

Donations

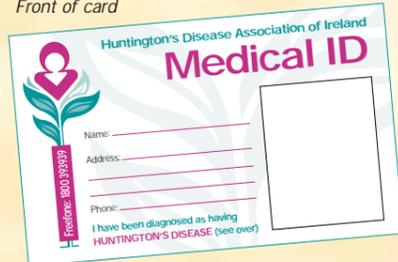
We would like to express our sincere thanks to staff and students at Pearse college for their efforts in raising €1050 for HDAI during a quiz night. Thanks to Frances and friends who are still sending in money from their parachute fundraising event last year. Many thanks to those of you who gave HDAI vouchers as Christmas gifts. HDAI is grateful to all of you who have purchased our glass mementos. Thanks to Heineken Ireland and DCC plc who each donated €200 to HDAI.

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



Views by people affected by HD from around the world

• I am pHD 2000, fired from work (while on sick leave), nearly had a breakdown (which only my counsellor knows about). NOBODY knows the severity of the paranoia, obsession and pscopathy. I do not have any movements. People would say that I didn't look like I had HD. Yet there is a burning hell inside my head, if it weren't for the pills...I would be dead.

• I am HD+. Many of my problems are mental (psychotic outbursts), I also have chorea though. My Mother was affected mentally as in she had hallucinations and refused treatment. We couldn't even blame bad medicine for the hauntings she experienced. Many people are uncomfortable discussing the mental aspects of this disease. Our disability is not one you would notice by looking at a picture...we appear to have one head, two arms attached to the shoulders, two legs just like everyone else but what goes on in our heads is incomprehensible to most.

• As a caregiver(s) I know that I am always struggling to try and understand and be empathetic with my pHDs. Wishing that I could understand what is happening with them. And as a caregiver, I know that often (more often than I like to admit) I get frustrated and am inclined to blame the pHD (person with HD) for making things so difficult.

Sometimes though when listening to the pHD I get an insight that is beyond belief. My pHD son has told me a number of times that sometimes it feels like his head is just empty all of a sudden, like his brain is gone...that he can be doing something and then there is just nothing. I can't even begin to imagine what it is like for those of you that have to live with Huntingtons all the time. I do know that the next time I see or feel myself starting to get frustrated, I will bring to mind the frustrations for the pHD and hopefully I will be able to show a little more patience and understanding."

Names were removed to protect people's identity

Tips to help with Financial worries!

There are times when we fear bills more than usual. It is important to 'face the fear'.

- Don't bury your head in the sand. The debt will not go away
- Talk. Debt can cause stress. Get it off your chest by talking to a member of your family, a friend or a professional.
- Plan. Make a list of the most important actions
- Change. Make any small action to work towards your plan

- Don't panic. There is plenty of help if you ask for it.

The Money Advice and Budgeting Service (MABS) is a free and confidential service for people with debt problems and money management problems. You can find out about your local MABS office through Directory Enquiries, Citizens Information Centres, their Web Site address at www.mabs.ie or by phoning us on 1800 393939.

The MABS service is free and you will not have to pay for any advice, assistance or information.

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

APRIL 24th • MAY 29th
and JUNE 26th

CORK

APRIL 3rd • MAY 1st
and JUNE 5th

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. 19
HDNL 2004

WOULD YOU LIKE TO WALK 10kms/6.2 miles?

The women's mini-marathon takes place on June 7th, 2004. Some members are taking part to raise funds for HDAI. Contact the office if you would like more information.

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

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

THIS IS YOUR NEWSLETTER. PLEASE SEND US YOUR VIEWS

CHECK OUT OUR NEW WEB ADDRESS

www.huntingtons.ie

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

Members Meeting & AGM June 12th 2004

Our AGM/Respite weekend takes place from the 11th - 13th June in Cuisle Respite Centre, Co. Roscommon. Cuisle is a unique holiday centre on the banks of the river Suck in Co. Roscommon. All facilities at Cuisle are fully accessible to people with disabilities. It is located within the grounds of Donamon Castle, one of the oldest inhabited castles in Ireland. This superb holiday destination is set in countryside traditionally renowned as the land of castles and ancient kings. There is a wide array of attractions within easy reach, including the River Shannon, Galway City, Knock Shrine, Yeats County and Strokestown Park House and Famine Museum. Facilities at Cuisle include: ensuite bedrooms with TV and telephone, Gymnasium, Sun Terrace, Special Interest Programmes, Tennis Court, Sports Field, Organic Garden and Coarse Fishing.

Please mark 11th - 13th June 2004 in your diary and book your place as early as possible. All are welcome. First time visitors are always made welcome by our regulars. We have received some bookings already so book early to avoid disappointment.

Towards an Expert Centre for HD

Bernie met with Breda Hayes, Director of Nursing and Rosemarie Reynolds of St. Marys to discuss further the possibility of

We are very pleased to report Professor David Craufurd has agreed to make a presentation at our 2004 members meeting.

David Craufurd graduated from the Medical College of St. Bartholomew's Hospital in London and did his postgraduate training in psychiatry at Manchester. He undertook a period of research on genetic testing for Huntington's disease in the University Department of Medical Genetics and has remained there ever since. He currently occupies the post of 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 International Huntingtons Association Conference will take place in Manchester and David is one of the key organisers for this conference.

We will be sending out further information nearer the event.

extending services for HD patients. We will keep you informed about this project.

Rachel Leads the Field



Bernie (left), Rachel (right) and James Dempsey pictured at the start of the Charity Ride.

The Monivea Charity Ride Committee in Monivea, Co Galway organised a 16km Horse Ride to raise funds for Down Syndrome and Huntington's Disease. Riders were encouraged to take part in Fancy Dress.

The ride took place in the beautiful village of Monivea on Sunday 7th March. Rachel Sarah Murphy the actress who plays 'Jo' in Fair City led the ride from the village supported by Bernie from The Huntington's Disease Association of Ireland (HDAI) and riders associated with the Galway Blazers and

Rachel, Denis and Bernie

local groups. Almost 50 riders trekked through scenic woodlands in brilliant sunshine stopping for a well-deserved break for refreshments at a local pub!

We are very grateful to Michael Dolan Chairperson, Mary Byrne Secretary, Sarah and the hard working committee for organising such a great day. We also received a warm welcome at The Galway Blazers end of season Hunt Dance on the night before in Lafferty's pub in Cartymore.

Sincere thanks also to some of our members who got sponsorship for Bernie and Rachel.



The Monivea Charity Ride Committee.

Catch Phrase - Prize

We are looking for a "Catch phrase" in one or two sentences to describe the work of HDAI e.g. Huntington's Disease Association of Ireland aims to improve the quality of life of all those affected by Huntington's Disease.

Have you any ideas for a "Catch-phrase"? A prize will be given for the catch-phrase chosen by the committee.



Vehicles for People with Disabilities Tax Relief Scheme

Drivers with Disabilities, Passengers with Disabilities and/or Family Member of a person with a Disability who purchase a vehicle for the transport of that person as a passenger may apply for tax relief on that vehicle.

Some people with HD meet the Medical Criteria. There are restrictions as to the size of vehicle and limits on tax relief refunded etc.

If you would like to apply you should:

Contact your Health Board Head Office and ask to speak to the Senior Medical Officer in the Disabled Drivers Section. A Doctor from this section must assess the person for whom the car is being purchased, and if approved, the Health Board will then issue a Primary Medical Certificate. (Refusals can be appealed to the Disabled Drivers Medical Board of Appeal, National Rehabilitation Hospital, Rochestown Avenue, Dun Laoghaire,

County Dublin, within 28 days).

The Office of the Revenue Commissioners, Disabled Drivers Section, Central Repayments Office, FREEPOST, Coolshannagh, Monaghan, Telephone 047 82800 provide an information booklet and application form for this scheme. Full details on the scheme are clearly explained in the 'Vehicles for People with Disabilities, Tax Relief Scheme' booklet.

See Case Study on page 3.

Appropriate Care

Every person with HD should have their case reviewed by a neurologist every 6 months to a year. The neurologist can then refer them for appropriate care.

Case Study - A members successful Application

The Primary Medical Certificate was issued to us within one week of being assessed. The Letter of Authorisation to allow remission of VRT was issued within two days. The staff in the Revenue Office are extremely helpful and courteous and will assist you in any way they can.

A new Nissan Almera 1.5, 4 door was purchased. The cost price was €20,250. Relief was applied for under the section "Passenger with Disabilities". My spouse qualified for the Primary Medical Certificate as a passenger under the category "wholly or almost wholly without the use of both legs" because he has HD. Although he can walk, he was deemed to have insufficient control of his lower limbs.

Because we had previously arranged with the Motor Dealer for the remission (non payment) of VRT when registering the vehicle, the price paid to the garage for the car was €11,250 - a saving of €9,000.

As the cost of adaptation must amount to at least 10% of the cost of the vehicle exclusive of VRT to qualify for relief under the scheme, we had to spend a minimum of €1,250 on modifications.

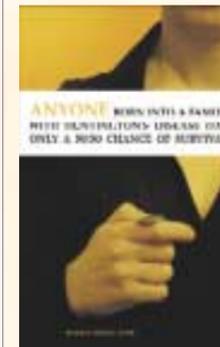
A total of €1,639.55 was paid to the Adaptation Centre for what we required but because the vehicle was then deemed to be VAT free, VAT of €284.55 was refunded to us. Total cost of adaptations therefore was €1,355. The total cost for the car was €12,605.

Incidentally, if you purchase a Nissan Vehicle for adaptation, Nissan will issue a cheque to you as their way of showing their appreciation to you for purchasing one of their vehicles. I cannot remember exactly the amount received, but it was almost €300.

Good Luck

If you would like more information on the above scheme you can contact the office. Let us know how you get on so we can write about your experience in our next newsletter.

Awareness



In our last newsletter we mentioned that in order to increase awareness we had met with "Chemistry" an award-winning Advertising Agency to discuss the possibility of an awareness building / education campaign for our Association. The company designed a poster (see photo) that has been displayed at various bus stops where there was free advert space available. As a result of this poster campaign we have been contacted by a number of media contacts. The RTE Documentary programme Nationwide featured a piece on Huntington's on 16th February 2004, they interviewed Bernie, Catherine, Kay, Jacinta, Rachel Sarah Murphy and Professor Andrew Green. In addition the Health supplement of The Irish Times also featured a piece on Huntington's.

So far we have had a mixed reaction to the poster from various members and professionals who have seen it. While some feel it is too strong most people were delighted that it created extra awareness. To date the majority of the feedback has been positive. The committee met to discuss its merits and agreed we should continue with the campaign. We will review all comments as we receive them. Please send us your views. Contact us if you would like a list of the poster sites.

Disability Legislation

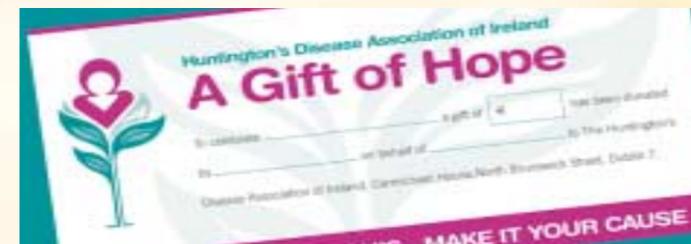
The Disability Bill is due to be published soon. As already reported HDAI have met with Minister Willie O'Dea and staff from the Department of Justice, Equality and Law Reform to discuss the need for Genetic protection in the forthcoming Disability Bill. We hope there will be sufficient protection against potential Genetic Discrimination by insurance companies, mortgage brokers and employers etc. We will keep you advised. Meanwhile if you have the opportunity please mention your concerns to your local politician.

Support for Carers

Many family carers forget to take care of themselves. Without proper support carers can become stressed, over anxious and physically ill. The Carers Association and others help carers by running a series of practical support and

training programmes to assist family carers. Please contact us if you want information on what's happening in your area or to let us know if you have taken part in such a course. If you feel you would benefit from counselling to help you cope, please contact the office. For information on Improvements to Carers

Allowance, Carers Benefit and Respite Grants, contact your local Social Welfare Office or telephone: (043) 45211 ext. 8778 & ext. 8940 or the Social & Family Affairs Information Services, telephone: (01) 704 3000, Leaflet Line: 1890 20 23 25 or www.welfare.ie You can also call the HDAI office for information.



What do you get the person who has everything?

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