

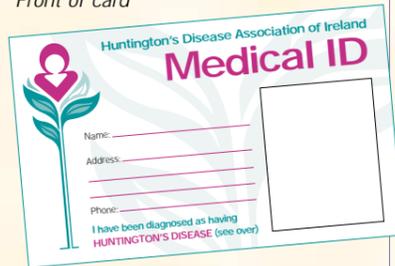
Membership

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.

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

Brainwaves

■■■ SECRECY

If you can't get rid of the family skeleton you may as well make it dance.
- *Attributed to George Bernard Shaw*

■■■ NEVER GIVE UP

Once there was a great forest fire, and all the birds and animals rushed to escape. A small bird went to the river and collected a drop of water. The other birds laughed. What are you doing? They asked. She replied 'I'm doing what I can'.

- *Native American Story*

■■■ ACKNOWLEDGE YOUR ACHIEVEMENTS

We ask ourselves, who am I to be brilliant, gorgeous, talented and fabulous? Actually, who are you not to be? You are a child of God. Your playing small doesn't help the world.

- *Nelson Mandela*

■■■ HOPE

We must accept finite disappointment, but never lose infinite hope.

- *Martin Luther King*

■■■ BE POSITIVE

Write the bad things that are done to you in sand, but write the good things that happen to you on a piece of marble.

- *Arabic saying*

■■■ LIVE

May you live every day of your life.

- *Jonathan Swift*

■■■ LOVE

A hug warms the soul and places a smile in the heart

- *Anonymous*

Donations

We would like to express our sincere thanks to Eva and family, Liam and all at The Bridge Tavern for raising €500 in a pub raffle on behalf of the Association, we are very grateful to all involved. Thanks to companies who recently made donations to HDAI these included: Ulster Bank Dun Laoghaire €50 and The Ulster Bank Staff Charity Fund (ROI) who very generously donated €2,500 to our Association. Thanks to Roisin for her generous donation from the Dept. 'swear box' (we won't say keep swearing!!)

A special thanks also to the NI representatives for their generous contributions at Cuisle.

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

We would also like to extend our grateful thanks to those members who donated generously but prefer not to be named.

Your support is a great source of encouragement to the committee and staff of HDAI.

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

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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. 16
HDNL 2003

NEED HELP?

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.

Updated Booklet

Please find our updated HDAI Booklet enclosed

A Visit to our Patron

A group of ten HDAI representatives visited our patron, President Mary McAleese in Aras an Uachtarain on 27th June 2003. We were warmly welcomed by the president who impressed us with her knowledge of Huntington's Disease.

The president complimented us on our achievements over the last twenty years and on the quality and clarity of our publications. Catherine Paradise, Chairperson of HDAI, presented the President with our specially commissioned glass memento (see article HDAI 1983 - 2003) to thank her for being such an active Patron.



We have since received a beautiful card with the following note:

"Thank you most sincerely for your kind gift. Your thoughtfulness and generosity are very much appreciated" Mary Mc Aleese, Uachtaran na hEireann.

CUISLE 2003

Our 12th AGM took place in Cuisle holiday centre, Co. Roscommon on June 7th 2003 with over 60 members attending on the day.



Unfortunately our Chairperson was unable to attend due to a foot injury so our Vice Chairperson conducted proceedings. Our auditor John Handibode presented our annual financial report and following our AGM we held an EGM to adapt changes to our Memorandum & Articles of Association to meet requirements of the Revenue Commissioners.

After the official business of the AGM and EGM was completed Marie McGill gave an interesting presentation on the work of the Scottish Huntington's Disease Association. Marie is Acting Director of the Scottish Huntington's Association (SHA) at present and has worked as a family support worker with SHA for some time.

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CUISLE 2003

(continued from page 1)

As well as being informative Marie's presentation was also humorous and included a list of comparisons between Ireland and Scotland (we have more than the rain in common!!)

Rosemarie Kelly, Genetic Counsellor at the National Centre for medical Genetics discussed the hereditary nature of HD and the service provided by the Clinic.

Rosemarie works with Professor Andrew Green at The National Centre for Medical Genetics and had previously worked with Professor Peter S. Harper in Cardiff. Professor Harper has had a book on Huntington's Disease published, it is available to loan from the office

60 members attended the meeting, this group included regular attendees, and many attending Cuisle for the first time. We were delighted to welcome five representatives from the Northern Ireland HD Association and would like to thank Jeffrey in particular for his wonderful singing.

We were very pleased to have Professor Mike Conneally and Rachel Sarah Murphy join us to celebrate twenty years of HDAI. Professor Conneally is a Distinguished Professor at the Indiana University School of Medicine, he was a key collaborator in the identification of the gene for Huntington's, he is a member of The Hereditary Disease Foundation and part of the Venezuelan Research Team. Professor Conneally was elected President of the American Society of Human Genetics for the year 2002. He also served as Secretary General of the World Federation of Neurology.

He has been a good advisor and friend to us over the years.



Rachel Sarah Murphy is the actress who plays 'Jo' in Fair City. 'Jo' is from a HD family and was the central character in the Huntington's Disease storyline on Fair City. Rachel, despite her busy schedule, has devoted a lot of her time and energy to meeting HDAI members and creating awareness on our behalf. One of our members presented Rachel with an exquisite wooden lamp which her husband helped create. Rachel was delighted with their very kind gift.

The entertainment was of a high standard with a lot of competition for Joaquim (our resident entertainer at Cuisle). A number of singers joined Ann (our regular singer) including Marie with her lilting Scottish accent, Rachel our very own celebrity and Jeffrey and Roisin.

The party mood 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.



Comments included:

- "The scenery was beautiful, peaceful and restful, the accommodation was first class, not to mention the atmosphere, the food, drink and 'craic'. We also enjoyed the speakers on Saturday afternoon- you learn something new everyday! And the comradeship we found, we came away feeling part of a family. God willing if invited we would love to go again".
- "Many thanks for a wonderful weekend, please put us down for 2004".
- "Thanks for inviting us. My mother and I had a great weekend, we really enjoyed it".

Equality

YOU ARE UNIQUE... just like everyone else.

Bernie, Patricia and Pat from the committee recently met with Niall Crowley from the Equality Authority and presented him with some of our publications in addition to a book by Peter Harper called GENETICS Society and Clinical practice. We want him to know about your fear of discrimination. 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.



HDAI 1983 - 2003

To commemorate the 20 year anniversary of our first minuted meeting of 19th May 1983 HDAI have commissioned Jerrpoint Glass to create a piece of glass significant to HDAI.

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. The Glass stand is engraved with the words:

"You helped shape the past... Who knows the future?"

We hope to present 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.



The following people will be presented with our HDAI 20 Year mementos.

• **PRESIDENT OF IRELAND AND PATRON OF HDAI:**
In recognition of her role as our Patron.

• **PROFESSOR MICHAEL CONNEALLY:**
In recognition of his work in the battle against HD and in particular his assistance with in the work of HDAI.

• **WILLIE KELLY:**
for his involvement in setting up the Association in the early days.

• **DEIRDRE McGRATH:**
for her involvement in setting up the Association in the early days.

• **BERNIE MORAN:**
for her involvement in setting up the Association in the early days and her continued work in developing the Association to date.

• **JOE KELLY:**
for his role as sole fundraiser in those crucial early years and for his continued support ever since.

• **MARGARET TANSEY:**
for her involvement in creating awareness by going public with her story in the early days.

• **MARGARET BLOOMER:**
for her involvement in creating awareness by going public with her story in the early days.

• **UNA GORDON:**
for her dedicated work as secretary of the Association for a number of years.

• **PHILIP BYRNE:**
for his dedicated work as Chairperson of the Association and committee member for a number of years and for creating awareness by telling his story to the media.

• **CATHERINE PARADISE:**
for her dedicated work as Chairperson and committee member of the Association for a number of years.

Our Glass Mementos are also available for purchase at €100 each, all proceeds go to the Association. If you would like more information please contact the office.

If you know of any company or individual who would be willing to purchase this piece we would be delighted to hear from you.

Rachel and Bernie at presentations to:



Margaret Bloomer



Philip Byrne



Catherine Paradise



Margaret Tansey