

## 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

"The good life" is a term we frequently hear but what is the good life? Many people assume the good life is having the money to do what you want, but is it? There are different types of happiness - drinking champagne on a yacht off a tropical island could be considered a very pleasant lifestyle (and who could argue!) but to achieve the good life or a meaningful life perhaps it is necessary to find realness in your life. Only you can decide what works best for you, here are some insights:

### BREATH

Do you take time out to breath? Close you eyes, sit or lie in a comfortable position, exhale then take a deep breath, hold that breath now release it slowly... and again.

### COMMUNICATE

Communication is a two way process - both parties should have time to talk and to listen.

### LOVE YOURSELF

Focus on your good points and lose your self-limiting beliefs.

### STAY IN THE MOMENT

Enjoy the present, today is yesterday's future.

### CARE ABOUT YOURSELF

Know when it is time to go home and put your feet up.

### HIGHLIGHT THE POSITIVE

When you feel your mood slipping, learn to recognise this and focus on happier thoughts.

### BE PATIENT WITH YOURSELF

Changing habits formed over years can take time.

### SEEK HELP IF YOU NEED IT

If what you are feeling is worse than the general blues contact a health professional.

## 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

OCTOBER 25th • NOVEMBER 29th  
DECEMBER - No Meeting

### CORK

NOVEMBER 1st • DECEMBER 6th  
and JANUARY 3rd

# Donations

We would like to express our sincere thanks to Frances and family, for raising €4690 in a sponsored parachute jump. Frances' two daughters and a family friend took part in the jump while others helped in seeking sponsorship. Thanks to those at Hollis St. and the John Player & Sons factory for their support of the event. Thanks also to Bank of Ireland who have also agreed to make a contribution. Grateful thanks to the three jumpers who bravely jumped on our behalf! (See photo on page 3)

Special thanks to Ann and her friends and family who recently donated €1070 to HDAI.

Many thanks to Flight Line who donated €250 to HDAI in June 2003.

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.

Remember we get a great boost from every donation. Someone once arrived in the office with a glass bottle full of 5ps and it helped us over a financial hurdle. If you have coins lying around we would be grateful for them. We have had a successful but very expensive year so all help is appreciated.

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](mailto:hdai@indigo.ie)  
Web: <http://indigo.ie/~hdai/>

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. 17  
HDNL 2003

## IHA 2003

World Congress on Huntington's Disease  
Toronto, Canada, 16th-21st August 2003



power came back after 36 hours but full power was not restored for 7 days. As the Canadian Government asked that all unnecessary use of power be curtailed our conference was cancelled by the conference centre - Marriot Eaton.

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. THEIR WEBSITE ADDRESS IS [www.genetics.ie](http://www.genetics.ie)

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

Bernie and a member of the committee attended this conference on our behalf. They found the conference very positive and worthwhile. Bernie remains on the International Huntington's Association Board. Here is a report of the event.

This was a congress fated not to be. Having been cancelled and re-instated several times due to the SARS epidemic in Toronto, we finally got there looking forward to an enlightening and uplifting event. However we were met by a blackout -(see headlines of Toronto Globe-above). We innocently thought this power failure would be sorted out in a few hours and all would be well!. But everything is bigger in North America - this was to last the whole week-(It seems Nuclear power stations take several days to start up again after a shutdown). Temporary

However, half the delegates and one third of the speakers were in Toronto at this stage and more were still trying to get there. Could the situation be rescued? To the Huntington's Disease Community this was a little challenge! We know about bigger problems!!

Phone calls were made - everybody regrouped - another venue was found- (Take a bow Ryerson University Campus)- and an alternative (albeit shortened )programme was drawn up. Everybody who was there agreed to stay and contribute as they had planned- (we couldn't leave anyway as all airports were in chaos!!). Those contributors within driving distance were prevailed upon to come in their cars. Our five day planned conference became a three day one but none the less uplifting for that!

**World Congress on Huntington's Disease**

(continued from page 1)

**CONTENT**

Dr. Ira Shoulson of the Huntington Study group of North America gave an overview on the present state of research into Huntington's Disease. The search for a cure goes on but much research is now being concentrated on delaying or postponing onset in those who are gene positive for the disease. He outlined two major studies now up and running.

**No 1 THE PHAROS STUDY**

Up to 1000 at risk individuals are needed for this. Enrolment started in 1999 and over 900 people have signed up to date. The organisation and control of this study is complex and exacting as each individual will be followed up at three monthly intervals over five years. They will be tested but won't have to know the result and the researcher who will know the result will

not know the individual to whom it refers (the technical term here is double-blind research).

**No 2 THE PREDICT STUDY**

Somewhat similar to above but the participants will be gene positive - know their status - and be pre-symptomatic. 500 individuals involved with 250 already signed up. Main emphasis on this study is to try to find clinical features specific to HD and then to find ways to modify them.

The French researcher Dr Marc Peschanski gave us an overview of his work on Gene Therapy and stem cell implantation. He did stem cell transplantation on five patients way back in 1996. In short two of the patients have since died (from causes unrelated to his research - he says) and the other three are doing fine and showing marked improvements in both motor and cognitive functions. 50 patients are now being monitored and prepared for further gene therapy.

We had talks on weight loss in HD patients (exact cause still not ascertained) cell-dysfunction, counselling issues - tests for cognitive dysfunction, pre-implantation diagnosis, reproductive decision making in HD families, intermediate genes (36-39 repeats), juvenile HD and other areas of relevance to the HD community.

Dr Bernhard Landwehrmeyer gave an outline of a pan-European study into HD (somewhat along the lines of the PHAROS study in North America) which is still at the planning stage.

All in all despite the obstacles and setbacks this was a most helpful meeting. The enforced informality and smaller numbers made for closer and more intimate interaction between the scientists and lay delegates. In particular I feel the scientists who were there will more than ever realise that their work-which for them is a matter of detached science- is for us a matter of life and death.

**A Safe Place to Live**

Monty Roberts became famous because he discovered it was not necessary to "break" horses. It was possible to change their behaviour by requesting change. He has since written a book called "Join up- Horse sense for people". In his book he looks at how people use force on one another and suggests alternative methods.

*"No one has the right to say 'you must or I will hurt you' to any creature, animal or human."*

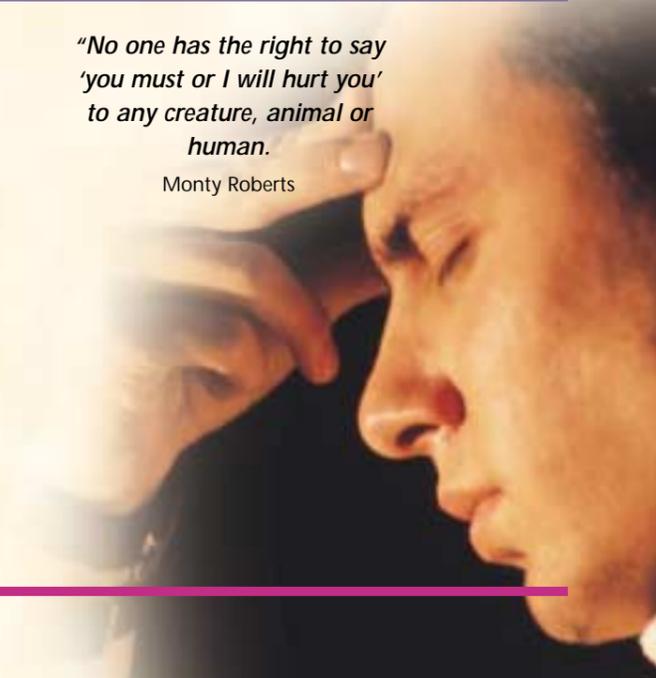
Monty Roberts

Have you used force at home or in work? Have you lost your temper with a person who relies on you? Are you a victim of bullying? Have you witnessed a family member suffer at the hands of a bully? Damage can be psychological and leave no physical scars.

Irish society has changed in relation to its tolerance of bullying behaviour. Change can be slow. You may have a role to play.

Please let us know if you need our support to protect yourself or to modify your own behaviour if you think others may see you as a bully.

Don't be too proud to ask for help.



**Access to Services**

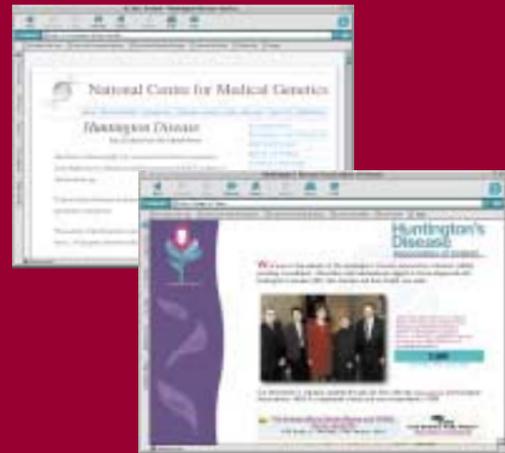
Bernie, Patricia and Pat from the committee recently met with Brendan Ingoldsby, Principal Officer Physical, Sensory and Intellectual Disabilities at the Department of Health to discuss an increase in our funding. This was a very successful but very expensive year for us so we applied to the Department of Health for a once off Lottery Grant earlier in the year. We have not had confirmation on this funding but we are phoning constantly to highlight our case.

In addition we informed Mr Ingoldsby about our members concerns with regard to renewing medical cards, applying for carer's allowance etc.

Mr Ingoldsby confirmed that he would speak to the Health Board with regard to Medical Card renewals, HDAI funding etc.

**National Centre for Medical Genetics**

The National Centre for Medical Genetics have recently developed their Website at <http://www.genetics.ie>. The Centre provides a comprehensive service for all patients and families in the Republic of Ireland affected by or at risk of a genetic disorder.



The Centre, under the directorship of Professor Andrew Green, is based in Our Lady's Hospital for Sick Children, Crumlin, Dublin.

The Centre provides Diagnostic tests for patients with clinical symptoms suggestive of Huntington disease (HD). It also provides Predictive tests for asymptomatic individuals who have a family history of HD. Predictive tests are only performed in conjunction with a counselling programme run by the National Centre for Medical Genetics. For specific information on services for Huntingtons Disease see <http://www.genetics.ie/services/hd/>

**Disability Legislation**

Professor Andrew Green, National Genetics Centre, Bernie, Patricia and Pat from the committee recently met with staff from 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.

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

We hope to work with other organisations looking for genetic protection and will continue with our efforts to influence the necessary decision makers on your behalf. Please let us know as soon as possible if you have any suggestions to propose for our Disability Legislation consultations.

**Flying High**



During the summer Tara, Patricia and Paul took part in a parachute jump to raise money for our Association. Apart from some minor irritations such as cow manure they all enjoyed the experience and landed to earth safely! We are very grateful to them for their bravery. Thanks also to Frances who coordinated the event and raised a very substantial amount of money on our behalf. (See Donations over the page)