

Donations

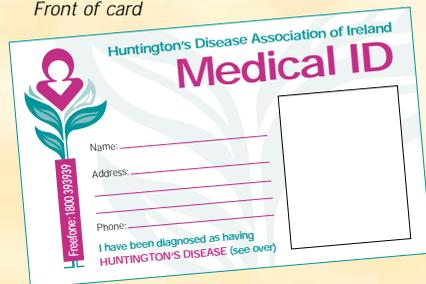
We would like to express our sincere thanks to Chris O'Hanlon for completing the mini marathon on behalf of HDAI and raising an admirable €600 in the process. The Teachers Union of Ireland's Credit Union sent us a very generous donation of €500 towards our work. Grateful thanks to the TUI Credit Union. Thanks to all those members who contribute and especially Bernie and Martina who sent in sponsorship recently.

We would also like to extend our grateful thanks to all those members who donate and fundraise on our behalf, your support is a great source of encouragement to the committee and staff of HDAI.

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



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.

HD Chair

If you need a HD Chair for a family member please let us know. 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?

What do you get the person who has everything?



Vouchers for €10, €20 and €50 are available for purchase from the HDAI office

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

JULY 31st • AUGUST 28th
and SEPTEMBER 25th

CORK

AUGUST 7th • SEPTEMBER 4th
and OCTOBER 2nd

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. 20
HDNL 2004

Report from Cuisle AGM

Our 13th AGM took place in Cuisle holiday centre, Co. Roscommon on June 12th 2004. Approximately 60 members attended on the day with 54 enjoying the weekend there. Our committee reported on the years activities and presented our annual audited accounts. Our members elected their representatives for the year ahead.

After the official business of the AGM we had two speakers providing information on HD. Our members then had the opportunity to relax and catch up before the evening entertainment.

After a very enjoyable meal Joaquim, a favourite at Cuisle provided the entertainment. He was well supported by some of our members. A number of singers joined Ann (our regular singer) including Rachel, Philip, Stephen and two brave new novices to Cuisle Pat and Mary.

The socialising lasted until the early hours with many persisting until dawn!

We would be grateful if those of you who were at Cuisle would send us in your comments regarding the weekend. For those of you who did not attend we would welcome your suggestions on how to make this weekend more accessible to you.

Our Members at Cuisle made the following comments:

- 'Just great' - *Shirley & Phil*
- 'Excellent as always' - *Yvonne*
- 'Good luck to everyone in the future and thanks very much for everything' - *Martina*
- 'Best weekend ever, thanks for everything. Had a ball' - *Jacinta*
- 'Thanks very much for a great weekend' - *Mary & Eva*
- 'Best of luck for the coming years', - *Frances & Frank*
- 'Great weekend, had a ball and a massage. Thanks Mark, Damien & Stephen!' - *Anne*
- 'Brilliant weekend again' - *Donal*
- 'Great weekend, good meeting and nice company' - *Philip & Nuala*
- 'We had a ball, good food, good crowd and an interesting meeting. Thank you all' - *Mary & Ed*
- 'We really enjoyed the weekend. Thank you' - *Patricia & Michael*
- 'Thanks to all for arranging the weekend. Wonderful time all round. Speakers interesting and informative. We all enjoyed our weekend. Looking forward to next year' - *Anna*

Into the West

Support Group Meeting - Castlebar
24th July 2004 - Phone office for details of venue.
We are hoping to host a Support Meeting once a quarter in the West of Ireland and will have a trial meeting on 24th July 2004 in Castlebar. We enclosed a survey in our Q4 2003 newsletter and of those who responded Castlebar was the most popular choice. If there is anyone who would prefer a private meeting with Bernie our Development Officer on the day please contact the office and let us know.

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

**CHECK OUT OUR NEW
WEB ADDRESS**

www.huntingtons.ie

OUR OLD ADDRESS IS
STILL VALID BUT THIS ONE
IS EASIER TO ACCESS

**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

FAIR CITY STORYLINE

We have been advised Fair
City intend to revisit the
Huntington's Disease
storyline the week
commencing July 13th
2004.

**SUPPORT GROUP
MEETING - CASTLEBAR**
24th July 2004 - phone
office for details of venue

Cuise AGM (continued)

Speakers

Dr David Craufurd gave a presentation on the behavioural aspects of Huntington's Disease. He is Senior Lecturer in Medical Genetics and honorary Consultant in Neuropsychiatric Genetics at the Central Manchester Healthcare Trust. His research interests include Huntingtons Disease and the genetic counselling process. The 2005 World Federation of Neurology and



Bernie and David Craufurd

International Huntingtons Association Conference will take place in Manchester and David is one of the key organisers for this conference.

Dr David Craufurd arrived at Cuise on Friday evening and was available to answer questions from members. He had to return to Manchester Saturday evening to fly to Munich Sunday morning. We appreciate him creating time from his busy schedule to meet us at Cuise.

Bernie presented David with a HDAI Crystal memento as a token of our appreciation for all his hard work and generosity.

Professor Bernhard Landwehrmeyer gave a presentation on the EURO Huntington's Disease Network. European scientists and medical doctors from 13 countries have established the "EURO Huntington's Disease Network"

in order to facilitate research on Huntington's Disease. The network receives funds from a private American foundation and is thereby independent of an industrial sponsor.

The network hopes to provide a platform for professionals and people affected by HD and their families to facilitate working together throughout Europe. It hopes to facilitate natural history studies and interventional trials to help find a cure.



Bernie and Bernhard Landwehrmeyer

Recognising Support

After dinner on Saturday night Bernie on behalf of HDAI presented our Glass mementos to a number of people in order to acknowledge their significant contribution to improving the lives of those affected by Huntington's Disease.

These included:-

Dr David Craufurd: In recognition of his work in the battle against HD and in particular his willingness to assist HDAI when requested to do so.

Professor Bernhard Landwehrmeyer: In recognition of his work in the battle against HD

Rachel Sarah Murphy: Since playing her character at risk to HD (Jo) in Fair City, Rachel has devoted a lot of her time and energy to meeting HDAI members and creating awareness on our behalf. She has also gone beyond the call of duty in taking part in a Charity Horse Ride to help raise funds for HD. Rachel was delighted with her gift.



Bernie presenting Rachel with her gift.



Jacinta and Rachel

Jacinta and Kay: for their bravery in creating awareness by going public with their stories in Nationwide last February

Francis Stacey: for her magnificent energy in raising funds for HDAI, throughout the year.

HDAI Member: for a private donation of €5000. The donor wishes to remain anonymous.

Ray Sheerin of Chemistry Strategic Communications Ltd: to acknowledge their contribution to the increased awareness of the Huntington's Disease Association of Ireland by creating our bus stop posters free of charge.

Mary O'Rourke: to acknowledge her contribution to the development of the Huntington's Disease Association of Ireland by authorising a development grant in the early days.

Fundraising Events

Monivea Charity Ride

The Monivea Charity Ride Committee in Monivea, Co Galway collected a total of €14,330 as a result of their 16km Horse Ride of which €7,165 was donated to HDAI.

Bernie and Rachel Sarah Murphy ('Jo' in Fair City) took part in the ride. They returned to Monivea at the end of April to collect a cheque on behalf of HDAI

We are very grateful to Michael Dolan Chairperson, Mary Byrne Secretary, Sarah and the hard working committee for all their hard work.



The Committee of Monivea presenting a cheque to Bernie and Rachel. Thanks to Ger Cooke for this photo.

Pearse College Quiz night



Pictured here are Eileen O'Shaughnessy and Antoine O'Riain, organisers of the Pearse College Annual Charity Table Quiz. Sincere thanks to the staff and students who raised €1050 for HDAI as a result of the quiz night

Kilconly GAA Club

The Kilconly GAA club held a sponsored walk on St. Stephens Day to raise funds for their club and a designated charity. This year they selected HDAI as their chosen charity. The club raised an impressive €3,500 for HDAI. Two of our members Ann and Margaret are pictured collecting the cheque on behalf of HDAI. Many thanks to everyone involved in this event.



Pictured (left to right): Danny, Noreen, John, Bernie, Ann, Margaret, Ann and Pauline

Mini Marathon

Pictured (below) relaxing before the mini marathon are Gretti, Bernie, 'Betsy' (Greg), Aisling, Susan, Gemma and 'Danielle' (Donal). Danielle and friends raised a very valuable €948 for HDAI. With Betsy and Danielle flashing those lashes who could resist!



Sir Peter Harper Awarded a Knighthood

Peter Harper a Welsh scientist who has spent 35 years helping unravel the mysteries of genetic disorders recently received a knighthood for his services. Sir Peter Harper, professor of medical genetics at the University Wales College of Medicine, Cardiff, and a consultant at the University of Wales, said he was "proud, surprised and very pleased" to receive a CBE in the Queen's Birthday honours. "Basically, I feel it acknowledges what a lot of folk have done, not just me, and that's why I'm very pleased."

"When I started there was very little you could do. You could give the right genetic information but it was very limited -

there were no genetic tests and little understanding of what was causing these diseases." "But now we can deal with most conditions, we have tests that confirm risks and we're now at the exciting stage where we're starting to see therapies being developed."

Sir Peter has had a long-standing research interest in inherited neurological disorders, especially Huntington's disease and myotonic dystrophy. He has been extensively involved in the practice and development of genetic counselling, and is author of the much used book Practical Genetic Counselling. More recently he has been involved with social and ethical aspects of medical genetic developments and co-authored the book 'Genetics, Society and Clinical Genetics'. He is a member of the UK regulatory body Advisory Committee on Genetic Testing and has helped to develop public policy in the UK and internationally in relation to Medical Genetics.