

RTE Radio Interview on Huntington's Disease

On Tuesday 22nd March, RTE RADIO One hosted a panel discussion on Huntington's Disease which featured on Outside the Box, a programme for and about people with disability. Presented

by Olan Mc Gowan, the programme featured a discussion with Bernie, Catherine and Anne from HDAI. It also featured an interview with Rachel Sarah Murphy (Fair City). If you would like to

listen to this broadcast, please click the 'Listen Now' link on our website www.huntingtons.ie

West of Ireland Support Meeting

A support meeting took place in Castlebar on Saturday 12th of March. The next meeting will be held in Cuisle, Roscommon at 11am on the 11th of June. Our AGM and Members Meeting will follow to suit people who have a distance to travel. Members are also invited to stay in Cuisle on Friday and Saturday night.

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



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 and we hope to host an Information Stand at this meeting. We do not know how many people can attend at present. If you or a member of your health care team are interested in attending please let us know.

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.



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. Our AGM takes place in Roscommon, June 11th.

DUBLIN

June 18th • July 16th
August 20th • September 17th

CORK

June 4th • July 2nd
August 6th • September 3rd

CASTLEBAR

September 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.



NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 23
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 book now if you have not already done so. All are welcome.

Jim Pollard will speak at our members meeting in Cuisle on June 11th. Jim is a special education teacher and healthcare administrator who has worked with people with Huntington's Disease for the last 18 years. He recently toured England and Wales speaking to healthcare professionals for the HD Association of Great Britain. He is a regular speaker of both the International and European Huntington's Associations. He is the editor and author of "A Caregiver's Handbook for Advanced Stage Huntington's Disease" which has been published by HD societies in seven countries in North America and Europe. Jim is Director of Huntington's Disease (HD) programs at Laurel Lake Center for Health & Rehabilitation in the USA. Jim's presentation is of particular value to carers. Those of you who met Jim at Cuisle in 1999 will know how committed he is to making a difference for HD patients and families.

Getting There

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. Please let us know if you have transport problems.

Family Support



As mentioned in our November newsletter Bernie plans to take a break from the Association for a year or two. The Association plan to employ Catherine Paradise (pictured left) as a Family Support Officer on

a temporary, part time basis in Bernie's absence. Catherine will resign as Chairperson and committee member in order to fulfil this role. Catherine has been a dedicated member of our committee for many years. She has valuable experience of HD and looks forward to working with you.

On behalf of our members, HDAI committee extend a sincere thank you to Bernie for her tireless work for the Association. Our AGM will be a chance to celebrate our success to date and Bernie's time as a founder member and Development Officer of HDAI. We look forward to Bernie's return after her well-deserved rest.

July Fundraising Walk

There is a change to the fundraising walk in Co. Mayo mentioned in our last newsletter. The walk is now 8km and will take place on Saturday 23rd July. It will leave Balla Community Centre at 7pm. Some of our members are taking part to raise funds for HDAI. Please contact the office if you would like to take part.

How Do You Cope?

Most of the changes in our life will cause us some degree of stress. Stress has been defined as the demand placed on our body or mind and our body's reaction to it. Everyone experiences stress; it is one of the facts of life we cannot avoid. What is important is how we deal with stress. Stress is not always bad, sometimes it gives us the energy necessary to complete a desired goal. We can limit the harmful effects of stress by choosing the best method of response to stressful events. Sometimes, when we are feeling depressed, anxious, confused or unable to cope, talking to supportive friends, family members, or joining a support group may be very helpful.

- Relaxation, exercise and a healthy balanced diet are proven methods of relieving stress.
- Fruit and vegetables are important for a healthy diet. Homemade soups or fruit juices and smoothies are a good way of increasing intake.
- Excessive sugar, fats, caffeine and alcohol put a strain on the body.
- Drinking water regularly throughout the day helps to rid the body of toxins.
- Deep-breathing, yoga, meditation or massage work well as effective stress reducers for many people.
- Studies reveal aerobic exercise can reduce anxiety by up to 50%. Walking, jogging and taking part in group sports can also help you sleep.
- A good nights sleep is very important. Stress can cause insomnia or restless sleep but this can be minimised by avoiding caffeine and large meals in the late evening.
- Nicotine is a stimulant; therefore cutting down or giving up smoking will eventually bring more relaxation. This process is difficult but there are a number of organisations and support groups to help. You can find out more by calling Smokers Quitline 1850 201203
- Constantly dwelling on a stressful event continues the stress. Take time to analyse the problem, discuss it with supportive friends or family and work out a strategy for dealing with the problem. You will feel more in control by working out coping mechanisms.
- Take time out for you:- read a book, watch your favourite film, meet a friend or take a short break.
- Look for the positives: avoid criticising yourself or those close to you. If criticism is unavoidable remember constructive criticism works best. Do not just focus on the negatives, remember to appreciate those who help out and acknowledge their worth.
- Don't try to do too many things at once, prioritise tasks. Laughter is a good stress reliever.

Please contact us if you need help.

HD Chair Sponsorship

We have been successful in our application for funding for HD chairs to the Brussels based group Femmes d'Europe. Femmes d'Europe seeks to promote and extend understanding and co-operation between the women of the European Union and is 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 for new chairs. A special thanks to Mary Mooney for her help and support.

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.

Fundraising Events

TANEY CHURCH SPORTS SERVICE

Taney Church, Dundrum host an annual Sports Service in thanksgiving for the gift of sport. This year the collection for their sports service was dedicated to Huntington's Disease in memory of Les who was a friend of Taney Church. Micheal O'Muircheartaigh, GAA Sports Commentator and Journalist addressed those present and gave an entertaining reflection of his sporting experiences. The Enniskerry Gospel choir led the singing at this service. The Ecumenical Service for the Gift of Sport invited our Chairperson Catherine to give a talk on HD and the work of the Huntington's Disease Association before the collection took place. The collection raised a very impressive €2000 for HD. We are very grateful to John Meldrom, Brian Wilkinson and all at Taney Church for their kindness. Catherine and our committee members who attended this service found it very rewarding and uplifting.

Friends Remembered

Thomas Murphy who died as a result of HD has made a bequest of €6,348.70 to HDAI. We would like to thank Thomas, his friends and family for considering us. We plan to acknowledge Thomas's contribution in some way and we will let you know in a future newsletter.

We are grateful to the family and friends of Olivia who made donations of over €2,500 in her memory to HDAI. The Association extends their sympathies to Olivia's family.

Sincere thanks also to the Downes family who donated €1000 to HDAI in memory of Sheila.

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.

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



St Mary's have ran a successful pilot study of their 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 as you can see from the interview below.

Q: How did you hear about the leisure day at Cuan Aoibheann?

A: Bernie from HDAI approached me and my family and brought us to Cuan Aoibheann to meet Dorothy and see the place.

Q: How did you feel about it?

A: I loved the idea and could not wait to start.

Q: After your first day was it all you thought it would be?

A: It was and more, it was really worth getting up for.

Q: How did you find the staff?

A: Very caring and full of fun, a laugh.

Q: How did you feel about the residents?

A: They were a laugh, I liked them, they are great.

Q: How did you feel about being involved in their activities?

A: I liked Bingo and the singing.

Q: What was your favourite activity?

A: The Jacuzzi.

Q: Was there anything you would like to change?

A: No.

Q: Would you like to continue?

A: Yes, yes, yes.

Q: What has this leisure day done for you?

A: It has given me independence from my family and friends that I can have my thing to do. It has given me hope and a great sense of being special. Thank you to the staff and residents at Cuan Aoibheann.

If you would like to avail of this service, please contact us. We will provide accommodation for anyone outside the Dublin area who may need it.

Book Review

One member phoned to let us know the recently published novel 'Saturday' by Ian McEwan has a reference to Huntington's Disease. Catherine read this novel over Easter, these are her views:

I read this novel called 'Saturday', one day in the life of the protagonist Henry Perowne. Henry is a neurosurgical consultant who is successful owns an S500 Mercedes and is married to Rosalind who is a lawyer. He has a son who is a musician and a daughter who is a poet.

During the course of this one day, 'Saturday', Henry plays squash, visits his mother and is involved in a minor car crash. Page 84 gives a description of 'Baxter' who was driving the other car "his gait is distinctive with a jazzy little twist and dip of his trunk as though he's punting along a gentle stretch of river."

On page 93 Henry thinks to himself, 'if a parent has it you have a fifty fifty chance of going down too. Chromosome four. The misfortune lies with a single gene, in an excessive repeat of a single sequence - C.A.G.

The novel goes on through Henry's day. Later, Baxter and his friend Nigel break in to Henry's house, they attack Henry's father in law giving him a broken nose. Baxter threatens the family with an old french kitchen knife. He forces Henry's daughter to undress and read her poetry aloud.

The family overpower Baxter after Nigel runs off and leaves him. He falls down the stairs and is semiconscious at the bottom. The First Aid they give him is well researched, the jaw thrust tongue lift used to clear his airways - the first aid given when spinal injury is suspected.

Baxter has a depressed skull fracture and two clots. Henry is called in to the hospital because the neurosurgeon who should be operating is at home with flu. Baxter is operated on and then Henry goes home to his family who are shocked by the evenings events.

The novel is 279 pages long and seemed too long for one day in anyone's life. However the descriptions of Baxter who has HD appear to be accurate as far as I can tell.

Awareness

HDAI hosted an information stand at the Annual Occupational Therapists of Ireland Conference in March. We received a lot of positive feedback on our information booklets and the awareness poster.