

Stay Focussed

We all hear people complain that life is moving too fast nowadays. In the 'old days' neighbours just called in, we didn't need to make appointments to visit adult children, siblings or extended family. We may feel under pressure to compete with our peers and feel we must work hard to get on, have the right car, house etc. Work may then take over, leaving less time to juggle family time and leisure.

If we have too much to do our mental and physical health are in danger. Sometimes doing less can therefore allow us to accomplish more. We may try to juggle many tasks at once, however, by focussing on what we are doing, completing the task and moving on to the next task we put our mind and body under less pressure. In this way we become more efficient.

Routine, Respect and Reassurance are important words to remember when caring for HD patients. In order to make life easier for ourselves we can take hints from expert advice on creating better environments for HD patients.

These include:

- Simplifying the environment
- Removing distractions creates a calm environment.
- Try to limit the number of activities to one at a time.
- When stressed avoid busy and noisy places.
- Establishing routine
- Schedule important activities.
- Allocate time to relax and take exercise.

- Plan healthy and nutritious meals and give yourself time to enjoy the food.
- Ensure you get a good night's sleep.
- Prepare for changes in advance.
- It is easier to cope with change if we have adequate information and are aware of upcoming changes in advance.
- If we sleep, eat and exercise sufficiently we will have more energy to complete a day's tasks. This allows us to concentrate and remain focussed on the tasks we must carry out each day. Being focussed allows us to 'live in the moment' and not get stressed about the past or the future. We all need routine, respect and reassurance to help us make life easier.

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.



Reverse of card

HDAI Library

We were successful in a recent Dormant Accounts Fund application for a library facility in our office. All members are welcome to come and use this facility. Call the office for information.

We try to keep a stock of relevant books in our library. These are available to our members on request. Is there a book you know off that you would like us to add to the library? Perhaps a book on caring or a similar related subject?



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 THIRD Saturday of the month. The West of Ireland meeting is held on a quarterly basis. The support meetings offer our members the opportunity to meet in a relaxed atmosphere to swap stories and avail of peer support. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information

DUBLIN

November 19th • December 17th • January 21st

CORK

December 3rd
January 7th • February 4th

CASTLEBAR

December 10th
March 11th

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

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. 25, Q4 05
HDNL 2005

International Huntington's Association & World Congress on Huntington's Disease, Manchester 2005

HDAI was well represented at the 2005 World Congress on HD, held in Manchester on September 10th -13th 2005. Anne, Bernie and Catherine were in the advance party in order to attend a European HD Network meeting planned for the preceding days. They were joined by Anna and Pat for the Congress proper and the group were delighted to have with them John and Eileen from Cork who kept us all on our toes and provided much entertainment for us in the evenings. This congress as usual was a joint meeting of the International Huntington's Association (meeting for the 16th time) and World Federation of Neurology Research Group on HD (meeting for the 21st time). This was the second congress to attempt a truly joint meeting with every presentation open to all delegates whether professional or lay. This had been the plan for the last congress in Toronto, Canada which unfortunately was badly truncated by the major power shortages. No such misfortune visited this congress which I'm happy to say was a model of efficiency and thoroughness, a complement to the brilliant organising committee (Bernie from HDAI included).

The Congress programme was varied, intense, interesting, amusing, moving, sad and uplifting by turn. Your delegates stuck with it right to the end and we were all rewarded with credits for attendance by The Royal College of Physicians!! The presentations covered genetics, pathogenesis, clinical aspects (neurology, neuropsychology, neuropsychiatry and genetic counselling) of HD, drug discovery and development, the latest therapeutic advances, clinical trials, public policy, care and coping strategies and education. It was a truly

comprehensive look at HD and the overall impression left with us was of a deepening of the scale and scope of research with well focussed groups leading us remorselessly to a final eradication of HD.

In relation to a cure for HD we were updated on some major research areas.

(a) Henry Poulson (USA) outlined progress to date on a process known as RNA interference (RNAi) - interference with the creation of the harmful HD protein (shooting the messenger). It holds promise as a potential therapy for human diseases because it can be used to silence disease related genes. If we can prevent the HD gene from building up it's harmful protein we can stop disease onset. The process has been successfully carried out in mice but there's some way still to go before the science can be tried in humans. One problem here, which still has to be properly overcome is how to shut off the toxic gene products without interfering with the normal gene function.

(b) Steve Dunnet (U.K.) outlined progress in cell therapy (stem cell implantation). This is taking place in many countries around the world and progress is apparent. However this progress is proving difficult to measure. It varies in different patients with some showing no improvement. Measurement can be complicated by psychological factors and by the need to relearn old skills from new.

The trials have suffered setbacks by the deaths of some patients - which may or may not be

NEED HELP
THIS
CHRISTMAS?

IF YOU REQUIRE HELP
PLEASE CONTACT US IN
WRITING

CHECK OUT OUR
WEB ADDRESS

www.huntingtons.ie

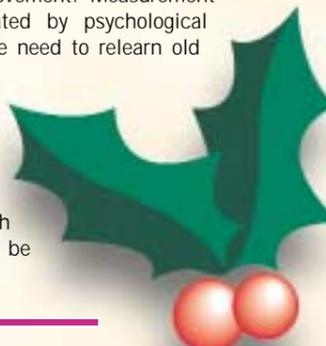
WEST OF IRELAND
SUPPORT MEETING
IN CASTLEBAR ON
DECEMBER 10th

DUBLIN SUPPORT
MEETING
NOW ON THE THIRD
SATURDAY OF EACH
MONTH

GENETICS

THE NATIONAL CENTRE FOR
MEDICAL GENETICS HOLDS
GENETIC CLINICS IN DUBLIN,
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DETAILS OF SERVICES ARE
AVAILABLE BY CONTACTING THE
CENTRE ON TEL: 01 409 6739 OR
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THIS IS YOUR
NEWSLETTER. PLEASE
SEND US YOUR VIEWS





related to the trials. The supply of suitable cells is an ongoing ethical issue and this complicates the ability of some centres to function normally. A new trial involving 60 patients has started in France and should add to the progress being made in this area.

(c) James Gusella (USA) outlined a new and potentially fruitful area of research which is to be opened up. We all know that age of onset and rate of progression of HD

can vary greatly even when patients have similar CAG counts. There seems to be other factors at work here (other genes) which inhibit onset and slow progress. The search is on to locate and identify these modifier genes. Perhaps when found they can be helped in their work in some way.

(d) Karl Kiebertz (USA) did a review of pharmacological therapies and trials involving the taking of various pills. It is obvious that substances like creatine, CO Q10, tetrabenazine etc have therapeutic effects but it is proving difficult to find the optimum amounts of each to take. He has concluded that (a) there have not been enough comprehensive trials to date, (b) most trials have been successful only in

identifying drugs that don't really work! (c) more trials must involve a combination of drugs.

There were over forty presentations in all at this congress. Many involved caring for HD patients at all stages of the disease. They were all valuable but impossible to detail here. Suffice to say the knowledge gleaned from the presentations has been internalised by your delegates to be disbursed through our committee as needed. Highlighting four presentations might seem lop-sided but I think it serves to show the thinking involved, the work being done and the progress being made in eradicating this blight from our planet.

CREATING AWARENESS

The Clinic

This drama set in a multi-disciplinary Health Clinic in Clarence Street, Dublin commenced their HD related storyline in their episode on November 6th.

Dr. Richard Mc Kenna is struggling to deal with his wife Annie's illness, yet trying to keep his home and work life separate. His teenage daughter Flossie is devastated when she discovers that she too could have Huntington's disease. Trying to pretend everything is okay and not accepting help so far has failed. Richard finally comes to

the realisation that he must face up to his wife's illness.

The Clinic contacted us and met with some of our members in order to research this storyline.

We are happy to have the opportunity to highlight the traumatic effects of HD without the need to expose families. HDAI hope that through greater awareness we can improve patient care and fight discrimination. If you are able to watch the HD storyline on The Clinic please let us have your comments.



The Irish Examiner

The Irish Examiner featured Huntington's Disease in their 'Feel Good' section of Friday November 4th. The Irish Examiner contacted us and spoke to Catherine, Bernie and

other family members. Sarah Winckless was also interviewed for this article and her photo made the front page of this section.

Annual Magazine

We are hoping to produce an annual magazine which would feature articles from members, events during the year, members feedback etc. We plan to produce the first issue next Spring. Please let us know if you have a photo, story, poetry etc which you would like included in this magazine.

HD CHair

Please let us know if you need a HD Chair for a family member or if you have one that is in need of repair. Alternatively if you have one you do not need and would like someone else to make use of it we can arrange this. Please contact the office.



Catherine, our Development & Family Support Officer, is going to New York for five days in November and is taking John, her son. John recently had a 40th birthday and this trip is his present.

Catherine is looking forward to seeing her grand daughter Sarah and also her cousins Margaret and Catherine. Catherine can be reached through the HDAI office or on mobile 087 051 7772.

Report on Members Meeting: Sarah - A Breath of Fresh Air

HDAI held a members meeting in Wynn's Hotel, Lower Abbey Street on Saturday 24th September. Sarah Winckless winner of an Olympic bronze for the UK rowing team at the 2004 Olympic Games was our guest speaker. Sarah is also the proud owner of a world championship gold medal.



Our Chairperson Anne presents Sarah with a Thank You Gift

As one of our members remarked 'Sarah is a breath of fresh air'. Sarah related her story to us in a positive and honest manner. She was in her final year at university when she decided to take the predictive test for HD. Sarah recounted how her mother's

diagnosis suddenly put things into perspective and explained many previous misunderstandings between them. She felt taking the test was the correct decision for her. Despite receiving a bad result Sarah was determined to complete her studies and pursue her long time ambition of representing her country at the Olympics. Sarah was initially a Discus thrower and only took up rowing as a social sport at university. Sarah discovered she had a natural ability for rowing and enjoyed the team aspect of the sport. She was asked to join the university rowing team and from then on rowing became her sport. She was chosen to represent the UK at the Australian Olympics but unfortunately was ruled out due to injury. Sarah believes this may have made her even more determined to succeed next time round and despite fierce opposition Sarah and her rowing partner won a bronze medal at Athens.

Sarah told us her mother is a great inspiration to her. She has always been determined to enjoy life despite HD and it was a very proud moment to share her glory with her mum in Athens.

"Thank you for your hospitality, I was made to feel so welcome by everyone over in Ireland..., it was great for me to see the mutual support the families give. I would love to come again in the future and if there is anything I can do please let me know".

West of Ireland Support Meeting

The West of Ireland Support Meeting was held in Castlebar on September 10th. Members met for a lively chat, exchanged fundraising ideas and had a discussion on an interesting article on Stem Cell Research recently published in the National Geographic. The meeting took place in an atmosphere of good company with delicious scones and tea and coffee. The members present also discussed the recently published leaflet 'In Their Own words'. Those present were touched by the quotes from members who attended the AGM in Cuisle, 'they were so real' summed up the positive feedback. Goodbyes were said knowing true friendships were made in a supportive atmosphere. So be sure to come along to the next West of Ireland support meeting in Castlebar on December 10th - *Bernie Spellman*.

Monthly meetings continue in Dublin and Cork. Call the office for information.

Fundraising Events

Charity Walk Balla

The proceeds of the July Charity walk held in Balla, Co. Mayo were presented to Bernie Spellman on behalf of the HDAI committee on Friday 9th September in Balla (pictured below).

A lively group of walkers and runners attended the presentation. In total the proceeds came to €5,359. The presentation was followed by a great night of 'craic agus caint', food and champagne. Even Fido, the resident dog in the bar participated.



We are very grateful to Ann and Margaret for their outstanding energy and organisational skills. Thanks also to all their friends and sponsors who contributed to the success of the walk. The friendly staff of 'The Old Woods' bar provided great service and lovely food on the night. We are already looking forward to next year.



Mark's bounceathon

Mark (left), is one of our youngest fundraisers. Earlier in the summer he organised a 'bounceathon' on behalf of HDAI. We are very grateful to Mark for organising this original event and raising money for us. We hope he enjoyed himself on the day.

Mini Marathon

Thanks to Marie for raising €125 and to Paula for raising €235 through taking part in the Mini Marathon.

Donations

We would like to express our sincere thanks to members for their recent donations. We are very grateful to: Bernie for €569.11 forwarded on behalf of friends and family, Jack and Marie for their €200 donation, Vera and Kieran for their €100 sponsorship, Eileen for her €100 donation, Emmet Browne of Wyeth for €150, the Teachers Union of Ireland Credit Union for their €150 donation and Allegro TV Productions Ltd for €100. Thank you to all those members and friends who have donated recently and to those who sent in their membership contributions. Your support is a great source of encouragement to the committee and staff of HDAI.

Fundraising In Memory of Michael O'Brien

Ellen Kelly held a race night in Dublin in memory of her friend Michael O'Brien, a US HD family member to raise funds for The Hereditary Disease Foundation (HDF). The night was a great success and raised over €3,200 for HDF.