

## Sponsorship & Fundraising

### The Wicklow Golf Club

We would like to express our sincere thanks to The Wicklow Golf Club who recently raised €3380 for HDAI. The Golf Club has also fundraised for us in the past and we are very grateful for their continued support and generosity. This considerable sum of money is greatly appreciated and will be put to good use. Thanks to everyone who helped in this fundraising effort.



## Respite for Christmas

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

## Medical ID Card

A free Huntington's Disease ID Card is available. Please send your Photograph and relevant details to the HDAI office and we will take it from there.

Front of card

Reverse of card



## Book Update

We are updating our HD Booklet - Facing Huntington's Disease A handbook for families and friends, if you would like to review the booklet and give your opinion on what could be included/updated please contact the office and we will send you a copy. If you already have the booklet we would welcome any advice you are willing to give us.

## Donations

Thanks to all of you who sent in their membership forms. 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.

## 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 39 39 39 for more information.

**DUBLIN**

OCTOBER 26th and  
NOVEMBER 30th

**CORK**

NOVEMBER 2nd and  
DECEMBER 7th



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**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. 13  
HDNL OCTOBER 2002

## REPORT ON EHA 2002

**IF YOU NEED HELP**  
If you require help please apply 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.

**RESEARCH ARTICLES**  
See Enclosed Report on EHA 2002

**WOULD YOU TELL YOUR STORY**  
Contact HDAI if you would like to tell your story in the press or in our newsletter!



### Fair City

Do you watch Fair City? The Fair City research team have been in contact with us lately and are considering introducing a HD story line.

The European Huntington's Association Meeting took place in Zurich Switzerland from 19th to 23rd September 2002. Bernie, Patricia and two members of the committee attended. We found the conference very positive and worthwhile. Bernie resigned as President of the EHA but still remains on the Board.

Professor Bernhard Landwehrmeyer gave an excellent presentation on the process of cell degeneration in Huntington's Disease and described potential processes that could halt the process.

Professor Landwehrmeyer is involved in a European Study Group to develop possible treatments for HD. Bernie, Asuncion (Spain) and Max Klein (Netherlands) will attend meetings of the study group as some studies are controversial

Dr Suzanne Braga hosted a very interesting panel discussion on "The Prudent Care of Oneself", the panel comprised of Max and Francesca two people suffering from HD, spouses of HD patients and carers. Christiane Lokhamp from the International Huntington's Association and Jim Pollard USA, who many of you met at Cuisle, also participated. This discussion was very interesting and the panel advised the audience of their own coping strategies. We got great insight from Max and Francesca who stressed the need for a sense of humour and a relaxed attitude. The points below emerged from the discussion.

Dr Kathryn Furrer spoke about HD families in Val Mustair, a geographically isolated location in Switzerland. Marie McGill, family support worker and Acting Director of the Scottish Huntington's Association compared similarities between and a rural population in Switzerland and Scotland.

Dr Suzanne Braga hosted a panel discussion on Ethics in general with particular emphasis on Genetic Testing - reflecting on options and choices and on Dying with Dignity. The panel consisted of four doctors who answered questions from the audience.

51 delegates representing twenty European countries were represented at the conference

The Swiss Association organised an excellent meeting. Bernie as President of the EHA presented committee members with a small gift for all their hard work.

### THE PRUDENT CARE OF ONESELF

- Maintain a sense of humour
- Avoid people who fuss and cause stress.
- Accept practical help
- Phone a friend
- Take time out. For example, listen to music.
- Think, "What is," not "what isn't"!
- Separate the person from the behaviour.
- Accept your limitations and also the limitations of others.
- Get all the information. Then make decisions at your own pace.
- Live in the moment. Admire today.
- Life is not a battle; it is an art, an adventure, and a continuous act of being creative.

If you need help or counselling or are having difficulty eating or sleeping please give us a call. If you are the spouse of a pHD you may also find counselling beneficial in helping you cope you're your changed role. We could fund consultations with a counsellor in your area.

## Our New Committee and Chairperson

We now have nine members on our committee with representatives from Cork, Limerick, Kildare and Dublin. Two new members joined the committee in August 2002. Catherine Paradise has been elected current Chairperson of HDAI. Catherine served as Chairperson in the past and has been an active and dedicated member of the committee for many years. Catherine's energy and enthusiasm is of great benefit to HDAI.

## 1983-2003 A Lot Done...More to Do!

Woody Guthrie, the USA folk singer is probably one of the world's most famous HD patients. Following Woody's diagnosis in 1967 his wife Marjorie established the American HD Society, the first in the world. In addition Marjorie worked to set up HD lay organisations in many other countries. She was a tireless fighter for the HD cause and an inspiration to all who met her.

In May 1983 Deirdre McGrath, Willie Kelly and Bernie Moran met with Dick Bates to seek advice on establishing a HD Association in Ireland. At that time it was thought that the disease was rare. No figures existed on the prevalence/incidence of the disease in this country. As the group progressed, it became obvious that the problem was far greater than first suspected.

The Huntington's Disease Association of Ireland was formally launched in 1985 and despite a relatively low profile is now in contact with over 300 families. To accommodate its growing membership, HDAI became incorporated in 1998.

The Association is in an ideal position to use the expertise gleaned over many

years from the International HD Community. The International Huntington's Association has over 35 member countries and is in contact with a further 20 countries.

Dr. Nancy Wexler, one of the leading HD researchers in the world, made the following comment in a speech at the Huntington Society of Canada's annual meeting:

*"Individual people can make an impact, and you're a group like this all across the country you make a bigger impact, and when you're international, you make an even bigger impact. There is absolutely no question that the Huntington movement we're all part of is considered one of the most successful in the entire world. And what are we? Just individuals getting together and saying 'this disease cannot get me down, I'm going to conquer this thing'. And we're going to do it in the lifetime of ourselves and our children."*

In order to celebrate our achievements we would like to mark our 20th anniversary in 2003. Let us know what you feel has been important in the last 20 years and what you would like to see in the future.



## Disability Legislation

The National Disability Authority is co-ordinating a Disability Legislation Consultation Group (DLCCG) to facilitate dialogue within the disability sector. The DLCCG have organised meetings in Cork, Galway and Dublin to get peoples views but there is also the opportunity to make written submissions. Bernie and Patricia attended the Dublin meeting and emphasised the need to include an adequate genetic section in disability Legislation. We need to remember that genes are not there to cause disease but the status of our genes is related to our health. We must ensure that this status is not used against us. In their draft Proposals the DLCCG have outlined the below vision:

### An Ireland where:

People with disabilities, as members of that society exercise the same rights and obligations as others and achieve equality with other members of society.

Mainstream agencies achieve benefits for people with disabilities and include them in decision-making.

All obstacles to equal partnership have been removed.

Please let us know as soon as possible if you have any suggestions to propose for our Disability Legislation submission.

## Educational Talks

We are considering holding educational talks for professionals - give us the name of people you think would be interested in speaking or indeed listening!

## Regional Representatives

We are considering various options for the future; let us know if you would be interested in representing your area.

## Visit with Northern Ireland Committee

Our administrator and two members of the committee attended a members meeting of the Northern Ireland Huntington's Association in Belfast in early October. This meeting gave us the opportunity to meet with the board

(some of who you know from Cuisle) and members of the the Northern Ireland Association who gave us a warm welcome. Marie McGill family support worker and Acting Director of the Scottish Huntington's Association

visited health representatives to discuss the needs of Huntington's patients in Northern Ireland. She gave members present an account of her weeks work. We have asked Marie to speak at Cuisle next year.

## Advance Directives

Nobody knows what the future holds however sometimes we can plan in advance to lessen the impact of change on our lives. Some people use advance directives to advise others what they want in relation to health care decisions. An advance directive is a document that allows a person to let others know the

type of health care decisions that they want made on their behalf if they reach a stage where they cannot take part in the decision. For example the document might include a request that certain treatment should or should not be given in certain situations if the people are not competent to decide themselves at the

time. An Advance Directive is not a legal document and the legal position on them is not clear at present however it allows people to have their voice heard. If you would like any advice on Advance Directives please contact the office.

## Role of an Advocate

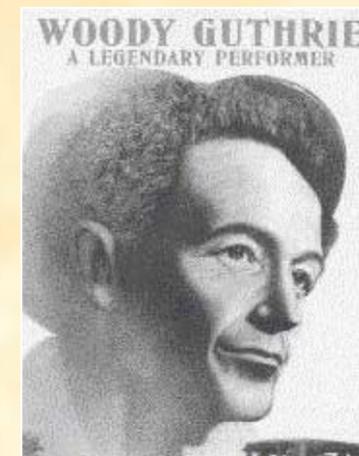
At times we all need someone to 'champion' our cause. This is particularly true if we are ill or too busy caring for others to take the time to have our voice heard. An advocate is someone

who is there to uphold our view or speak for us when we are not able to speak for ourselves. An advocate can be a friend, family member, peer, or professional (legal, healthcare etc) who will present

our views when necessary. An advocate should be skilled at listening and understanding so that they can uphold the views of the people they represent.

## Woody, a Human Right's Advocate

Woody Guthrie's wife Marjorie was a great advocate for patients and families with HD however Woody himself was a self styled human right's campaigner and used some of his songs as a voice for people who were powerless to speak for themselves, he composed "Plane Wreck at Los Gatos (Deportees)" after reading, early in 1948, that a plane deporting migrant farm workers back to Mexico had crashed. It was the last great song he would write, a memorial to the nameless migrants "all scattered like dry leaves" in Los Gatos Canyon, where the plane crashed....



### DEPORTEES

The crops are all in and the peaches are rotting,  
The oranges piled in their creosote dumps;  
They're flying 'em back to the Mexican border  
To pay all their money to wade back again

#### CHORUS:

Goodbye to my Juan, goodbye, Rosalita,  
Adios mis amigos, Jesus y Maria:  
You won't have your names when you ride the  
big airplane,  
All they will call you will be "deportees"  
My father's own father, he waded that river,  
They took all the money he made in his life:  
My brothers and sisters come working the fruit  
trees,  
And they rode the truck till they took down and  
died.

Some of us are illegal, and some are not wanted,  
Our work contract's out and we have to move on:  
Six hundred miles to that Mexican border,

They chase us like outlaws, like rustlers, like  
thieves.  
We died in your hills, we died in your deserts,  
We died in your valleys and died on your plains.  
We died 'neath your trees and we died in your  
bushes,  
Both sides of the river, we died just the same.  
The sky plane caught fire over Los Gatos  
Canyon,  
A fireball of lightning, and shook all our hills,  
Who are all these friends, all scattered like dry  
leaves?  
The radio says, "They are just deportees"  
Is this the best way we can grow our big  
orchards?  
Is this the best way we can grow our good fruit?  
To fall like dry leaves to rot on my topsoil  
And be called by no name except "deportees"?