

## RAISING AWARENESS

One of our members was very impressed to see Andy Irvine wearing a HD tea-shirt while performing at one of his recent gigs. *Andy - Thanks for your support.*

## DONATIONS

- **TUI Credit Union** recently donated €200 to HDAI for our work. Grateful thanks to you for your continuous support of our work.
- **Sap Holdings** - Tom Walsh of Sap Holdings, a horticulture and landscaping business in Co Tipperary sent us a very kind cheque of €1,000 recently. A big thanks to Tom and to Paddy and Brigid for remembering HDAI.
- **Seal Systems Ireland Limited** donated a very generous €7,500 to HDAI. Seal Systems Ireland supply construction sealants and waterproofing solutions to construction companies. The company makes regular charity donations and this year chose HDAI as we were recommended by David Byrne our Auditor as a charity who carries out our work on a shoe string! A big Thank You to David and to Ray Brennan of Seal Systems who also happens to be a Woodie Guthrie fan.
- **Park West Charity Golf** - The 2008 Park West Charity Golf Outing took place at Luttrellstown Golf Club Castleknock on Friday 16th May. The day was hugely successful with the weather also contributing. The event organised by the Park West Charity Committee (Louise French, Úna O'Connor & Mick Arthur) is now in its 6th year. Proceeds were shared between local charities with €1000 donated to HDAI. We are very grateful to Una O'Connor who put our name forward as a recipient.

## MEMBERS DONATIONS

- Thanks to Tess for her collection of €225 from family and friends.
- We are very thankful to Stephen, Joan, Sean, Marion, Paddy, Angelina, Marie and George for their recent generous donations.

Thanks to you all for your membership contributions.

## HDAI LIBRARY

We have a stock of relevant books in our library. These are available to our members on request.

## 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.

## COFFEE MORNINGS

You are very welcome to join us at our Coffee Mornings/Support Meetings in Cork from 11.00am to 1.00pm on the first Saturday of each month. The West of Ireland meeting is

held on a quarterly basis. In Dublin, meetings have relocated to a city centre hotel. We hope to host a carers workshop every third month in Dublin and Cork. Our Family Support Officer or

a committee member will host the meetings. Tea, coffee and scones are provided. Contact the HDAI office on 1800 393939 for more information.

### WEST

September 13th - Castlebar

### CORK

August 2nd 2008 - Support Meeting  
Sept. 6th 2008 - Support Meeting  
October 4th 2008 - Carers Workshop

### DUBLIN

August 16th 2008 - Carers Workshop  
Sept. 20th 2008 - Support Meeting  
October 18th 2008 - Support Meeting



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

## ACKNOWLEDGE KINDNESS - THANK YOU

### In this edition Pat has nominated his neighbour for a big Thank You



My wife was diagnosed with HD in 1999. She lives at home and is receiving full-time professional care. Life can be stressful at times but thanks to many friends, work colleagues and acquaintances we have managed to stay upbeat and positive as much as possible. Our next door neighbour Nora has been brilliant in every way. She drops in daily with her two terrier dogs - "the three bitches have arrived" she will cheerily say, and invariably my wife gets uplifted as the terriers sit in her lap and

play with her. This is great in itself but in addition Nora is constantly loaded with beautifully home baked cakes and goodies of all kinds. She is there for all emergencies and has been a solid rock of support all along to all of us. It's Nora's birthday this month so a Big Happy Birthday and a Thank You from us all.

Thank you from Pat & family

Nora will receive a bouquet of flowers from HDAI on behalf of Pat & family.

## LEISURE DAY

Would you like to attend a therapeutic leisure day in the Phoenix Park? This one day service allows a patient to use therapeutic facilities such as a Jacuzzi, massage, or music therapy etc.

St Mary's run an enjoyable leisure day at their therapeutic centre which is located in a very scenic area of the Phoenix Park. Contact the office for more information.

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



CHECK OUT OUR  
WEB ADDRESS

[www.huntingtons.ie](http://www.huntingtons.ie)

SUPPORT MEETINGS  
SEE DATES ON PAGE 4

### GENETICS

THE NATIONAL CENTRE FOR  
MEDICAL GENETICS HOLDS  
GENETIC CLINICS IN DUBLIN,  
CORK, GALWAY AND LIMERICK.  
CONTACT DETAILS -  
TEL: 01 409 6902  
AND [WWW.GENETICS.IE](http://WWW.GENETICS.IE)

THIS IS YOUR  
NEWSLETTER. PLEASE  
SEND US YOUR VIEWS

NEWSLETTER OF THE HUNTINGTON'S  
DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

ISSUE NO. 35, Q3 08  
HDNL 2008

## REPORT ON 2008 MEMBERS MEETING AND AGM

Our AGM/Respite weekend took place on the weekend of 6th - 8th June at our usual location in Cuisle, Co. Roscommon.

Over 60 people were present for our AGM and Members Meeting on Saturday, with the majority staying over in Cuisle from Friday night to Sunday morning. We had our return bus service from both Dublin and Cork again this year.

Anne our Chairperson welcomed new members and regular attendees to Cuisle. She reported on the years activities and thanked the HDAI committee along with Liz and Patricia for their commitment throughout the year. Pat our treasurer reported on the years financial accounts. Pat and Eileen resigned from the committee and Ann thanked them for their valuable contribution and particularly for their great sense of humour and their ability to look on the bright side. Anna, Anne, Catherine, Doreen, Denis, Pat, Jennifer, Mary, Maria and Yvonne were elected to the committee for the year ahead.

Our Members Meeting took place after the AGM. Annemarie O'Connor gave a very informative presentation on the nature of the service provided by the Money Advice and Budgeting Service (MABS) and spoke about how people can access their free, confidential and independent service.

### MABS

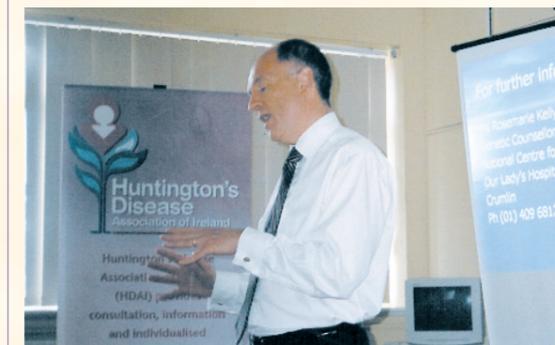
- Enables people to take control of their finances;
- Educates people with budgeting and day to day management of their money;
- Negotiates with creditors on behalf of individuals as necessary;
- Offers alternative credit options by working with the credit union;
- Gives advice on entitlements;
- Provides ongoing support to people who overcome their financial problems.

MABS offices are located throughout Ireland. For further information see their website: [www.mabs.ie](http://www.mabs.ie) or call the MABS Helpline 1890 283438.

Professor Kieran Murphy, chairman of the Department of Psychiatry at the Royal College of Surgeons in Ireland and Consultant Psychiatrist at Beaumont Hospital, gave a very interesting presentation on the predictive testing process for people at risk of HD. He discussed the importance of HD family members making their own decision on whether or not to proceed with the testing process.

**During the testing process people are referred to a psychiatrist who will:**

- Assess the individual's capacity to make the decision to undergo testing;
- Assess the individual's vulnerability to an adverse test outcome;
- Discuss issues associated with genetic testing.



Prof Murphy speaking at Cuisle

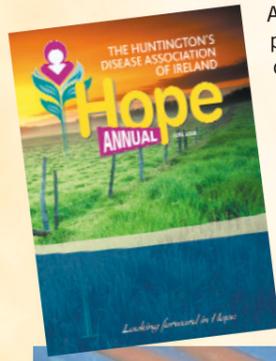
Professor Murphy discussed the pros and cons of taking the test and emphasised that there is no right answer with regard to taking or not taking a predictive test. He reminded people that HD is just one disease - we still have to watch out for the bus!

(continued from page 1)

Since the availability of the predictive test at The National Centre for Medical Genetics in 1998 approximately 150 people at risk of HD have been seen at the clinic. On average one third of people choose not to receive their result. 52 people were found to have the HD gene and 54 people were found not to have the HD gene.

Professor Murphy discussed every individual's right to deal with the risk of HD in their own way and stated that for some people denial can be a healthy response to dealing with this risk.

After the presentations our 2008 Hope Annual (pictured left) was distributed to members. Thanks to all who sent articles and pictures.



Jennifer losing her curls



Liz giving Phil a new look

Liz delivered a Carer's workshop on Saturday morning. Therapies including Massage, Chiropody and Reflexology were also available.

We were fortunate with the weather again this year and members had the opportunity to take a stroll in the castle grounds and catch up with old friends in pleasant sunshine. Jennifer and Phil entertained us all by carrying through with their sponsored head shave.

We celebrated our year's work over dinner on Saturday evening, followed by music and dancing. Joaquim, a regular entertainer at Cuisle shared the stage with some of our own entertainers. As usual the socialising lasted until the early hours!

The team at Cuisle provided an excellent service to us again this year and we value their friendly, obliging and supportive approach.

## PREGNANT LADIES... DO NOT BE DECEIVED!

As I sit here in my bedroom awaiting the delivery of my daughters first child it gives me the opportunity to relate our family's experience. On the one hand it occupies my time and *ar an lamh eile* it may be of use to those who might have Huntingtons Disease (HD) and would like to avail of Umbilical Cord Blood Stem Cell Preservation.

One would get the impression from an article by Susan Mitchell in The Sunday Business Post (March 16th, 2008) that there are no problems in obtaining this service in the State. It is pointed out that twenty one consultants have agreed to facilitate stem cell preservation under a new deal between Vivas Health and Medicare Health and Living. This new deal means that Medicare is the first company in the country to be authorised by the Irish Medical Board to carry out the stem cell preservation work. All this appears very positive but the reality is somewhat different.

Instead of buying the expected baby a cot or pram I decided to arrange for the storing of stem cells from its umbilical cord and spoke with a representative of Medicare. There is no need to explain the process here except to say that it is similar to taking a blood sample. One of the difficulties was that Medicare would only accept the blood if it had been taken by a person who had been trained in the process. It turned out that that

the only people in the hospital involved-Cork University Maternity Hospital (CUMH) who were acceptable, were two consultants, and my daughter was told that one would not do the procedure while the other told her that the procedure was so simple that 'anyone could do it' - the implication being that he was not going to do it. While the midwife was well capable of taking the blood sample she would not be acceptable to the company storing the blood. I had already paid a refundable deposit of five hundred euros to Medicare and time was running out - so I asked to speak to the Master of the hospital seeking clarification. I received a phone call from him pointing out that, as an organisation they did not provide the service. It appears that they cannot prevent individual consultants from co-operating at an individual level but because they had not been indemnified by the private company involved (Medicare), they were not co-operating. Coincidentally, on the morning of the 13th of March a woman from the Cork area was interviewed on Morning Ireland about how she had the cord blood harvested in a Cork hospital. It appears that the procedure was done earlier in a particular Cork hospital before all the maternity hospitals were recently amalgamated in the CUMH!! A lot of the recent interest in this topic has been generated by an article in the Irish

Medical Times (29/02/08) written by Gary Culliton. In an interview with Professor Colin McGuckin, the many therapeutic uses for cord-blood stem cells are discussed. Prof. McGuckin criticises the situation in Ireland where some Irish maternity hospitals have refused access to babies' umbilical cords because they were to be stored at a private facility. A joint memo last August from the masters of the Coombe, Rotunda and National Maternity hospitals stated that "there is insufficient scientific evidence to support the practice of taking routine cord blood for stem cell retrieval". So, there seems to be a number of reasons given for not providing the new technique. Rather than a flat refusal, for whatever reason, some maternity hospitals are choosing not to support cord blood collection unless there is a direct medical need. Let the customers be aware that the latter is not the case in CUMH. It was pointed out to the consultants and the master that there was a risk of the baby having HD but to no avail.

This letter highlights the problems involved in obtaining the service in one particular case and warns any ladies who expect to avail of it that it is not as readily available as it appears - particularly if you live in the Cork area!.

Name with Editor.

## ACTIVITIES FOR Young People

Despite the cloud bursts five young people took part in the Sea Safari earlier this month. We started off with a warm lunch to sustain us on our battle with the elements.



We certainly got to bounce around on the waves but we all had a lot of fun! If you would like to take part in the next outing please contact me.

Elizabeth, Family Support Officer.  
Tel: 1800 39 39 39 or  
087 051 7772.

## BOOK REVIEW - Stress and How to Deal With It

by Eddie Fitzgerald SDB and Éilís Bergin PBVM



This booklet was available to those present at Cuisle. We have some remaining copies available so let us know if you would like one. According to Noel Edwards this booklet is "all you ever wanted to know about stress, but were too busy to read a big fat book about!" Featured on TV's "Late Late Show" and on Gerry Ryan's radio show, it is a down-to-earth and highly effective stress management programme by two internationally experienced presenters of stress management workshops. Designed to help people create their own personal stress management programme.

This booklet deals with:

- The causes of stress
- The effects of stress
- The remedies for stress
- Relaxation Techniques
- Type A & B personalities
- Time Management
- Breathing
- Nutrition
- Meditation
- Irrational Beliefs
- Coping Skills
- Imagination
- Positive Self-Talk
- Exercise
- Stress-busters

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## Fundraising Events

### Head Shave



Phil and Jennifer 'lighthheaded'

Jennifer and Phil courageously and with good humour, allowed Liz to shave away their tresses, all for a good cause. Jennifer, with support from friends and family raised an enormous €2,611 as a result.

Phil who is still busy with her line dancing classes and always ready for new opportunities to raise money for HDAl, collected over €700 from her head shave (which included the proceeds from auctioning her remaining shampoo). Liz skillfully gave the ladies a 'Sinead O Connor' look so there were no tears after all!

### Women's Mini Marathon

A number of our members took part in the 2008 Women's Mini Marathon to raise funds for Huntington's Disease.

- A big thanks to Josie who completed the 10k again this year raising a very substantial €300 for HDAl.
- Bernie Spellman and friends sponsored Cecile and Nora with their combined effort amounting to an excellent €1075. Thanks for your constant support.
- Thanks to Nicola who took part on our behalf and raised a marvellous €818 for HDAl.

Thanks to all who took part. We know that a lot of effort goes into participating and getting sponsorship so a BIG Thanks to you all.

### Shop Collections

Thank you to Catriona and her supporters for their great work in collecting €754 for HDAl

### Liffey Descent

A big Thank You to John Daly who competed in the canoe race on the river Liffey again this year and raised a very impressive €780 for HDAl. Thanks also to all the Daly family and to Betty and John in particular for their continuous support and well wishes.

### 50/50 Golf Tour

Peter Grogan very kindly offered to do a 50/50 golf tour, playing 50 golf clubs in 50 days, in aid of HDAl and the Marie Keating Foundation. Peter started his first course on 23 May 2008, and had a launch night in the Malahide GAA club. Peter and his wife Eileen also ran a raffle. Peter hurt his wrist in the course of his tour and Eileen generously stepped in to complete the course.

Thank you also to Toyota Dealers Carol & Kinsella, Walkinstown for lending Peter and Eileen a brand new Toyota Avensis to travel to the courses and raise awareness.



Patricia and Pat from HDAl thank Peter, Ivan and Eileen for helping to raise awareness.

Thanks to KMD Design (our newsletter designer), Bank of Ireland Smithfield, Marks & Spencers, The Body Shop Liffey Valley, Jury's Inn Customs House Quays, Dublin and The Gresham Metropole, Cork for sponsoring prizes for Peter's 50/50 raffle.

We are very grateful to Peter for raising awareness for HD on his various golf courses, in local papers which covered the event and on his radio show "It's all in the song" each Thursday at 11.30am on Dublin City FM103.2. A keen music fan, Peter decided to include Huntington's Disease while at a concert to mark the 40th anniversary of famous folk singer Woodie Guthrie last October.

### Turning Trash to Cash for HDAl

HDAl continue to collect old mobile phones. If you have any old mobiles you no longer need we would be happy to receive them.