

## Sponsorship Cards

If you have any outstanding cards from the *Balla 8km Fundraising Walk*, Ann would like to receive them before the end of August.

## Donations

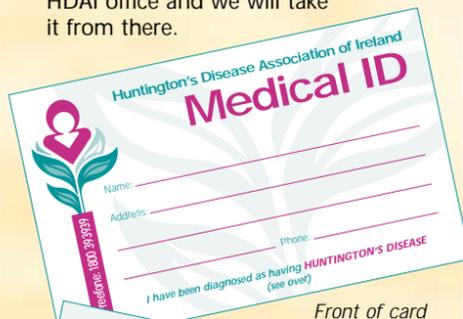
We would like to express our sincere thanks to members Margaret and Pdraig for their recent thoughtful donation. Thanks to Peter for his donation of €200. Thank you to all those members and friends who have donated recently and to those who sent in their membership contributions. Your support is a great 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

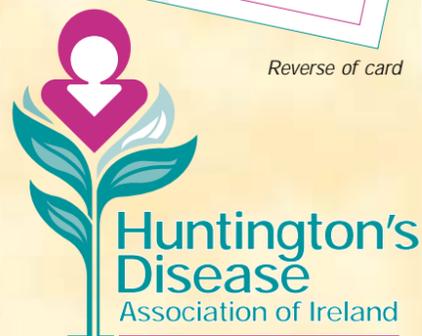
A free Huntington's ID card is available. Please send your Photograph, address, phone number and an emergency contact person's phone number to the HDAI office and we will take it from there.



Front of card



Reverse of card



## Awareness for HD

### Do you watch the RTE 1 TV Drama - The Clinic?

This drama is set in a multi-disciplinary Health Clinic in Clarence Street, Dublin and follows the lives of the inhabitants of the clinic, the daily challenges they face, their personal joys and sorrows

and the frailty of human life. The Clinic contacted us recently because they hope to feature a HD related storyline in one of the episodes of their next series.

The next series starts on Sunday night 18th September and the HD story will possibly feature in episode eight. We will give you more details nearer the time.

## IHA / WFN 2005 Meeting in Manchester

The World Congress on Huntington's Disease takes place in Manchester, England from 10th-15th September 2005. The Congress is a joint meeting of The World Federation of Neurology Research Group on Huntington's Disease and the International Huntington Association (IHA). Scientists, other professionals and representatives of IHA members will meet at a joint meeting at this congress. HDAI representatives will attend and we hope to host an Information Stand at this meeting. We will report on the meeting in our next newsletter.

## HDAI Library

We try to keep a stock of relevant books in our library. These are available to our members on request. Is there a book you would like us to add to the library? Perhaps a book on caring or a similar related subject? If so, 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 Saturday of the month. We will also hold a support meeting in the West on a quarterly basis. Contact the HDAI office on 1800393939 for more information.

### DUBLIN

August 20th • September 17th  
October 15th • November 19th

### CORK

September 3rd • October 1st  
November 5th • December 3rd

### CASTLEBAR

September 10th  
December 10th

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

MEMBERS MEETING  
SEPTEMBER 24th 2005

CHECK OUT OUR  
WEB ADDRESS  
[www.huntingtons.ie](http://www.huntingtons.ie)

WEST OF IRELAND  
SUPPORT MEETING  
IN CASTLEBAR ON  
SEPTEMBER 10th

DUBLIN SUPPORT  
MEETING  
NOW ON THE THIRD  
SATURDAY OF EACH  
MONTH

## GENETICS

THE NATIONAL CENTRE FOR  
MEDICAL GENETICS HOLDS  
GENETIC CLINICS IN DUBLIN,  
CORK, GALWAY AND LIMERICK.  
DETAILS OF SERVICES ARE  
AVAILABLE BY CONTACTING THE  
CENTRE ON TEL: 01 409 6739 OR  
VISITING THEIR WEBSITE AT  
[WWW.GENETICS.IE](http://WWW.GENETICS.IE)

THIS IS YOUR  
NEWSLETTER. PLEASE  
SEND US YOUR VIEWS

NEWSLETTER OF THE HUNTINGTON'S  
DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

ISSUE NO. 24, Q3 05  
HDNL 2005

## Report on 2005 Members Meeting & AGM

Our AGM/Respite weekend took place on the weekend of 10th - 12th June in Cuisle, Roscommon.

70 people attended our AGM on Saturday, June 11th, with the majority staying over in Cuisle from Friday night to Sunday morning. This year we had a return bus service from Dublin and Cork.

During the AGM our committee reported on the years activities and presented our annual audited accounts. Catherine resigned from the committee to take up her position as Family Support Officer. Edward also resigned due to difficulty travelling to meetings. Our members then elected their representatives for the year ahead.

Huntington's Disease for the last 18 years. He is a regular speaker of both the International and European Huntington's Associations.



Jim in action at Cuisle.

Jim gave an entertaining and interactive talk from a patient's perspective. He set tasks to those present in order to give them an insight into how everyday tasks become difficult for pHDs. Dressing oneself for example can become a complex task for pHDs. Jim asked those present how many years of caring they had and combined the results to establish that there was approximately 600 years of experience present.

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. Do you have a comment?.

This year we provided Chiropidy, Reflexology and Chinese Massage for those present. All who took part enjoyed these therapies and found them beneficial.

After the meeting our members had the opportunity to relax and catch up before the evening entertainment.



Edward receiving HDAI Crystal Memento at Cuisle.

Two new volunteers, Bernie and Jennifer, joined the committee giving us nine committee members. Catherine thanked Bernie for her hard work to date as a founder member and Development Officer of HDAI and presented her with a bicycle on behalf of the members. Catherine reminded Bernie she has honorary life membership of HDAI and that we look forward to her return after a well-deserved rest.

After the official business of the AGM Jim Pollard provided information on the care of HD. Jim has worked with people with

## Report on 2005 Members Meeting & AGM (continued)

At our celebratory dinner on Saturday evening Bernie presented Edward with a HDAl Memento to recognize his dedication as a committee member for many years. Bernie also presented Jim Pollard with a HDAl Crystal memento as a token of our appreciation for giving his time voluntarily to speak at Cuisle. Ann & Margaret were also presented with HDAl Crystal mementos for their valuable work in helping to establish a support meeting in the west and for their tireless fundraising for the association.



Ann and Margaret receiving HDAl Crystal Memento at Cuisle.

Jacinta thanked Bernie on behalf of HDAl members and Anne presented her with flowers and chocolates.

Joaquim then provided great entertainment with help from our own singers including Ann, Philip and Shane. The socialising lasted well into the night.

### Members at Cuisle gave the following feedback

Edward and Mary would like to thank all for another great weekend. Treatments fantastic, meeting interesting.

Thank you for a lovely weekend. It was better than a five star hotel. Great craic.

- Doreen

Thank you for a wonderful weekend.

- John

Had a great weekend.

- Susan

I had such a brilliant time from start to finish. Will definitely be back next year for the best craic ever and of course the reflexology.

- Laura

The thing I look forward to most in the year.

- Ann

Brilliant as usual

- Margaret

Great place. Great food. Great Staff.

Great friends. Roll on next year.

- Anne

## You are Invited to a Members Meeting

Saturday, September 24th

HDAl will hold a members meeting in Wynn's Hotel, Lower Abbey Street (off O'Connell St.) on Saturday 24th September 2005 at 1pm. We are delighted Sarah Winckless winner of a bronze medal for the UK rowing team at the 2004 Olympic Games will speak at this event.



Sarah (left) won a bronze medal for rowing at the 2004 Olympic Games. Sarah works as a consultant database manager for a marketing company and is a graduate of Cambridge University. Sarah took up rowing in Cambridge, she took part in the 1998 World Championships and went on to compete at the World University Games in her single scull and won a silver medal.

Sarah's mother was diagnosed with Huntington's disease in 1996 and Sarah herself took the test shortly afterwards. She said the fact that she carries the gene did not affect her preparation for the Olympic Games.

Ironically Sarah's mother worked as lab assistant for the scientist who identified the Huntington's gene.

Sarah said her mother's positive approach has helped her family learn to live with Huntington's rather than fear it. She admires her refusal to give up. Sarah recalled how she was very calm when she first got her result but about a week later the tears flowed and she phoned the counsellor who had dealt with her during her test. She then threw herself into doing her final exams, buying a house and rowing. 'I can't fight it, so there's no point in fearing it. If it happens, it happens. I'm going to live my life and get on with it. The more positive I can be the better. That's what Mum has shown'.

We invited Sarah to speak at this meeting so that we could all celebrate her success. Sarah is also an inspiration to us all on how to conquer adversity and live life to the full. We are delighted she is taking time out of her busy schedule to visit us. This meeting is also a chance to meet other family members and meet the HDAl committee and family support officer. We hope you can make it. Please complete the attached booking form by September 12th if you wish to attend this meeting.

## Family Support

Catherine Paradise commenced her new role of Family Support Officer on July 1st. Catherine has worked with HDAl in a voluntary capacity for many years. She has valuable experience of HD and looks forward to working with you. If you would like to speak to Catherine please call the office on 1800 393939.

## Fundraising Events

### Mini Marathon

A number of our members took part in the 2005 Women's Mini Marathon to raise funds for Huntington's Disease. Some of our more courageous members and friends even changed gender for the day by sporting fancy frocks in order to do so!

Special thanks to Danielle, Starlena, Betsy, Anne, Bernie, Grainne, Aisling Susan and Rosie who had a lot of fun on the day and captured it on camera. See photo below.

Grateful thanks to all who took part and all who gave sponsorship including:- Sinead and Josie, Chris, Ursula and Frank, Jennifer, Eileen and Pat, Frances and friends, Eilis and Mark. We have received an incredible €3450 as a result of mini marathon fundraising. We know that a lot of effort goes into participating and getting sponsorship so a BIG Thanks to you all.



(left to right): Grainne, Aisling, Susan, Rosie, Betsy, Starlena, Anne, Bernie and (front) Danielle.

### Fundraising In Memory of Michael O'Brien

Ellen Kelly recently contacted our office to advise us of a fundraising event she is undertaking in Ireland in memory of a HD family member. Ellen is planning a "Race for HDF" on Thursday 29th September, 2005 in Doheny & Nesbitt's, Baggot Street, Dublin to raise funds for the Hereditary Disease Foundation (HDF). Ellen has asked that anyone who may know of any businesses or individuals who may want to help with either a monetary or product donation to please contact her at 086 8134861.

In the Spring of this year, Michael and Christopher O'Brien, the 4th and 7th children of David and Alice O'Brien of Oswego, New York, were seeking to become the first American brothers to summit Mount Everest. Their intent was to raise \$100,000 (approx. €80,000) for The Hereditary Disease Foundation ([www.hdfoundation.org](http://www.hdfoundation.org)) which funds research for cures for diseases such as Huntington's, Parkinson's and Alzheimer's. It is one of the most highly rated charities in the US (100% of personal donations go directly to the researchers) and was of great personal significance to the O'Brien brothers. Their mother and older sister have both passed as a result of Huntington's and at least one other family member is currently suffering from its effects. On May 1 Michael tragically fell to his death on Mount Everest. Christopher, having graduated from Medical School just last month, joins Michael's family and friends who will continue the fight to find a cure. To find out more about this tragic, sometimes inspirational, story see [www.obrienseverest.com](http://www.obrienseverest.com).

## Professor Michael Conneally's Retirement

Professor Michael Conneally, Ph.D., Distinguished Professor, Department of Medical and Molecular Genetics, is retiring after 40 years of service to Indiana University School of Medicine. Many of you will have met Professor Conneally at Cuisle over the years. He is a native of Ballygar, Co. Galway and regularly visits Ireland. He has been a good advisor and friend to HDAl over the years and was a recipient of our specially commissioned crystal memento at our AGM in 2003.

A Symposium to celebrate his work: "40 Years of Progress in Population Genetics: A Symposium in Honor of P. Michael Conneally" took place on June 27, 2005.

We advised President Mary McAleese as Patron of our Association of Professor Michael Conneally's retirement and she kindly forwarded a message which was presented to Professor Conneally at his retirement event.

In her message she said "As patron of the Huntington's Disease Association of Ireland, I am delighted to have this opportunity to congratulate Professor P. Michael Conneally on the occasion of his retirement"

Pictured below are two of our members Ann & Denis who visited a HD Chapter in Michigan on a recent visit to the USA. Pictured (left to right): Bob & Ruth Lentner, Douglas Cameron and Ann & Denis.

