

Donations

We would like to express our sincere thanks to Mary and members of her Resident's Association who raised €505 from a raffle at one of their coffee mornings in the Autumn. They raffled one of our HDAI mementos on behalf of the Association.

Thanks to a member for his very generous donation of €5000.

Thanks to The Teachers Union of Ireland Credit Union for their generous donation of €500.

Many thanks to All Saints Church Raheny who recently donated €200 to the Association.

Thanks to all of you who have purchased our glass mementos.

We would also like to extend our grateful thanks to all those members who donate, 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

Huntington's Disease Association of Ireland
Medical ID

Name: _____
Address: _____
Phone: _____

FreeFone: 1800 393939
I have been diagnosed as having HUNTINGTON'S DISEASE (see over)

Huntington's Disease is a hereditary brain condition. It causes unsteady gait, slurred speech and/or confusion. It is sometimes mistaken for intoxication.

IN CASE OF EMERGENCY, PLEASE CONTACT

YOUR UNDERSTANDING IS APPRECIATED

<http://indigo.ie/~hdai/>

Reverse of card



From the Heart of Ireland

What have broadcaster Gay Byrne, TD Liz McManus, Dubliner John Sheahan and MP Gerry Adams got in common with student Raymond Foley, housewife Patricia Smyth and teacher Sean Lyons?

Answer: They have all donated their time and their talent to the newly published 'From The Heart Of Ireland' (ISBN 0863223168) - a collection of inspirational true-life stories compiled to raise funds for the benefit of Laura's Hope, an international charity devoted to finding a cure for Huntington's disease.

This unique collection boasts a wide range of contributors of diverse backgrounds, drawn from the four corners of Ireland and beyond. Some of the authors are well known to the general public as broadcasters, politicians, writers and journalists; others are well known figures within their professions or occupations; and others are pretty much the man or woman in the street. Their stories are inspirational and positive, often focusing on a turning point in a person's life.

Brendan Power, who collected the stories and put the book together, is originally from Fethard on Sea in County Wexford. He is a powerful motivational speaker, and an expert in sales productivity who was recently described as being in the top 2% of salespeople in the UK. He got the idea for the book after a friend lost his daughter to Huntington's. 'Laura Evans began to show symptoms of the disease at the age of thirteen, and eventually died of the rarer juvenile form of the disease in October of 2001, when she was just twenty-eight years old', said Brendan. 'Laura's great hope the last few years of her life was that a treatment would be found before it also claimed her sister Andrea who is now thirty-three years old, and showing symptoms of the disease'. 'Warren and Arlene, Laura's parents, were determined to do something to help



others and launched Laura's Hope; I was only too happy to do my little bit'.

The book has been compiled in such a way that whenever you have got a few minutes to spare - even while the commercials are interrupting your favourite TV programme - you can read a full story, or two. You can dip in and out whenever the mood takes you and in just a few minutes gain inspiration from one of the many stories.

Amongst the contributors is TV host Mary Kennedy, musician Con Cluskey of the Bachelors, politicians Marian Harkin and Liam Twomey, journalists Mary Kenny and Angela Doyle; authors Ultan Cowley, Soibhe Lally and Martin Malone; businessmen Bill Cullen and Feargal Quinn, and world famous sports physiotherapist Gerard Hartmann. Raymond Foley is a gifted young artist who has provided a number of illustrations for the book.

Brendan says, 'I really wanted it in the shops in time for Christmas because it means you can give someone a great present and help others at the same time'.

Brendan Power

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 29th • DECEMBER - No Meeting • JANUARY 31st

CORK

DECEMBER 6th • JANUARY 3rd and FEBRUARY 7th

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. 18
HDNL 2003

RESEARCH

HDF Commits over \$20 million in 2003 to find new treatments and a cure for Huntington's Disease

The Hereditary Disease Foundation is a non-profit, basic-science organization dedicated to the cure of genetic disease. 100% of all publicly donated funds is directed to the support of biomedical research. The Foundation focuses on Huntington's disease and continues its support of cutting-edge science, including the development of mouse models, studies of protein-protein interactions, strategies for gene therapy, and intercellular signaling in striatal neurons. Through grants, fellowships, the

Foundation continues to build a research community committed to the cure of Huntington's disease and related disorders.

"Families with Huntington's Disease should take heart in our all-out push to find a cure for HD"

Professor Nancy Wexler, President of the Hereditary Disease Foundation New York - www.hdfoundation.org

Summary of the Year's Activities

2003 has been a very busy year for HDAI. We received greater awareness as a result of the HD storyline on Fair City and the various media attention following on from that storyline. We would like to thank once again the Fair City Research team, and the actresses Rachel Sarah Murphy and Ann Marie Horan who took time to meet our members and committee to learn more about the condition. We received calls from many new members as a result of increased awareness. Here is a summary of some of our work throughout the year.

ONGOING WORK

HDAI provide information / advice to family members and health professionals on a variety of issues including: nutrition and diet, managing symptoms, physiotherapy, predictive testing, applying for medical cards, applying for carer's allowance, seating, aids and appliances, etc.

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

GENETICS

PROFESSOR ANDREW GREEN IS AVAILABLE AT (01) 455 8111 IF YOU NEED INFORMATION ON PREDICTIVE TESTING. HE AND HIS TEAM WILL ADVISE YOU. THEIR WEBSITE ADDRESS IS www.genetics.ie

DO YOU HAVE ANY TOPICS YOU WOULD LIKE DISCUSSED OR ARTICLES TO CONTRIBUTE? THIS IS YOUR NEWSLETTER

CHECK OUT OUR NEW WEB ADDRESS

www.huntingtons.ie

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

Summary of the Year's Activities (cont).

We continue to provide support to members and families as and when required.

The Committee meet monthly to discuss HDAI's work and future progress. They approve family aid and respite for members.

Cuisse was a great success again this year with many members attending for the first time, we hope to see more people availing of this respite weekend in 2004.

Our HDAI booklet has been updated and sent to members. We are very grateful to International Huntington's Disease Organisations for material made available to us. Thanks to Professor Andrew Green and his team for their help in editing the booklet and to The Northern Area Health Board for providing funding towards publishing this booklet. Copies are available from the office.

LOBBYING

HDAI representatives met Minister for Health Michael Martin in Cork last January to discuss the needs of HD patients. Following this meeting we met with Brendan Ingoldsby, Principal Officer Physical, Sensory and Intellectual Disabilities at the Department of Health.

In April we met Niall Crowley of the

Equality Authority to discuss the work of HDAI and mention the need for legislation to protect against genetic discrimination. Rachel from Fair City took the time to attend both meetings.

Along with Prof. Andrew Green we met with Dept of Justice staff to discuss Disability Legislation. Following on from this meeting we met Minister of State William O'Dea at Department of Justice.

Bernie attended an Irish Council of Civil Liberties seminar on Disability Legislation.

MEDIA

Bernie and Philip were interviewed on the Pat Kenny radio show. In addition, Bernie did interviews with Limerick FM, East Coast Radio and the People newspaper regarding the HD storyline on Fair City. The Cork Echo and Insight magazine also featured articles.

Insight Magazine featured an article on HD and the related storyline on Fair City.

ADVANCING CARE FACILITIES?

HDAI met Marion Meaney, Manager of Disability Services, Dublin West in Cherry Orchard.

Bernie and Patricia attended meetings in St Mary's with healthcare staff to discuss developing services for HD with the possibility of a HD specialised center there in the future.

Bernie and Patricia met Dr Janice Redmond, Neurologist at St James Hospital to discuss services for HD patients.

NETWORKS

Pat and Bernie represented HDAI at the International meeting in Toronto. Bernie remains on the IHA Board.

We are members of various networks including GIDO, DFI and NAI and meet to discuss relevant issues.

OTHER INFORMATION

A group of ten HDAI representatives visited our patron, President Mary McAleese in Aras an Uachtarain in June 2003. We were warmly welcomed by the president who impressed us with her knowledge of Huntington's Disease.

We have commissioned a special Glass memento to commemorate the 20 year anniversary of our first minuted meeting of 19th May 1983. This piece is a Crystal ball and Dice on a glass stand. The crystal ball represents the future and the dice signifies the chance of inheriting Huntington's Disease.

We presented these Glass mementos to a number of people in order to acknowledge their significant contribution to the development of the Huntington's Disease Association of Ireland over the last twenty years. These included President Mary McAleese, Professor Mike Conneally, Bernie and committee members who have made a significant contribution to HDAI. These special pieces are available to purchase from the HDAI office.

We are grateful to our members for their membership fees, donations and fundraising contributions since January 2003. Many thanks to all our members and friends for their generosity and energy!



What do you get the person who has everything?

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

Chemistry

Fair City's introduction of a HD storyline in January 2003 and subsequent radio and press interviews has helped to raise some positive awareness for HD throughout Ireland. As a result we have had contact from many new people who are at risk to HD, which in turn has led to an increase in our membership (in the past as a lot of you will know many people were misdiagnosed with Alzheimer's, Parkinson's etc.) We now realise that there are many families in Ireland who are affected by HD but are not aware of our services. In addition there are many misconceptions about this condition throughout Ireland. In order to increase awareness we recently met with "Chemistry" an award-winning P R company to discuss the possibility of an awareness building / education campaign for our Association. The company have advised us that they will consider working on our behalf free of charge, however we would have to pay for third party production and media costs. They recommend using press to create awareness and have negotiated some free advert space on our behalf.

An awareness campaign will:

- Inform additional families at risk about our services.
- Inform health care workers where to find support and information.
- Highlight the need for anti-discrimination protection.
- Educate the general public on Huntington's Disease.
- Help maintain funding to continue our work.
- Break the cycle of fear and frustration for those at risk to / affected by HD.

We are happy to have the opportunity to highlight this traumatic disease without the need to expose families. It can be wise to restrict the amount of people knowing about the disease as people at risk could be discriminated against, be it through financial discrimination, employment, insurance etc. HDAI hope that through greater awareness and better legislation we can fight discrimination.

Disability Legislation

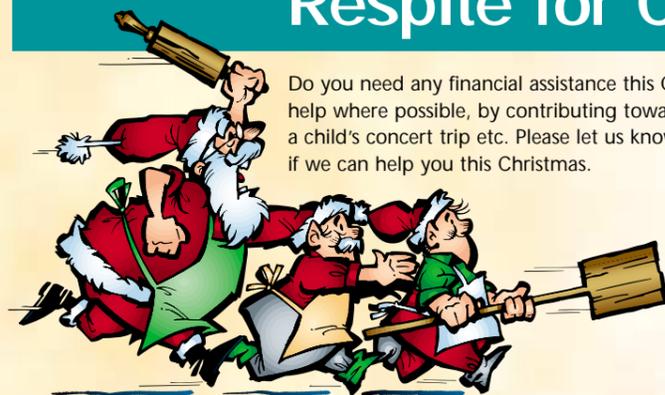
Professor Andrew Green, National Genetics Centre, Judy Windle, Genetic Inherited Disease Organisation, Bernie and Pat from the committee recently met with Minister of State Willie O'Dea at the Department of Justice, Equality and Law Reform to discuss the need for Genetic protection in the forthcoming Disability Bill. Potential Genetic Discrimination by insurance companies, mortgage brokers and employers needs to be legislated against. We look forward to working together to influence positive change.

The National Disability Authority, The Human Rights Commission and The Law Society held a public conference on 'Global Trends in Disability Law, Setting a Context for Irish Law Reform' on September 13th last. Representatives from the disability, legal and human rights sectors spoke at this meeting. Speakers included Stefano Sensi, Human Rights Officer at the Office of the High Commission for Human Rights in Geneva who discussed the preparation of a UN Treaty on human rights for the disabled, Barbara Nolan, European Commission who discussed Advancing the Equality Agenda in Europe, Caroline Gooding, Disability Rights Commission UK talked about the experience of the British Courts in applying the ECHR in relation to Disability Issues, Patricia Rickard Clarke, Law Reform Commissioner who discussed legal capacity, proposals for law reform, Donal Toolin, Forum of People with Disabilities presented a paper on 'Equal Citizens: proposals for Disability legislation' Gerard Quinn Professor of Law NUI Galway discussed Effective remedies and other challenges - an international perspective and Rory O'Donnell Director, National Economic and Social Council presented a paper on 'Beyond justifiable rights - standards and equality'.

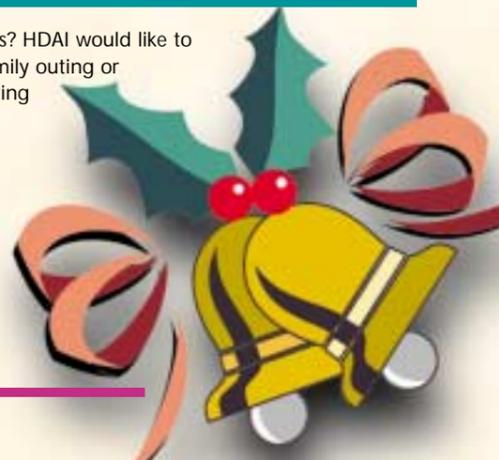
Bernie and Patricia attended the conference and availed of the opportunity to mention our concerns to a number of the delegates present.

If you have the opportunity please mention your concerns to your local political representatives.

Respite for Christmas



Do you need any financial assistance this Christmas? HDAI would like to help where possible, by contributing towards a family outing or a child's concert trip etc. Please let us know in writing if we can help you this Christmas.



Towards an Expert Centre for Huntington's Disease

Bernie & Patricia met with Dorothy McGarry and Rosemarie Reynolds of Cuan Aoibhean, St. Marys to discuss the probability of extending services for HD patients. Options include a relaxation day for people with HD to use the facilities at Cuan Aoibhean on an out patient basis. Clients would provide their own transport to and from Cuan Aoibhean. We will keep you informed about this project.