

RESEARCH

The Huntington's Disease Society of America (HDSA) reported in their Winter 2004 newsletter that HDSA Funded Research exceeds \$23 Million.

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. If you know a medical professional who may be interested in attending 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



Making Life Easier

There are products on sale to help alleviate the difficulties associated with Huntington's Disease. Examples include: drinking aids such as dysphagia cups and long straws to help people with swallowing difficulties, eating aids such as weighted utensils, utensil straps, and special dishware to provide better control and reduce spills,

medication aids such as pill crushers and splitters to help people who have trouble swallowing whole pills, personal care supplies such as dry shampoo and bathroom safety equipment to help prevent falls. If you would like further info on these products please contact the office.

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.

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? If so, let us know.



Donations and Membership

We are grateful to Aileen Regan of Pharma Ltd for a kind donation of €500. Thank you to all those members and friends who have donated recently and to those who fundraise on our behalf. 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 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 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

February 19th • March 19th
March 16th • May 21st

CORK

February 5th • March 5th
April 2nd • May 7th

CASTLEBAR

March 12th

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. 22
HDNL 2005

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

**PLEASE NOTE
THE DUBLIN
SUPPORT
MEETING HAS
BEEN CHANGED
TO THE THIRD
SATURDAY OF
EACH MONTH
TO AVOID BANK
HOLIDAY
WEEKENDS**

CHECK OUT OUR
WEB ADDRESS
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

Members Meeting & AGM June 11th 2005

Our AGM/Respite weekend takes place from the 10th - 12th June in Cuisle Respite Centre, Co. Roscommon. All facilities at Cuisle are fully accessible to people with disabilities. Please mark 10th - 12th June 2005 in your diary and book your place as early as possible. All are welcome.

GETTING THERE - A number of members who returned their survey forms mentioned difficulty in travel as a reason they could not

attend our respite weekend. Please let us know if you can not attend due to travel difficulties and we will try to work something out. We provide a return bus service from Dublin to Roscommon.

The bus leaves Dublin on Friday evening and returns Sunday afternoon. We are considering providing a similar bus service from Cork city via Limerick if there is sufficient interest.

West of Ireland Support Meeting

Due to the success of our West of Ireland support meeting in Castlebar last July we are planning to host support meetings in the west on a quarterly basis on the second Saturday of March, June September and December. The next meeting will be held in Castlebar on the 12th of March (same venue as before). The June meeting coincides with our AGM and so will be held in Cuisle, Roscommon. We will host a meeting on September 10th and December 10th in Castlebar. Fourteen people attended the last meeting and we are hoping for similar

interest 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.

10km Fundraising Walk

Some of our members are taking part in a 10km fundraising walk in Co. Mayo on 16th July 2005 to raise funds for HDAI. Please contact the office if you would like to take part.

Olympic Bronze Medallist Sarah Winckless Visit

Sarah Winckless, winner of a bronze medal for the UK rowing team at the 2004 Olympic Games carries the gene for HD. We featured Sarah's story in our last newsletter. As Sarah is an inspiration to us all on how to conquer adversity and live life to the full we have invited her to a members meeting in Ireland so that we can all celebrate her success. Sarah has a heavy training commitment until August therefore **Saturday 24th September** has been proposed as a possible date for an afternoon members meeting in Dublin. We'll give you more information nearer the event.

HDAI Survey

Thanks to all of you who completed and returned our survey. This survey provides useful information to the Association on what we do well and what can be improved upon. Most respondents expressed satisfaction with the work of HDAI and many provided worthwhile suggestions on how we can improve our service to members. Please take the time to return your survey if you have not done so already.

Comments included:

- I tested positive for the HD gene in a predictive test. Being able to meet and talk to other carers and positive people with the gene is a positive for me and my family. Being given information and having questions answered by HDAI is greatly appreciated. Knowledge is power!*
- Most people involved with HD have a thirst for knowledge but are short of time. Quality speakers attract big audiences and would offer real opportunities to meet and share views and then build support network that would be re-enforced with Cuisle and coffee mornings*
- I feel bad that two of my siblings in their forties have to go into a nursing home for old people. This is not the place for them. If there was a home for people with HD it would be easier for them and their families.*
- I would like to see a meeting for those in the family who have not HD. A programme with steps to help us live our lives without feeling guilty for not having HD*
- Most of the general public never heard of HD. It can be isolating not being able to discuss it as there seems to be a stigma attached to it. I feel if there was more publicity about it that it might help to break down barriers.*



Neurologists

We recently sent a letter to neurologists in Ireland to inform them of a number of issues. These were:

Concern regarding common misunderstandings between HD patients and their neurologists. We believe HD patients should not be delegated to a junior doctor as the expertise of the most senior specialist is required. We have asked them to look at ways to develop guidelines on best practice in relation to the first and repeat visits for HD patients which allow for the symptoms of the disease.

Distressing incidents reported to us from patients and family members include:-

- Patients left waiting for hours, stared at, unnerving others and being unnerved by others;
- Patient information discussed by name with another HD family;
- The diagnosis of a patient in their seventies sent in a glib letter to their GP;
- A patient file lost for nine years, followed by a delayed appointment;
- A delayed and unhelpful response to a family in crisis.

We are aware of the severe shortage of neurologists in Ireland but feel there is room for improvement with HD patient visits.

In addition there is concern regarding the potential for our members to be actively misrepresented. Links between neurologists and drug companies in the biotech debate are worrying.

We also informed the neurologists of our new bus stop poster campaign, the Euro HD Network, and the 2005 World Federation of Neurology and International Huntingtons Association conference in Manchester from 10th-15th September 2005.

Can you please advise us if you have had problems with neurologist appointments, alternatively please let us know if you are happy with your appointments. We have advised neurologists that we are happy to work with them to devise a system to improve patient visits.

Fundraising Events

We would like to express our sincere thanks to Mary, Elaine and friends for organising a fundraising night (pictured left) to raise funds for Huntingtons Disease. They raised an impressive €763.48. Thanks to Betty, John and family for raising €650 through the 2004 mini marathon. All Saints Church raised €200 from their coffee morning, special thanks to Anna and friends for their continued support. Thanks to Dolan's in Limerick who sent us a further €180 from their fundraising cycle of last summer.



Eileen Clancy pictured with prize winner Billy Fitzpatrick at the Pearse College staff raffle which raised €650 for Huntingtons Disease. Grateful thanks to Bernie, Eileen and all at Pearse college for their kindness and support.

Communication and Huntington's Disease

Some ways we can help a person with Huntington's Disease (HD) communicate to us more clearly:

- Go to a quiet place where you can hear the person with HD (speech may be slurred or at a low volume)
- Allow enough time for the person to speak - do not hurry them up. Speech will be less clear if a person hurries. Also the person with HD needs time to respond, as there can be problems with retrieval of words.
- Sit or crouch at eye level with the person with HD so they do not have to strain upwards as this can make speaking more difficult.
- Wait for up to a few minutes for a reply to a question
- Ask the person to repeat phrases you did not understand. Do not ask: "what did you say there?", instead say "did you mean....."? This sounds more positive and shows that you are open to what the person says.
- Do not pretend to understand if you do not.
- Pay attention to what the person says and repeat their words so they will hear what you have understood.

- Ask the person to show you by pointing, or use a communication book. Encourage the use of gestures and facial expressions to get the message across.
- If the person is having difficulty getting their speech started, offer cues and prompts. Try to find the topic - 'home', 'friends', 'going out' etc, however be careful not to put words in someone's mouth.
- Give choices. Rather than saying: "What do you want to have for dinner"? give a choice - "Do you want mince or chicken"? Choices are very helpful as people with HD may not be able to retrieve words from memory, but can recognise words they hear. Other examples include: asking "are you going swimming tonight or Tuesday"? instead of "when are you going swimming"?
- As speech becomes more difficult, choose a format where the answer can be "yes" or "no".

TO HELP A PERSON WITH HD UNDERSTAND BETTER

Some ways we can help a person with HD understand us:

- Use short simple sentences and assess understanding of the person frequently during important conversations.
- Break the task or instructions down into small steps (sequence things correctly). It is much harder to understand a sentence like 'before you are having your bath, you are having your dinner' than 'you are having your dinner, and then you are having your bath'.
- If you think a person is confused, speak more simply and use virtual clues to demonstrate what you are saying. Point to the light, when you are going to switch it on or off. Try to rephrase the main idea, but make sure you have first given time for a response.
- Do not skip from one subject to another.
- The person may have trouble following a conversation if there is more than one person talking.

People with HD need to be heard. Experts now know what families always knew. The patient is aware.

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

In 2004 Bernie met with Breda Hayes, Director of Nursing and Rosemarie Reynolds of St. Marys, Phoenix Park to discuss further the possibility of extending services for HD patients. St Mary's are now running a pilot study of a leisure day service for people with HD. This is a one day service where a patient can use therapeutic facilities such as a Jacuzzi, massage, or music therapy etc. One of our members has already availed of this service and found it very enjoyable. If you would like to access this service, please contact us. We will provide accommodation for anyone outside the Dublin area who may need it.

HDAI Poster



Poster at Liffey Valley Shopping Centre

Our new awareness poster was launched on 27th December 2004. The poster is on display at various shopping centres and bus stops throughout Dublin. It is also on display at locations in Cork, Limerick, Galway, and Waterford City and in regional counties including: Mayo, Kildare, Kerry,

Longford, Wicklow and Tipperary. Our website www.huntingtons.ie provides a facility to send your comments on this poster. To use the comment card scroll down on the homepage until you reach the section 'Can we have your views on our latest awareness poster' then click on the prompt provided and you will find the comment card. You can also call the office on 1800 393939 to give us your comments.

We are grateful to Ray Sheerin, and his team at Chemistry who are again providing their services free of charge.