Tel: 01 872 1303. FreeFone: 1800 393939.  
Fax: 01 872 9931. Minicall: 08224 24837.  
E-Mail: hdai@indigo.ie  
Web: www.huntingtons.ie

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.



### NEED HELP?

IF YOU REQUIRE HELP  
PLEASE CONTACT US IN  
WRITING

### CHECK OUT OUR WEB ADDRESS

[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  
6739 AND WWW.GENETICS.IE

### THIS IS YOUR NEWSLETTER. PLEASE SEND US YOUR VIEWS

## AGM & RESPITE WEEKEND 2006

in Cuisle, Co. Roscommon

June 9th - 11th

Book early to avoid  
disappointment



HDAI representatives meeting members of Femmes d'Europe in Brussels.

NEWSLETTER OF THE HUNTINGTON'S  
DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

ISSUE NO. 26, Q1 06  
HDNL 2006

## Do you need Support?

If you are currently experiencing headache or heartache as a result of HD please do not suffer emotional or physical pain alone. Many of us can be too engrossed in everyday struggles to look for outside help. The long term nature of HD is wearing on everyone within the family.

The practical demands on the carer are increased as they deal with the emotional impact of the decline of a loved one. Many people feel frustrated by the lack of respite care, gaps in understanding from medical and healthcare professionals and a general lack of awareness of HD. It is also painful if

friends and other family members fail to understand the stress and turmoil you encounter. Some family members experience a constant tension in the home. It is an added burden to provide support and care for the sufferer while protecting children from the realities of HD.

Catherine is available as Family Support Officer to offer support and advice to anyone who needs it. Catherine has valuable experience of HD and looks forward to meeting anyone who needs support and advice. All contact is treated in strict confidence.

## Femmes D'Europe

Femmes d'Europe is a Brussels based group of women who seek to promote and extend understanding and co-operation between the women of the European Union. It was founded in 1976 as a non-political, independent organisation which raises money for charity. The Association, through the work of its members and the generosity of its sponsors and donors, raises money to make a specific contribution to fund projects

for the advancement of science, culture and education. We are very grateful for their grant of €10,000 in 2005 towards supplying HD chairs to those in need. A special thanks to Mary Mooney and Pat O'Loughlen for their help and support.

HDAI were invited to attend Femmes d'Europe's 2005 project presentation ceremony, held in the European High Commission building in Brussels. Two representatives attended in order to give an account of the work of HDAI and the specific use of the HD chair.

## Research on Huntington's Disease

We are all aware that there is no known cure for HD at present and that existing symptomatic treatments are limited. In a recent article published in Clinical Science (2006) The Brain Repair Group, School of Biosciences, Cardiff University say "Recent advances have identified multiple pathological mechanisms involved in HD, some of which have now become the focus of therapeutic

intervention. New prospects offer hope for delaying and possibly halting this debilitating disease."

We are not aware of any clinical trials been undertaken in Ireland at present. If you have been offered an opportunity to participate in any such trials we would be grateful if you could contact our office and let us know. All information received will be strictly confidential.

## EuroHD Network Working Groups

The following Working Groups are established within the Euro-HD network (EHDN):

- |                         |                      |   |   |
|-------------------------|----------------------|---|---|
| • Behavioural Phenotype | • Genetic Modifiers  | • Juvenile HD - Has HDAI representation | • Quality of Life - Has HDAI representation |
| • Biomarkers            | • Health Economics   | • Motor Phenotype                       | • Symptomatic Rx                            |
| • Brainbanking          | • Imaging            | • Standard of Care                      |   |
| • Cognitive Phenotype   | • Neuroprotective Rx |   |   |

If you would like more information on these working groups contact our office or look at the EHDN website <http://www.euro-hd.net/html/network/groups> - If you feel you have relevant knowledge or experience and would like to get involved we would be delighted to hear from you.

## Juvenile Huntington's Disease

Juvenile Huntington's Disease (JHD) refers to anyone who develops signs or symptoms of HD before they are 20 years old. It is a relatively rare condition and only about 5% of people affected with HD will develop symptoms this young. This can make it an isolating experience for the person affected by HD, their family, and any professionals that are helping them.

The HDA for England & Wales obtained a grant from the Department of Health to develop services for families with JHD and as part of this developed a 2 year qualitative

study of JHD. The field work for the study has been completed and the work is being prepared for publication.

Bernie continues to represent HDAI on the EuroHD Network working group for JHD. She is keen to get all those interested to meet for a few hours during the annual meeting in Cuisle in June. Please contact Catherine if your family are affected by JHD and/or if you would like to be part of that group. We would like to learn more about the situation for families in Ireland. All information will remain strictly confidential.

## Medical Cards

In October 2005 the income guidelines for both full and doctor only medical cards were increased by twenty percent. Doctor only medical cards cover the cost of attending a GP but do not cover prescription costs. Medical card applicants are now means tested on their disposable income. That is income after tax and PRSI, mortgage payments, childcare expenses and travel to work expenses. Figures compiled in December 2005 show that 1.159 million people in Ireland receive free medical cover. Some HD patients over the income limit have been successful in obtaining a medical card. If your application was turned down you can appeal the decision. HDAI can write a letter of support to accompany your appeal. Please contact the office for details.

If you feel you have had to go through unnecessary hassle in applying for a medical card please let us know. We would like to inform the Health Service Executive of any such difficulties our members face.

## Annual Magazine

We are hoping to produce an annual magazine which would feature articles from members, events during the year, members feedback etc. We plan to produce the first issue in the next couple of months. We hope to have a question and answer page so please send us any questions you may have. If you have a photo, story, poetry etc which you would like included in this magazine we would be delighted to hear from you.

## In Their Own Words

At our AGM in Cuisle last year Bernie asked members present to advise HDAI on: **1)** One question they would like to ask a global expert and **2)** One thing they would like to tell a global expert. As a result a document entitled 'In Their Own Words' was created and was available to all those interested at the 2005 World Congress on HD in Manchester last year. Please find a copy enclosed. We would be grateful to have your comments on this.

## Fundraising Events

### ■ Mini Marathon

We continued to receive funding from mini marathon participants towards the year end. The total sum received from this source in 2005 was €3,911.10 in 2005.

### ■ Dublin City Marathon

Sincere thanks to Francs who participated in the Dublin City Marathon last October and raised a very impressive €1625 for HDAI.

### ■ Dancing

Our members are always coming up with novel ways to help us in our work. Last year Phil contacted us to let us know she intended to teach line dancing classes and donate the proceeds to our Association. To date Phil has raised over €300 on our behalf.

### ■ A Special Gift

Another novel fundraising idea came from Seamus and Nonie O'Toole who are friends of a HD family member. Seamus and Nonie recently celebrated their fortieth Wedding Anniversary and told their friends and family to donate to the Irish Red Cross or The Huntington's Disease Association of Ireland instead of buying them gifts. As a result we received a donation of €1890. Many thanks to Seamus and Nonie for their kindness and generosity. Grateful thanks also to Ann who collected donations on our behalf.

### ■ Tara Glen Captain's Charity

We are very grateful to The Tara Glen Golf and Country Club for donating €9730 to HDAI as a result of their annual Captain's Charity event. Thanks to Billy Slyne as Captain for nominating HDAI as a designated charity.



Billy also took time out from his busy schedule to visit our office and present Catherine with a cheque. Thanks also to Pat and Gay for their help.

## Therapeutic Facilities Towards an Expert Centre for Huntington's Disease



St Mary's ran a successful pilot study of their leisure day service for people with HD in 2005. This one day service allows a patient to use therapeutic facilities such as a Jacuzzi, massage, or music therapy etc. HDAI recently met with the director of nursing at St Mary's and visited their stand alone therapeutic centre.

The centre is located in a very scenic location inside Phoenix Park with deer relaxing in the gardens.



THE DAY STARTS AT 10PM WITH THE FOLLOWING TIMETABLE AS A GUIDELINE:

1000hrs	A guided tour of the facility. Tea / Coffee
1030hrs	Jacuzzi.
1300hrs	Lunch
1400hrs	Recreational Activities i.e. Bingo, Sonas session, Hand massage
1500hrs	Tea / Coffee, snack
1515hrs	Snoezelen Session or Holistic massage
1600hrs	Home

Drama or music therapy may also be available on certain days.