

DONATIONS

- The Robert Horne Group donated a very generous €2,500 to HDAl.
- Heineken Ireland were again generous to HDAl with a contribution of €350
- Special thanks to Eileen and the Teachers Union of Ireland Credit Union who continue to support us. They recently donated €500 towards our work.

We are very grateful to our members and friends who sent us kind wishes and donations over the Christmas season. These included:

- Mr and Mrs Kara for their generous donation of €500
- Jack and Marie for their kind wishes and donation.
- Sandra and Stan for their thoughtful card and donation. We wish you all the best in your relocation.

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 HDAl.

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 HDAl office and we will take it from there.



2007 MINI-MARATHON

The 2007 Flora Women's Mini-Marathon takes place on Bank Holiday Monday, 4th June 2007. Entry forms are available in the Evening Herald every Thursday or Saturday and also online at:

<http://www.womensminimarathon.ie/registration/register.asp>

Closing date for entries is 24th April 2007.

RESPIRE FOR CARERS - HDAl receives support from The Community Foundation for Ireland

HDAl were successful in our application to The Community Foundation for Ireland to provide a respite grant to carers who seek our support. There is a grant of €100 available for the primary carer of a HD patient. It must be used towards the cost of relaxation therapies or counselling. For further information on this grant please contact our office in writing or by telephone: 1800 393939.

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.

Huntington's Disease - Can you help to write a book?

Members of the Juvenile Huntington's Disease working group of the European Huntington's Disease Network (EHDN) are creating a book about JHD. Please see leaflet enclosed.



HDAl Library

We have 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? If so please let us know.

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. From July we intend to change the Dublin meetings to a city centre hotel and host meetings on every second month in the hope of regaining numbers. April and May will continue as normal. July will be at a city centre hotel - contact the office for information. The West of Ireland meeting is held on a quarterly basis. The support meetings offer our members the opportunity to meet in a relaxed atmosphere to swap stories and avail of peer support. Our Family Support Officer or a committee member will host the meetings. Tea, coffee and scones are provided. Contact the HDAl office on 1800393939 for more information.

DUBLIN

April 21st • May 19th
June - No Meeting

CORK

April 7th • May 5th
June 2nd • July 7th

WEST

Cuisle, June 9th and
Castlebar, Sept. 8th

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 HDAl.



NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 30, Q1 07
HDNL 2007

CHECK OUT OUR
WEB ADDRESS

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

THIS IS YOUR
NEWSLETTER. PLEASE
SEND US YOUR VIEWS

Members Meeting & AGM - June 9th 2007

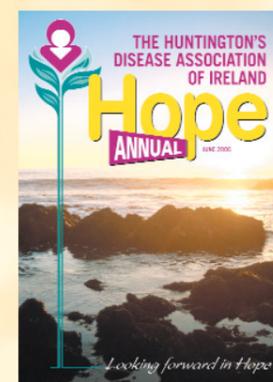
Our AGM/Respite weekend takes place from the **8th - 10th June** in Cuisle Respite Centre, Co. Roscommon. All facilities at Cuisle are fully accessible to people with disabilities. Please mark these dates in your diary. We will be sending out information in April.

Guest speakers for our members meeting on Saturday afternoon will include Alice Wexler, author of *Mapping Fate: A Memoir of Family, Risk and Genetic Research* and Carol Clayton, who will discuss cognition and HD.

We plan to have therapies available again this year as the Chiropody, Massage and reflexology therapies available last year proved very popular.

If you can not attend due to travel difficulties 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 also hope to provide a bus from Cork again this year if there is sufficient interest.

Annual Magazine



We will be launching our second edition of our annual magazine Hope Annual at Cuisle in June. The magazine has personal stories, information on services, a chill out section with competitions and recipes and a young peoples section. There is still time to contribute. If you have any personal stories, useful information, photos or jokes etc we would be delighted to hear

from you. We are also hoping to run a short story competition for Adults and also for Young People (Under 12 and Under 18).

We look forward to receiving your contributions.

International Brain Awareness Week

International Brain Awareness Week ran from 12th to 16th March 2007. This annual event promotes awareness of developments in brain research and the importance of developing successful treatments for neurological conditions. The Neurological Alliance of Ireland (NAI) is an umbrella group representing neurological charities. They use Brain Awareness Week to highlight the lack of services for patients with neurological conditions. They organised a series of free public lectures on brain research in Trinity in association with the Trinity Institute of Neuroscience.

Mind Matters, RTE Radio One features HD

Mind Matters is a science series on RTE Radio One. The second series began on March 6th 2007 and featured Huntington's Disease.

Parkinson's Disease, Epilepsy, and other conditions will be discussed in future programmes. Ella Mc Sweeney, producer of Mind Matters, interviewed a HD patient, a carer, a person at risk and a family member who received a good test result. She also interviewed a number of professionals. Professor Michael Conneally discussed his research work in Venezuela towards locating the HD gene.

Professor Patrick Morrison who carries out genetic testing in Belfast City Hospital talked about questions relating to environment and other possible genes having an effect on the onset of HD. Geneticist Sarah Duke from the National Centre for Medical Genetics spoke about the scientific aspect of the testing procedure. Dr Anthony Hannan an Australian scientist discussed research carried out on mice in an effort to determine the effects of environment on HD onset. Dr Hannan and his research team have gone on to explore how genes and the environment interact in the brain at molecular and cellular levels. For more information on the programme see <http://www.rte.ie/radio1/mindmatters>. You can subscribe to the series as a podcast - the feed is

www.rte.ie/radio1/podcast/podcast_mindmatters.xml.

Can you ask for help?

Spring has arrived, in theory at least! The winter months can take their toll on our moods. Many people feel gloomy when the days are shorter, the clouds greyer and the rain more persistent. For some people preparing for Christmas takes a lot of energy and overspending is common. By the time January has started some of us may be under the weather due to too much spending and socialising. Some people may have weakened their immune system and are more prone to catching colds and feeling irritable. It is important to be able to recognise how we are feeling so that we can take steps to help ourselves. There are also others we can turn to for help and advice.



■ If you have financial worries The Money Advice and Budgeting Service (MABS) is a free and confidential service for people with debt and money management problems. They have offices throughout the country, website: www.mabs.ie

■ A chat with your GP or Public Health Nurse or a visit to a good local health shop can provide advice on dietary supplements which can boost your immune system and increase your energy levels. Perhaps you can make time to visit your local library to look up books on nutrition and exercise.

■ If you are a carer you may feel over burdened and unappreciated. You can call HDAI on Freefone 1800 393939 for support and advice. Other organisations such as The Carers Association provide support and advice for carers.

■ Perhaps you are worried about being at risk to HD. If you need to talk in confidence about your worries you can call Catherine our Family Support Officer on Freefone 1800 393939. The Irish Association for Counselling and Psychotherapy (IACP) has information on IACP approved practitioners. Their telephone number is; 01 230 0061 and their website is: www.irish-counselling.ie. Your GP may also be able to recommend counsellors in your area.

■ If your HD symptoms have already started and you are worried about the future you may welcome talking to someone in a similar situation. We have monthly/bi-monthly support meetings in Cork and Dublin and quarterly meetings in the West of Ireland. Our annual respite weekend in June is held in Cuisle, Roscommon and offers members the opportunity to meet and chat with other people from HD families. For more information call Catherine on Freefone 1800 393939.



Some of us start off a new year with determination to achieve the new-year resolutions we promised ourselves. Healthier eating, a better exercise routine or de-cluttering our living space are fairly common new year resolutions. Even if we are not as successful in achieving these as we hoped, it often feels good to try. Sensible exercise, healthy eating and drinking and a good night's sleep can help us feel better physically and emotionally.



If these changes are not enough it is important to recognise that we may need outside help. Struggling to cope may do more harm than good in the long term.

Fundraising Events

Tesco Bag Packing

Frances, Joe, Anna, Tony, Jimmy, Betty, Mary, Shauna and Joan with Family and friends took part in three days of bag packing at Tesco Merion in Dublin to help raise awareness and funds for HDAI. The event was extremely successful and raised €2636 for HDAI. We are very grateful to Tesco Merrion in Dublin 4 for giving our members the opportunity to carry out their Tesco bag packing charity event there. Thanks to all for their hard work packing bags and informing shoppers about HD. Thanks to all who donated.

Sloan Rangers Line Dancing

Phil and her friends continue to donate to HDAI through their regular line dancing classes. They are planning another dance marathon for March.

CBS Naas

CBS Naas organised a fundraising event for HDAI as part of their Rag Day. Thanks to all the students and staff who helped with this event which raised an impressive €1000 for our work.



(Front, left to right): Brendan, Anna, Nicole pictured with Aine and Bernie (behind).

Port Tunnel Run

Congratulations to Bernie, Aine, Brendan, Anna and Nicole who braved the weather and took part in the December 2006 Port Tunnel Run to raise awareness and funds for HDAI. Thanks also to Austin and Louise who worked hard to raise sponsorship. This event raised €755. Thanks to everyone who took part.

Lobbying for better services in election year

HDAI representatives had a meeting with Minister for Health, Mary Harney, in September 2006 in order to stress the need for better services for HD patients and their families. We advised her of problems such as:

- *Lack of Neurologists / Non existence of Multi-disciplinary Teams*
- *Chronic Lack of Genetic Counsellors*
- *Difficulties in obtaining/renewing Medical Cards*
- *Inadequate Funding*
- *Lack of Support for carers and families*
- *Lack of Day Centre Facilities*
- *Non Recognition of HD*
- *Insufficient Resources for Long Term Care*

We would welcome a 'one day' multi-disciplinary hospital appointment with the patient having access to Speech therapy, Occupational Therapy, Social Workers, Psychologists, Psychiatrists, Nutritionists, Dieticians, Dentists and Counsellors in one visit.

As this is an election year there is much debate about the inadequacies in the health service. If you have the opportunity to lobby any political representatives we would be grateful if you could highlight some of the issues listed above.

The Irish Council for Bioethics Public Consultation Survey on Stem Cell Research

The Irish Council for Bioethics is considering the ethical issues surrounding adult and embryonic stem cell research and wishes to survey public opinion in Ireland on this matter. The Council invites interested members of the public, professional and voluntary organisations to participate in the consultation by completing a questionnaire. A supporting information leaflet on stem cell research is available from their office Telephone: (01) 477 3217 or website <http://www.bioethics.ie/index.html>

The Irish Council for Bioethics (Comhairle Bitheite na hÉireann) was established in 2002 as an independent, autonomous body to consider the ethical issues raised by developments in science and medicine.

The establishment of the Council was recommended by the Government Report of the Inter-Departmental Group on Modern Technology published in 2000.

The Council is funded by a grant from Ireland's National Policy and Advisory Board for Enterprise, Trade, Science, Technology and Innovation (Forfás).

It states it's Terms of Reference as:

1. To identify and interpret the ethical questions raised by biomedicine in order to respond to, and anticipate, questions of substantive concern.
2. To investigate and report on such questions in the interests of promoting public understanding, informed discussion and education.
3. In light of the outcome of its work, to stimulate discussion through conferences, workshops, lectures, published reports and where appropriate suggest guidelines.