



NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

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NL Centre Visit

Quotes from the delegation.

"I will not forget the contented expression on the face of the residents. They were relaxed and secure in the knowledge that their needs would be met and they would be supported through this difficult illness." **Bernie.**

"It was very interesting to discuss care methods and therapies and to meet with some of the clients. Visiting the unit has given us useful ideas regarding design and space required". **Acting/Assistant Director of Nursing, St Marys Hospital.**

"Thank you to HDAI for giving us the opportunity to visit a specialised centre. It was a worthwhile experience and while I got some good ideas it also highlighted the strengths of our own facility here". **Occupational Therapist, Cherry Orchard Hospital.**

"It was a good opportunity to network and hear other opinions. It was very educational and gave an insight into the need for social interventions in such a purpose built unit." **Clinical Nurse manager, Peamont.**

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.

In HDAI we dream of a centre for people with Huntington's Disease (pHD) with an outreach service for their family. This "home from home" would gather the best information from all over the world and from the real Irish experts-the patients themselves and their families. Ideally this expertise would be available to anyone in the country but the patient would decide where he/she would live. Some would spend a few weeks in the centre for respite care. Some would choose long-term care. All could enjoy a few days (once or twice a year) to be pampered and to have an expert team assess their changing needs. Someday soon I hope? Our dream has recently taken a little more shape as we try to influence some people who may make this much needed centre a reality. As part of this ground work HDAI brought a delegation from three hospitals to visit the HD centre in the Netherlands. If we could move the building and its staff over here we would have realised our dream!

Gerrit Dommerholt, Development Officer, International Huntington Association was a perfect host. The Centre is one and half hours by train from Amsterdam. We were in need of direction so Gerrit met us at our hotel and explained our timetable for the day. The staff at the centre met us and explained their work in great detail. They were generous with their time and knowledge. We then went for a visit around this spacious unit.

The centre is located in the local town and residents are free to go out if they are able. The risk is assessed as some may need help but the staff are guided by the belief that a life without risk is no life. It is important not to over protect anyone.

The multi disciplinary team include Doctor, Psychologist, Nurse, Nurses Aid, Speech Therapist, Physiotherapist and Music Therapist. There were three nursing staff to 21 residents. The team meet regularly to review the progress

and needs of each pHD. The pHD can see their file at anytime and are involved in decisions relating to their care including the big issue of tube feeding.

The doctor aims to use the minimum of medication. Staff are trained to manage disruptive behaviour. Every effort is made to get to the root of the problem and to understand the emotion behind the aggression. If all else fails they have a small time out room where a pHD can sit with a member of staff until the rage subsides.

Each pHD has their own room. The room is 18 square meters, by comparison nursing home rooms are usually 15 sq m. The doors and hallways are wide. Many of the young residents have electric wheelchairs. They can eat in the large community room which is also available for social events and meetings. There is a room available for the visiting hairdresser and the visiting dentist.

It is important not to limit a child's life by making them a mini adult with too many responsibilities. They are often not equipped to handle that pressure. The HD centre considers the entire family. Everyone wins when the centre anticipates the needs of the pHD and their family.

The centre is one of two in the Netherlands and has a waiting list of 5 years. The staff and residents took great pride in showing us their beautiful home.

We at HDAI are confident that we can influence the development of a similar unit here in Ireland. We are very grateful to our colleagues and friends in the International Huntington Association Network who allow us to learn from them.

Catherine and Bernie





October Meeting

Our meeting on October 16th 2001 with Carmen Leal the author of "Faces of Huntington's" and "Portraits of Huntington's" at Dr Steevens Hospital, Dublin was very successful with approximately 36 members present. Carmen talked about the need to help people understand that there is joy in life, even with a diagnosis of Huntington's Disease. She stressed that everyone has a special job they can do and that this job may change over time. She discussed the need to work together to create awareness to help others understand and also to help find a cure for HD.

A special thanks to Declan Nolan and The Eastern Region Health Authority for providing us with the venue and refreshments free of charge. One of our members present on the night gives her account as follows:

There was a very good turnout on the night. Carmen's presentation was wonderful. She is a most accomplished speaker as well as an excellent singer.

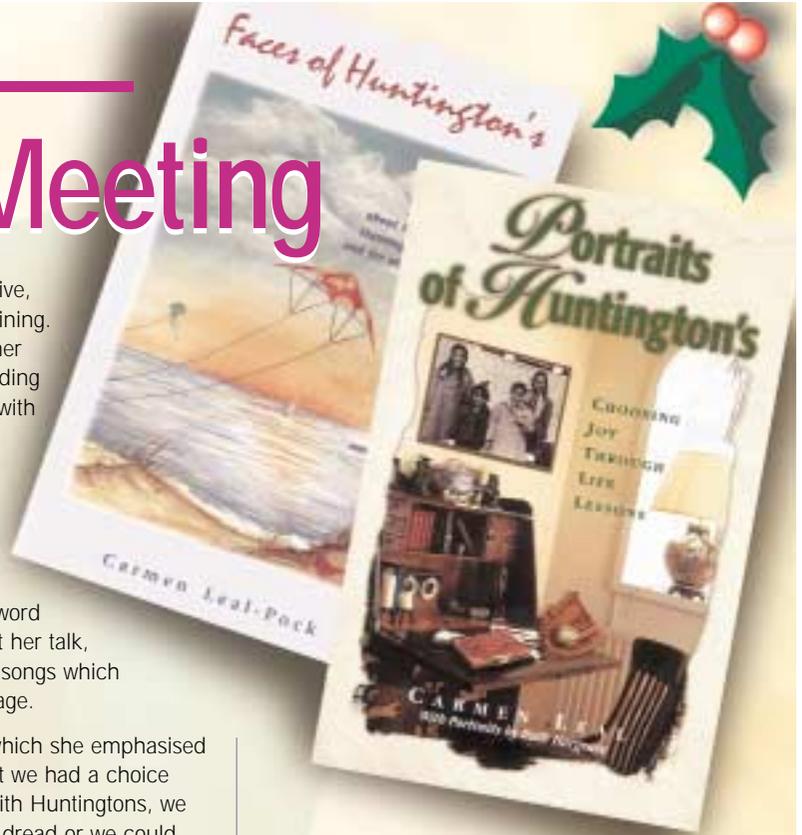
Her talk was informative, witty and very entertaining. She talked all about her own experience of finding out about, and living with Huntington's, her day to day struggles and all the problems associated with it. Needless to say, all present in the room could relate to every word she said. Throughout her talk, Carmen sang several songs which highlighted her message.

Her message to us, which she emphasised very strongly, was that we had a choice about how we lived with Huntingtons, we could live in fear and dread or we could choose to approach our lives in a more positive manner. Only we can make that choice, to take out all the small moments of happiness and focus on them and try, as best we can, to put the bad and negative times into perspective. She made constant reference to her "memory bracelet", a bracelet bought for her by her husband. She associates all their good memories shared together with links in her memory

bracelet. Perhaps we could all do with a 'memory bracelet'!

Following the talk, the customary cup of tea was served and afterwards, we adjourned to a nearby hotel where something a little stronger was served.

A good night was had by all.



A Users Experience

Every person has their different view on Huntington's Disease so I won't try to explain it for them. But what I will do is explain how having a parent with HD affects my life and maybe somebody can relate to how I feel.

I first found out about Huntington's around one and a half years ago. My parents decided to tell my brother, sister and myself that dad had the disease. It wasn't long before both my younger sibling were in tears. Me, I didn't know what to feel. At times I still don't. To put myself straight on what I was dealing with, I checked the medical dictionary. It defines Huntington's as "random twitching and general clumsiness, mood swings are inevitable, there is difficulty making decisions and memory loss". It also states that sufferers "commonly live 15 to 30 years and that no cure was available. Right there and then I knew what it meant to me and how I felt. It meant that this

disease would be tearing my family apart. It meant I'd be losing my dad. How did I feel? I felt like Eddie Jordan seeing his only chance of a podium finish being dashed as Trulli is knocked off the circuit by Coulthard - angry, upset and the question of 'why?' comes to mind. As you probably have guessed, I'm a Formula One fanatic.

Around the house I have more work to do so my dad can have more time to himself. When my friends call for me, the only reason I can give for not being able to come out is that I'm busy. That's fair enough. Still, there are times when I'm asked to go places when they know I'm not able to and they wonder why I'm not coming with them.

I'd love to tell my friends why I'm busy or can't come out, but only a few of them I can really trust and the others have problems of their own without having to worry about mine.

By now I've accepted that my dad has HD and there's a possibility that I have it also. I enjoy each day as it comes and take the best out of everything. I know that there are people my own age going through the same experience as I am, and the only thing I can say is that in future years, things can only get better!

Ashling, Aged 15



Cuisle 2002

We are delighted to inform you Professor Michael Conneally; Secretary General of the Neurological World Federation is our main speaker at our 2002 Annual Meeting.

Our AGM will take place in Cuisle Holiday Centre, Co. Roscommon on Saturday 8th June. As usual accommodation will be provided on Friday 7th and Saturday 8th June so please mark these dates in your Diary!!





Member's Report on Outing to Farmleigh

On Saturday the 3rd of November, a group from the Huntington's Association visited Farmleigh House in the Phoenix Park.

Edward Cecil Guinness (the first Earl of Iveagh) purchased the house in 1873 and immediately engaged James Franklin Fuller to re-design Farmleigh. The existing house was extended, a third storey was added and a new entrance hall constructed. The surrounding grounds were also re-designed to complement the newly enlarged house. A large lake and boathouse were constructed, an ornamental dairy created beside the lawn and a large classical fountain installed behind the house. Later in 1901 a new conservatory was added to adjoin the ballroom. Gwendolen (Edward's wife) was a keen gardener and she oversaw the transformation of the gardens - she planted the Cherry Walk, which leads to the Sunken Garden and introduced a compartmentalised layout in the Walled Garden.

This beautiful house and grounds was purchased by the Irish Government in June 1999 and since then, have been extensively and painstakingly restored to their former glory by the Office of Public Works.

The tour of the house was enjoyed by all and afterwards the group adjourned to the nearby Aishling Hotel where light refreshments were served. As always, it is a wonderful opportunity to meet up with old friends and acquaintances and to catch up with all the news and gossip. As with every occasion when HD families get together, the camaraderie of fellow members always plays a very important part of our every day lives.

**We are organizing another trip to Farmleigh on 23rd February for those of you who were unable to attend. Please advise as soon as possible if you would like to attend, as numbers are limited.

Lobbying for Rights of People with Disabilities

A conference to inform the content and context of disability rights legislation in Ireland "Get Your Act Together" was held on December 3rd. This conference was organised by The Disability Federation of Ireland, The Forum of People with Disabilities, People with Disabilities in Ireland and The National Association for the Mentally Handicapped of Ireland. Speakers present at the conference included:

- **Minister Mary Wallace**, Minister for State at the Dept. of Justice, Equality & Law Reform,
- **Kathryn Sinnott**, a founder of the Association of the Severe and Profoundly Mentally Handicapped of Cork and of the Hope Project and also a patron of the Irish Autism Alliance.
- **Gerard Quinn**, professor of Law at NUI, Galway and a member of the Human Rights Commission and of the European Social Rights Committee of the Council of Europe.
- **Dr Pauline Conroy**, a social policy analyst and director of the research and design company



Ralaheen, Ltd. She assisted the International Labour Organisation with their drafting of a forthcoming Code of Practice on disability issues in the workplace and is an expert with the Justice and Home Affairs Directorate of the European Commission.

In her address The Minister for State Mary Wallace spoke about the need to ensure genetic information does not result in people being discriminated against, she mentioned that a number of people have discussed this issue with the Dept. Of Justice, Equality & Law Reform and that HDAI is an example of an organisation concerned with the use of genetic information. (HDAI recently met with members of the Dept. to discuss this).

A representative from HDAI also attended this conference and once again stressed the need to ensure the rights of people with / or at risk from a genetic disease are protected against discrimination.

We sincerely hope the forthcoming Disabilities Bill will provide for their protection. If you have the opportunity to lobby any Government representatives please highlight this issue.

Medical ID Card

The new 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.

Huntington's Disease Association of Ireland
Medical ID

Name _____
Address _____
Phone _____

I have been diagnosed as having
HUNTINGTON'S DISEASE (see over)

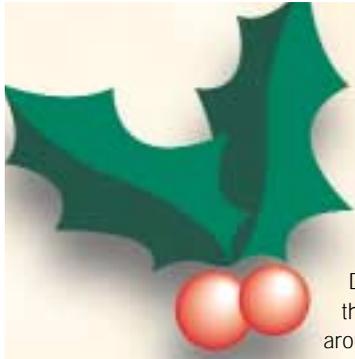
Donations

We would like to extend our grateful thanks to The Cheshire Homes Foundation and Alan O'Dwyer for their generous donations. In addition thank you to all our donors who gave generously but prefer not to be named. Your support is a great source of encouragement to the Committee and Staff of HDAI. Be assured the association will make excellent use of your contribution. We have self-addressed envelopes printed to facilitate donors. Please let us know if you require any and we will post them to you.

Medical Card

If you are applying for a medical card HDAI can support your application by writing a letter outlining the additional considerations for HD patients and their families. If you require such a letter please write to us or phone us on 1800 393939.





Living with Stress

Do you ever feel that you are racing around but getting nowhere, unable to get to sleep at night because you are still worrying about how much you have left to do? Do you find it hard to listen to what others are saying, or get frustrated with the way they behave around you? How stressed are you in your daily life?

- Lost your appetite?
- Constantly nibbling at snack food?
- Felt sick after eating?
- Bitten your nails or tapped your feet or fingers? / Been restless?
- Found yourself getting angry or upset?
- Felt you have to work extra hard or late?
- Been worked up by heavy traffic or other travellers?
- Struggled for perfection?
- Felt you don't spend enough quality time with your family?
- Found it difficult to sleep at night?
- Used cigarettes or alcohol when you are under pressure?
- Found it hard to make decisions?

- Found it hard to concentrate?
- Suffered from headaches?

We all face stress in varying levels and if it is not managed it can eventually cause health problems. There are some simple methods we can use to lessen the effects of stress:

- Take some deep breaths - use your diaphragm if possible as this allows you to take in more air.
- Stretching interrupts the accumulation of muscular tension. A lot of people carry stress in the shoulders so shoulder shrugs or stretching the arms can help to relieve this.
- Focus your thoughts - concentrate on the current situation - don't imagine frightening scenarios for the future.
- Rational thinking and positive self-talk help to interrupt negative thinking.
- Learn to pace yourself - Avoid doing multiple tasks at once - completing each task gives you motivation for the next.
- Talking problems over with an understanding and reliable confidant helps to reduce emotional tension.

- Maintain self-care. If you are Hungry, Angry, Lonely or Tired you cannot deal as effectively with a problem.
- Communicate effectively to resolve conflicts and clarify misunderstandings before they escalate into ongoing problems.

Bernie and Patricia are currently doing a Stress Management course therefore please contact us if you have a particular problem or feel you are having difficulty coping with the stress in your life as we may be in a position to help.



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?

Predictive Testing

Now that gene testing is available in the National Medical Genetics Centre many members may be trying to adapt to a changed risk. We can facilitate a support group for gene carriers if sufficient interest is available. Please contact the office if you are interested in such a support group.

How Did You Find Out?

We have heard some horror stories on how people were told HD was in their family. We know it's never nice to find out but we would like to hear how you would like to be told. We are very keen to have your views so that we can develop guidelines for General Practitioners. Please write in or phone us on 1800 393939.

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 11.30am to 1pm on the last Saturday of the month. Contact the HDAI office on 1800 393939 for more information

DUBLIN

January 26th • **February 23rd
March 30th

CORK

January 5th • February 2nd
March 2nd

**The venue for the Dublin February Meeting may be changed check with office.



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The articles which appear in this newsletter may not necessarily represent the views of HDAI.