

## 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.

## 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.

## DONATIONS



- We are extremely grateful to the Musgrave Family for their exceptionally generous donation of €10,000 towards aid for people with HD. Particular thanks to Emily, Avril and Stuart (pictured above) who took time to meet representatives of HDAI and personally presented this donation to our treasurer.
- Thanks to Roisin and the Clarke family who recently donated €250 to HDAI for our work.
- Thank you to Alice and to Bernadette for their recent donations.

## COFFEE MORNINGS

You are very welcome to join us at our Coffee Mornings/Support Meetings in Cork from 11.00am to 1.00pm on the first Saturday of each month. The West of Ireland meeting is

held on a quarterly basis. In Dublin, meetings have relocated to a city centre hotel. We hope to host a carers workshop every third month 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 1800 393939 for more information.

### WEST

December 13th - Support Meeting

### CORK

December 5th 2008 - Support Meeting  
February 7th 2009 - Carers Workshop  
March 7th 2009 - Support Meeting  
April 4th 2009 - Support Meeting

### DUBLIN

December 12th 2008 - Carers Workshop  
February 21st 2009 - Support Meeting  
May 16th 2009 - Support Meeting



Carmichael Centre,  
North Brunswick Street,  
Dublin 7.  
Tel: 01 872 1303. FreeFone: 1800 393939.  
Fax: 01 872 9931. E-Mail: [hdai@indigo.ie](mailto:hdai@indigo.ie)  
Web: [www.huntingtons.ie](http://www.huntingtons.ie)

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

## ACKNOWLEDGE KINDNESS - THANK YOU

### Mary (among others) believes Nuala from Cork deserves a big bunch of flowers

Those of you who attended our AGM and Members' Meetings will guess why!

I would especially like to thank Nuala for all her help with my mother, Eva, at our last members respite weekend in Cuisle. Thanks also for your cheery and friendly attitude in helping other members such as taking them to mass and helping out at meal times.

Mary - As well as being kind and helpful Nuala is always ready to join in singing and dancing and encourage others to take part. A big thanks for your kindness and for being a great sport. *Thank you from us all.*

Nuala will receive a bouquet of flowers from HDAI on behalf of Mary & family.



Sandra receiving her 'Thank You' bouquet earlier in the year.

Sandra says - "I was delighted to receive a beautiful bouquet of flowers from the Huntington's Disease Association at the request of my great neighbour that I am privileged to know. It is a humbling experience to know someone with HD and it has enriched my life. Thank you for the flowers".

## HD CHAIR

As mentioned opposite, we received a generous funding grant from the Musgrave family for aids and appliances for HD patients. Please let us know if you need a HD Chair or other equipment for a family member or if you have a chair that is in need of repair. Please contact the office.



Jackie catching up on sports news in her HD chair

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



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 6902  
AND [WWW.GENETICS.IE](http://WWW.GENETICS.IE)

THIS IS YOUR  
NEWSLETTER. PLEASE  
SEND US YOUR VIEWS

## RESPIRE FOR CHRISTMAS

**DO YOU NEED ANY  
FINANCIAL ASSISTANCE  
THIS CHRISTMAS? HDAI  
WOULD LIKE TO HELP  
WHERE POSSIBLE, BY  
CONTRIBUTING  
TOWARDS A FAMILY  
OUTING, A CHILD'S  
CONCERT TRIP OR  
HOUSEHOLD EXPENSES  
ETC. PLEASE LET US  
KNOW IN WRITING IF WE  
CAN HELP YOU THIS  
CHRISTMAS.**



## EUROPEAN HUNTINGTON'S DISEASE ASSOCIATION MEETING

The 5th Annual Plenary Meeting of EHDN was held in conjunction with the 12th meeting of the European Huntington's Disease Association (EHA) in Lisbon from September 6th to September 8th, 2008.

EHDN sessions were open to clinicians, scientists, delegates of the EHA and members of families affected by HD. Presentations included recent advances in HD (in both basic and clinical sciences). Participants also had the opportunity to take part in EHDN working group sessions.

### Hot Topics in the presentation section included:

- HD Pathology in non-CNS Tissue, Maria Björkqvist (Lund, Sweden)
- Gillian Bates (London, U.K.)
- Tracking Progression of HD - Does Imaging Help? Jan Kassubek (Ulm, Germany) Gillian Bates (London, U.K.)
- Cell Replacement Therapy, Anne Rosser (Cardiff, U.K.), Stephen Dunnett (Cardiff, U.K.)
- Coping Strategies, Katherine Moser (New York, USA) G. Bernhard Landwehrmeyer (Ulm, Germany)

HDAI were represented by Anna and Doreen from our committee and Liz our family support officer (all pictured below).



They had a busy schedule attending scientific presentations, working group sessions and networking with representatives from other countries. *Liz gives a summary of the conference below:*

- Anne Rosser and Stephen Dunnett (below) from Cardiff University gave a very interesting talk on cell replacement therapy. Scientists have identified the cells affected in a HD brain (medium spiny neurons). They have found these specific cells can be found in new cells such as embryonic cells. These embryonic cells can be put into the H.D brain to replace the defective cells.



The initial pilot phases of this research were so encouraging, even after a follow-up of 8 years that the research has expanded to include 60 or more HD patients in Europe. However the tests that they are carrying out are not large enough to be reliable and they will need to improve the protocols in order to get the levels and timing required for effective results and this will take time.

- Katharine Moser (New York) gave a fantastic and inspirational talk on her work as an occupational therapist in a Huntington's clinic and her personal struggle with having received a bad HD test result. Katherine grew up in Connecticut, part of a large Irish Catholic family. Like many families affected by Huntington's, Katie family regarded the disease as a curse. As a child she hated visiting her grandfather, he was staying in a Huntington's nursing home called Cardinal Cooke Health Care Centre.



• Katie (pictured above) graduated in 2003 with a degree in occupational therapy. She now works at the Cardinal

Cooke Health Care Centre. Katie has dedicated her life and time to those inflicted with her family disease including her uncle who she cares for in the centre. In addition she is involved in raising awareness and much needed financial support for Huntington's Disease in the USA. Katie has herself tested positive for HD but is determined to achieve her life goals.

The EHA seminars were less scientific in nature and offered a range of practical help to those on the cold face of H.D.

An interesting video was shown by an Italian institute which documented the huge changes in mid stage HD patients who underwent a range of holistic therapies, most notably focusing on speech therapy, and physiotherapy.

Balance, coordination and speech improved remarkably after a course of six weeks intensive work. I would strongly encourage all of our families to seek out these forms of therapy where possible.

Dr Christina Costa from the Fernando Hospital in Portugal gave a very informative talk on the medical practicalities of working with HD patients including feeding, communication, mobility and oral care issues. The setting and hospitality of Lisbon was beautiful and I would recommend it as a weekend break destination.

If you would like any more information on anything in this report don't hesitate to give me a call. Liz 1800 393939.

## HD Seminar at UCD

### "Huntington's Disease: The Secret Disease"

HDAI were invited by UCD School of Medicine and Medical Science to give a seminar on HD to medical students in September. Denis our chairman gave a very informative and moving account of HD from a family member and carer's perspective. His wife Ann was also present to meet students and answer questions. We received a very complementary letter from the course senior lecturers saying "The clarity of your presentation and the personal interaction with your wife Ann concerning the day to day issues of having HD made a huge intellectual and emotive impact on all those who attended. We have been asked to give further seminars to medical students and welcome this opportunity to raise awareness of HD.

## Standards for Residential Services for People with Disabilities

The Health Information and Quality Authority (HIQA), has published draft National Quality Standards: Residential Services for People with Disabilities. The standards will provide a national framework to set out what a quality, safe service for people with disabilities in a residential service in Ireland should be.

Dr. Marion Witton, Chief Inspector of the Social Services Inspectorate at the Health Information and Quality Authority said,

*"Our overall aim in creating the draft standards is to promote good, safe practice. We hope they will encourage the continuous quality improvement of residential services for people with disabilities in the coming years. The National Quality Standards outline what is expected of a provider of services and what a service user, their family and the public can expect to receive in residential care settings.*

*I firmly believe they will contribute towards allowing people with disabilities to live in a safe, caring and respectful environment."*

The standards address issues such as quality of life, staffing, protection, development and health, rights, the physical environment and governance and management. They aim to set out requirements for a good quality service for people with disabilities.

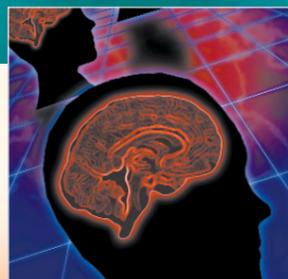
HIQA is now consulting with interested parties and the general public on the draft standards. Information collected from this consultation process will be used to inform the development of the final set of standards later this year.

Following their completion, regulations will be drafted by the Department of Health and Children to give statutory effect to the new standards. All residential services will then be inspected against these standards.

## Exercise Keeps the Brain Young

Trinity College has recently carried out research on whether exercise can protect the brain from degenerative change. Dr Aine Kelly Senior Lecturer in Physiology says "There is already evidence that older people who have been active through their lives - or take up exercise in later years - do better in cognitive tests and have a reduced risk of developing

Alzheimer's disease and other forms of dementia" The experiments measured brain activity in rats. After exercise there was an improvement in the animals learning activity. Dr Kelly concludes "The take home message is that exercise protects our ability to think, remember and plan". (A Picture of Health, 2008, Health Research Board)



## Fundraising Events

### Mini Marathon

Thanks to Orla, Christine, Jill, Jenny and friends who took part in the 2008 Women's Mini Marathon raising a marvellous €1,715 for Huntington's Disease.

The total funding from 2008 mini marathon has come to a very significant €4,133.

### Balla Walk

We are very grateful to Ann, her family and friends for once again walking the surface off the Mayo roads! Our Balla walkers were out again this year and raised over €3,100 while also creating valuable awareness for HD. Thanks to Mary, Rosemary and to everyone who contributed to the success of the walk.



Back row: Ann Hannon, Helen O'Connor, Kathleen Hogan, Joan Ring, Tony & Lorraine Corcoran, Evelyn Holian, Eddie & Mary Gallagher, Niamh Gately. Front row: Mairaid O'Malley, Bernadette O'Connor, Bernie Mangan, Kathleen Connern, Joe Hannon, Caroline Gately.

### 50/50 Golf Tour

Peter Grogan's 50/50 golf tour was a great success raising awareness and valuable funding for HDAI. Peter and Eileen worked very hard organising a launch night, travelling to different courses throughout Ireland and selling raffle tickets. We are extremely grateful for their generosity and energy.



### Dancing for HDAI

Phil, her family and friends held another successful dance "hoedown" and raffle for HDAI last September and raised over €1,200 for HDAI. Thank you to everyone who helped out with this event including Waterford Crystal and Darragh Equestrian Solutions for their gifts and the Lawless Hotel and DJ Vincent Lawlor for their help and support.

### Turning Trash to Cash for HDAI

HDAI continue to collect old mobile phones. If you have any old mobiles you no longer need we would be happy to receive them.

## Respite - A Great Experience

Fear apprehension, nervousness were my first thoughts on going to respite. A new experience is always difficult and being away from my wife and kids for the first time since my diagnosis of HD 9 years ago was daunting.

Five minutes after my arrival in the Irish Wheel Chair

Association centre in Clontarf changed all these thoughts and emotions. I had four nights of fantastic fun with new and very interesting people. We went to the dogs, the pictures, shopping and sightseeing. Food, friendship and fun were the order of the day. Feel the fear and go to respite. I did and enjoyed it thoroughly.

Thanks to Karen Cronin director of the Carmel Fallon Centre and all the excellent Clontarf staff there.

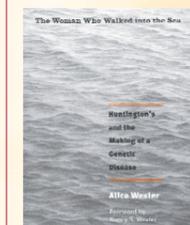
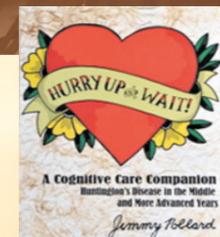
Michael



Karen Cronin, Director of Carmel Fallon Centre IWA Clontarf with Michael

## HDAI Library

Jim Pollard has published a book entitled: *Hurry up and Wait, A Cognitive Care Companion, Huntington's Disease in the Middle and More Advanced Years.*



Alice Wexler's new book is:

***The Woman Who Walked into the Sea, Huntington's and the making of a Genetic Disease***

We have these and a stock of other relevant books in our library. These are available to our members on request.

## ACTIVITIES FOR Young People

We are planning another outing in December - to a pantomime. It promises to be an enjoyable evening so please contact me if you would like to come along. Get in touch as soon as possible to book your seat.

Elizabeth, Family Support Officer. Tel: 1800 39 39 39 or 087 051 7772.