

## EHA Meeting

A joint meeting of the European Huntington's Disease Associations (EHA) and the Euro Huntington's Disease Network (EHDN) was held in Guadarrama, Madrid on 1st to 4th October 2004. Bernie, Catherine and Anne attended as HDAI representatives. Please refer to enclosed pages with information on both meetings. If you would like further information on any aspect of this meeting please contact the HDAI office.



"Shop 'til you drop" in Madrid.

## Gift Voucher

HDAI are included in the Post Office Gift Voucher catalogue. Perhaps you would like to give a HDAI gift voucher to someone for a Christmas gift.

## 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



## HD Chair

We have applied for funding for additional HD chairs to a Brussels based group Femme d'Europe. We will keep you advised on this development. In the meantime 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.

## 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 know of that you would like us to add to the library? Perhaps a book on caring or a similar related subject?

## Vehicles for people with disabilities - Tax Relief Scheme

Do you need to adapt your car? Drivers with Disabilities, Passengers with Disabilities and/or a Family Member of a person with a Disability who purchase a vehicle for the transport of that person as a passenger may apply for tax relief on that vehicle. If you would like more info contact the office or see the article on this subject in our March 2004 newsletter.

## Membership

We would like to express our sincere thanks to all of you who sent in your membership forms and for your kind contributions. Your support is always appreciated.

## Into the West

Our West of Ireland Support Meeting held in Castlebar last July was a great success. Fourteen people attended the meeting from throughout the surrounding area. HDAI hope to host this support meeting on a quarterly basis in 2005.

If you have any ideas as to how the Association can be more accessible to you we would be delighted to hear your views.

## Donations

We would like to express our sincere thanks to members Teresa and Mary for their recent thoughtful donations. Thanks to Chameleon Colour Systems in Co. Galway for their kind donation of €302, thanks also to Wyeth in Dublin for their donation of €200. Thank you to all those members and friends who have donated recently and to those who fundraise on our behalf. Your support is a great source of encouragement to the committee and staff of HDAI.

## 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 last Saturday of the month. Contact the HDAI office on 1800 393939 for more information.

### DUBLIN

NOVEMBER 27th • DECEMBER (No Meeting) • JANUARY 29th

### CORK

NOVEMBER 6th • DECEMBER 4th  
JANUARY (No Meeting)

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

THIS IS YOUR  
NEWSLETTER,  
PLEASE SEND US  
YOUR VIEWS.

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



# NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

ISSUE NO. 21  
HDNL 2004

## Been there, done that... getting the T-Shirt



I feel exhausted and overburdened and in need of a break. I advise others to take a break. It is now time for me to take some of my own advice and take time out. I must now revert to a more manageable pace until the end of this year. This will allow the committee to put a plan in place so that I can take a complete break from the AGM in 2005. The committee can still call on me in a crisis but not every crisis.

Our next AGM will be a chance to *celebrate our success* and my time as a founder member and Development Officer of HDAI. It is 22 years since the first meeting. I didn't really expect to be on call this long! I worked full time for HDAI from 1992 until 1995 but otherwise I was working full time in another job and making myself available in my spare time. The demands on me were way more than anticipated.

HDAI was developed by and for its members. It evolved in sustainable stages without adding to the burden of its

members. The first aim was to do no harm. Many members wish to keep their medical secret and must always have that option. Everyone's health record should be between them and their medical advisors. HDAI must never risk confidentiality for the sake of short-term gain. It was possible to get this far without changing shape for sponsors. It is up to all of you to ensure that it is enhanced and improved. It can remain informed and flexible enough to avail of every opportunity on your behalf without changing shape for vested interests. Let the committee know what you need and how you would like to see HDAI grow in the future. Be more demanding so they know your needs.

It was great to be part of the formation of a stage that can give a voice to a group who were voiceless. I am proud of the part I played in getting HD the attention it deserved. We didn't need to cultivate victims or martyrs. We are a vibrant community who happen to have to live with a devastating disease. Better information can ease the drama and reduce the misunderstandings.

People can't lose sight of hope or reality. The future looks brighter than we could ever have hoped.

There are more dedicated experts and more funding than ever. Keep well and be ready for every opportunity.

I include this old wisdom from Native Americans (on page 2) to remind us about the group we all work for.

NEED HELP?  
IF YOU REQUIRE HELP  
PLEASE CONTACT US IN  
WRITING

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

THIS IS YOUR  
NEWSLETTER. PLEASE  
SEND US YOUR VIEWS

### 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)

WE WOULD BE  
GRATEFUL IF YOU  
WOULD COMPLETE THE  
SURVEY ATTACHED AND  
RETURN IT TO US IN  
THE STAMPED  
ADDRESSED ENVELOPE  
ENCLOSED

### 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 ETC. PLEASE LET  
US KNOW IN WRITING IF WE CAN  
HELP YOU THIS CHRISTMAS.

## Native American Wisdom

### The seventh generation to come

*In our way our life, in our government, with every decision we make, we always keep in mind the seventh generation to come.*

*It's our job to see that the people coming ahead, the generations still unborn have a world no worse than ours - and hopefully better.*

*When we walk upon mother earth we always plant our feet carefully because we know the faces of our future generations are looking up at us from beneath the ground.*

*We never forget them.*

## Disability Legislation

The 2004 Disability Bill is now published and is currently being discussed before being passed into law. This Bill contains a section on Genetic Testing. It introduces safeguards for the use of genetic data. HDAI, The Genetic Inherited Disorders Organisation and Professor Andrew Green will attend a hearing of the Joint Committee on Justice, Equality, Defence and Women's Rights to stress the need to provide adequate genetic protection in this bill. We will keep you advised on progress. Meanwhile if you have the opportunity, please mention your concerns to your local politician.

## Olympic Bronze Medallist Sarah Winckless has Huntington Gene



Sarah Winckless, pictured above left, with her teammate, Elsie Laverick, 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 has a strong rowing background. Her father competed for Cambridge and her stepfather won World Championship medals and a silver medal at the 1976 Olympic games. 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 Games. Ironically Sarah's mother worked as lab assistant for the scientist who identified the Huntington's gene.

Sarah was delighted at 31 years of age to be chosen for the Great Britain 2004 Olympic Games rowing team. In an article in the UK Daily Mail on June 29th, 2004 "My Race Against Time" Sarah discussed how her Olympic effort pales in comparison to her mother who despite having Huntingtons Disease travelled to the Sydney Games to support her daughter. Sarah recalled how her mother was reluctant to visit the doctor when her symptoms first emerged but that one day, when she visited, her mother hugged her and told her she had been diagnosed with Huntington's Disease. Sarah said 'It was the first time her illness had been given a name and, in a way, just having a label was a relief. It meant I could read up about it, understand it and, having read science at Cambridge, rationalise it'. Sarah said her mother is determined to continue with her life despite her condition. 'She does as much as she can for as long as she can, and always has.

She is now 61 and her condition is deteriorating, but she still lives with her husband and my sister at home. I think her positive approach has helped us learn to live with Huntington's rather than fear it. Mum does find it difficult to get food down and I find it harder to understand

her speech, but the thing I admire most is her refusal to give up. She's only started using a wheelchair recently, and even that she fought'.



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. Sarah is unmarried and hasn't any children at present.

'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 had invited Sarah to our next AGM so that we could all celebrate her success however due to her heavy training commitment, June is not possible for her. We are hoping to organise a visit outside Sarah's training and we will keep you advised.

## Fundraising Events



### Limerick Charity Cycle

*Cycle Group receiving a cheque on behalf of HDAI*

Dolan's pub in Limerick was the starting point for a fundraising cycle from Limerick to Ballybunion. The cycle raised a very impressive €9,177 for HDAI. We are extremely grateful to those who organised this event. Our grateful thanks also to those who completed the cycle and all who sponsored them.



### Mayo Walk

*Bernie and Rachel with the group who walked for HDAI*

Ann and friends organised a group of walkers to take part in a local 10km charity walk in order to raise funds for Huntingtons Disease. This was a resounding success with €5,450 being raised for HDAI. Bernie and Rachel (Jo from Fair City) also joined the walkers on the day

## Mini Marathon

Frances organised family and friends to take part in the 2004 mini-marathon to raise funds for Huntingtons Disease. Her group raised €885 from this event. HDAI

presented Frances with a crystal memento this year in recognition of her energy and enthusiasm in fundraising for HDAI.

Thanks to all who took part and to those who sponsored Frances and friends.

## 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. The scientific programme will include presentations covering genetics, drug discovery and development, pathogenesis, clinical aspects (neurology, neuropsychology, neuropsychiatry and genetic counselling), the latest therapeutic advances, clinical trials, public policy and education. HDAI representatives will attend.