

## CONGRATULATIONS TO MIND MATTERS

**Mind Matters - On HD** won the Speech Programming award in the Phonographic Performance Ireland (PPI) Radio Awards, on 19/10/2007. The awards, established by the PPI and the BCI (Broadcasting Commission of Ireland), celebrate the art and skill of radio production and programming. Mind Matters, presented and produced by Ella Mc Sweeney, is a science radio series that gives an insight into conditions of the human brain. This

programme told the science story of H D. It included an interview with Galway-born scientist Michael Conneally who helped to isolate the gene in 1993, Geneticist Professor Patrick Morrison who talked about environment and other genes possibly having an effect on the onset of HD. Geneticist Sarah Duke from the National Centre for Medical Genetics spoke about the scientific aspect of the testing procedure. Dr Anthony Hannan an

Australian scientist discussed his research work on exploring how genes and the environment interact in the brain at molecular and cellular levels. The programme also featured family members including the heart-rending story of a Kildare family who are affected by the condition. The programme is podcast on the website

[www.rte.ie/radio1/mindmatters](http://www.rte.ie/radio1/mindmatters).

## EUROPEAN RARE DISEASE DAY

In order to raise awareness for rare diseases EURORDIS (a European patient-driven alliance of patient organisations and individuals active in the field of rare diseases) has designated the 29th February 2008 as European Rare Disease Day. The Genetic Inherited Disorders Organisation (GIDO) hope to host an event in Dublin to mark this day. Contact the office for details.

## DONATIONS

- Thank you to Michael Connern and friends for a generous donation of €200.
- Thank you to Jennifer for her big-hearted donation of €350 towards the young people's activity days.
- Sincere thanks to Richard & family and friends for their kind donations in memory of Margaret.
- Special thanks to Pat and the Postal Celtic Social Group for their generous donation of €250.
- Heartfelt thanks to Sandra and Stan in Scotland for your kind wishes and generous donation.
- Thanks to all our members and friends for your support.

## TRIBUTE TO MEMBERS

We would like to pay tribute, in our newsletter, to members who bravely cope with HD. Do you have a family member or friend you want to pay a tribute to? Someone who copes with HD while getting on with their daily life? If so please let us know.

## 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 HDIA 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 mornings. Tea, coffee and scones are provided. Contact the HDIA office on 1800 393939 for more information.

### WEST

Mar. 8th 2008 - Castlebar  
Jun. 7th 2008 - Cuisle

### CORK

Feb. 2nd 2008 - Carers Workshop  
Mar. 1st 2008 - Support Meeting  
Apr. 1st 2008 - Support Meeting  
May 3rd 2008 - Support Meeting

### DUBLIN

Feb. 16th 2008 - Support Meeting  
Mar. 15th 2008 - Support Meeting  
Apr. 19th 2008 - Carers Workshop  
May 17th 2008 - Support Meeting



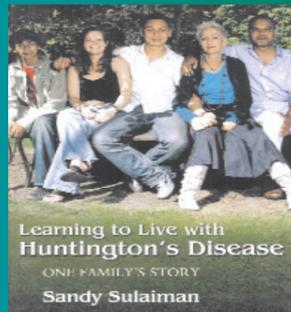
Carmichael Centre,  
North Brunswick Street,  
Dublin 7.  
Tel: 01 872 1303. FreeFone: 1800 393939.  
Fax: 01 872 9931. E-Mail: [hdai@indigo.ie](mailto:hdai@indigo.ie)  
Web: [www.huntingtons.ie](http://www.huntingtons.ie)

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 HDIAI.

## 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.



## HDIA LIBRARY

We have a stock of relevant books in our library. These are available to our members on request. "Learning to Live with Huntington's Disease" is a recent edition.

Is there a book you know of that you would like us to add to the library? If so, please let us know.

## ANNUAL MAGAZINE

Send in your contributions for next year. If you have any personal stories, useful information, photos or jokes etc we would be delighted to hear from you.

## PET CORNER

One of our members suggested we include a Pet Corner in our next annual. Here is your chance to send in a photo of your favourite pet or tell us about their antics!



NEWSLETTER OF THE HUNTINGTON'S  
DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

ISSUE NO. 33, Q1 08  
HDNL 2008

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

## WHAT SUPPORT DO YOU NEED?

HDIA would like to wish a Happy New Year to all our members and friends. Each new year brings new hopes as well as new challenges. Christmas is a time for family get-togethers, visiting friends and socialising. Although it is a wonderful time for many, for some people it can be a stressful time of year. If you found it difficult you may now feel alone and vulnerable at the start of a new year. Many of us can be too engrossed in everyday struggles to look for help outside our social circle.

HD is difficult for everyone within the family. The person with HD may feel very frustrated with a decline in independence. A spouse may be grieving for the decline of a loved one. Families often feel discouraged by the lack of

day care or respite facilities. Patients and family members often experience gaps in understanding from medical and healthcare professionals in addition to a general lack of awareness of HD. It is also painful if friends and other family members keep their distance.

The HDIA office can offer information on medical card applications, access to respite care, house refurbishments, genetic testing etc. Family support meetings and carers support workshops provide a forum for people to seek information and peer support from others in the same situation. Elizabeth is available as Family Support Officer to offer support and information to anyone who needs it. All contact is treated in strict confidence

## SUPPORT FOR CARERS

In 2007, through our Carer workshops, we began to focus specifically on the needs of those who live with and care for someone with Huntington's Disease.

We have had three carer's workshops to date, the first one being in Cuisle, with a follow up meeting in Dublin and Cork. The attendance at these has been fantastic and the feedback has been very positive.

As HD is a rare condition; isolation is often felt by those caring for a loved one. The workshops allow carers to meet and share their struggles and concerns with others in similar situations; this serves as a support to those who attend. They also provide tips on how carers can start to adopt a more positive approach to looking after their own needs.

For information on the workshops please call the office on Freefone 1800 39 39 39 or myself (Elizabeth) on 087 051 7772.



Take time to go for a walk or buy yourself those shoes!

## ACTIVITIES FOR Young People

We had our first young peoples day out in November of last year. The day was a great success and more details along with some great drawings will feature in our 2008 Hope Annual.

We went to the cinema and saw Ratatouille, ate far too many sweets and followed this with dinner in Thunder Road Café.

We hope to get more of you involved in the next day out, let me know your ideas and hopefully we can get them turned into a reality in the new Year.

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

# World Congress on Huntington's Disease 2007



(L to R): Liz, Catherine, Mary & Mike Connealy and Pat & Mary, Dresden 2007

The World Congress on Huntington's Disease (WCHD) 2007, took place in Dresden (Germany) in September 2007. Thanks to the German Huntington's Association, the International Huntingtons Association, the World Federation of Neurology Research Group and Euro HD Network for a very well run conference.

The scientific programme included presentations covering: genetics, pathogenesis, clinical aspects of HD (neurology, neuropsychology, neuropsychiatry and genetic counselling), neuropathology, biomarkers (imaging and biomarkers in body fluids), drug discovery and development etc.

There were also public policy, care and coping strategies and education sessions of interest to lay members

Mike Conneally chaired a session on the opening day. Milton Wexler received a well deserved tribute and both Nancy and Alice gave presentations. James Gusella presented a session on 'What the Future

Holds'. He referred to studies such as PREDICT-HD and COHORT which are taking place at present.

Jane S. Paulsen (USA) gave a presentation on the PREDICT-HD study. It uses a variety of tests to examine the nature and pattern of neurobiological changes and neurobehavioural changes that occur in the period leading up to a

diagnosis of HD. The intent of the study is to learn more about the beginning changes in thinking skills, emotional regulation, brain structure and brain function as a person begins the transition from health to HD. For more information on PREDICT-HD see: <http://www.huntington-study-group.org/>

Julie Stout (USA) discussed COHORT - a long-term observational study taking place at North American and Australian Huntington Study Group (HSG) sites. COHORT aims to collect information in order to learn more about HD, potential treatments, and to plan future research studies of experimental drugs aimed at postponing the onset or slowing the progression of HD.

<http://www.huntington-study-group.org/>

*"I attended the Congress for the first time this year. I was presented with a full and packed schedule. Not being very scientifically minded I was drawn to the more humanistic sessions that focused on the real impact of Huntington's on both the*

*sufferer and the family. I attended sessions on weight gain and weight loss in HD and found out that weight loss is not always going to appear as a symptom in HD, good diet and a good care plan can counteract weight loss and actually increase weight gain.*

*Depression is considered a common manifestation in HD. An interesting question was addressed: Is there a misdiagnosis of depression for apathy in HD? Anti depressants will lift a low mood however they will not treat apathy. The question now is how do we treat apathy?*

*In relation to what the future holds it was stated that in the past research was mainly concerned with symptomatic HD, and advanced HD, however current research is looking at pre symptomatic HD. In doing this they hope to learn more about the condition and perhaps learn how to halt the symptoms of HD from developing.*

*Jim Pollard gave a very interesting workshop from the HD person's point of view. Trying to understand how it may actually feel to think with HD helps us see things from the patient's point of view.*

*Above all I found the congress enlightening and stimulating. We are not alone in Ireland with HD, and the world's scientists, clinicians and lay people are working together and in that lies hope.*

*If any of you require more in depth information on the above please contact me".*

**Elizabeth**

## Acknowledge Kindness

In the HD world we experience many acts of kindness and friendship from friends, neighbours or perhaps work colleagues. If you want to thank someone please let us know. Confidentiality will be respected.

### THANK YOU!

I would like to nominate Gay Courage for a special thank you.

She has been taking care of my wife Catherine and us for the last 7-8 years. When I first met Gay I liked her. She is a lovely person in every way. Gay is very much part of our family. It has not been easy for her seeing the changes in Catherine but Gay has been there right through. In my heart I will never forget what Gay has done for Catherine. She well deserves the biggest bunch of flowers because she has a big warm heart.

Thank you from Mark Kelly.

*Gay will receive a big bunch of flowers from HDAI on behalf of Mark.*

## Woodie Guthrie Tribute Night

The Woody Guthrie tribute night in Whelan's, was a great success. Andy Irvine, a Woody Guthrie fan for many years, enjoyed a captivated audience as he sang Woody Guthrie songs while relating Woody's life story. Anne, our chairperson was invited to introduce Andy and took the opportunity to thank him and music promoter Derek Nally for organising the event.



Andy Irvine with Bernie, his No. 1 fan.

Andy Irvine was interviewed on Derek Mooney's radio show on RTE Radio 1. He gave a very interesting account of Woody's life and sang some songs. He talked about Huntington's Disease and mentioned the consequences for families living with HD. Catherine Paradise, a committee member, was also interviewed on the programme and discussed her father's illness and her 'at risk' status before she received a favourable test result. Catherine also mentioned the work of HDAI.



A great night was had by all

There were many HDAI members present on the night. The proceeds were split between Focus Ireland and ourselves. Derek presented us with a very welcome cheque of €1,080 towards our work.

# Fundraising Events

## Turning Trash to Cash for HDAI

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

## 60th Party Fundraiser

Congratulations and a big thanks to Michael Beetlestone who generously donated presents for his 60th birthday party to HDAI. In all Michael donated a whopping €1,391 to HDAI. Thanks to Maria and all friends and family who contributed.

## Tesco Bag Packing

Friends and family members took part in another two days of bag packing at Tesco in Dublin to help raise awareness and funds for HDAI. The group worked hard for two days and raised a magnificent €2,000 for HDAI. Our sincere thanks to Anne, Ashling, Grainne, Sean, Anna, Jennifer, Catherine, Mary, Shauna, Maria, Michael and friends who gave up their time and energy at this hectic time of year. The group raised a magnificent €1,700 for HDAI. We are very grateful to Tesco Merrion in Dublin 4 for giving our members the opportunity to carry out their Tesco bag packing charity event there. Thanks to all those who contributed to HDAI.

## Charity Auction & Line Dancing Hoedown

Phil and her friends were very busy this Autumn. On 21st September 2007 Phil organised a very successful charity auction with an "All Things Horsey" theme.

Signed Jockey silk was auctioned for €690, a horse rug €120 and a saddle & bridal earned €320. Other items included a Horse Drawn Caravan holiday, Polo lessons, Riding lessons and many more unique items. Thanks to the Woodenbridge Hotel, Co. Wicklow for providing a venue for the auction.



Some of the items auctioned

Thanks to all who contributed to the event and all who donated items for the auction including Fairy House Club Ltd., Leopardstown Racecourse, Waterford Crystal, Irish Polo Cross, Wicklow Polo Club, Sweet Fine Art, Joan Gelletlie, Carrigmore Farm, Castleknock Construction, STS Equestrian Ltd, A special thanks to Phil and family and to Maureen Doyle and Mary Shannon for their endless energy and support.

The following week Phil proved her relentless hard work by staging another fundraising dance hoedown. The proceeds from these events resulted in a staggering €7,700 for HDAI.

## Pub Night Fundraiser

We are very grateful to Mary Hiliard, her family and friends for raising €445 for HDAI through local pub raffles. Thanks to all at The Bridge Tavern and Sunset House who contributed to this event.

## Anna's Dublin City Marathon

Sincere thanks to Anna, who completed the Dublin City Marathon last Autumn and raised a huge sum of money (Stg £3,329) for HDAI. We are also extremely grateful to Moya for her very successful fundraising efforts.

## Balla Walk

The proceeds of the July Charity walk held in Balla, Co. Mayo came in at a final count of €4,930. A big thank you once again to Anne and her family and friends in Mayo.

## Craft Night

Friends of HDAI organised a craft making night to raise funds. Those attending had a very enjoyable night. Thanks to Aine Ni Dhonncha, Anne Mc Guire, Bernie Spellman and all who contributed to the success of the night which raised €950 for HDAI.



Friends of HDAI busy at work

## Dulux Paint

A very special thank you to all the staff of ICI Dulux Paints Ireland who very willingly forfeited their Christmas hampers and instead, donated the money (€2,100) to the Huntington's Disease Association of Ireland.



Pictured from left to right: Frank O'Boyle (Business Area Manager), Ernest Dover (Logistics and HR Manager), Mary Donegan (Sales Office Controller) presenting the cheque to Anne Lennon Bird (Chairperson HDAI) and Diarmuid Conifrey (General Manager).

## Christmas Swim

While most of us were dreaming of roast turkey Frank and his friends took to the sea off the Cork coast and braved the elements to complete a charity swim. Many thanks for your magnificent efforts and your €300 donation to HDAI.

## Tribute Night

Derek presenting Patricia with a cheque for €1,000 following the successful Woodie Guthrie tribute night in Whelan's recently.



## MOUTH-WATERING RECIPE



The committee were delighted to test Anna's mouth-watering Snickers Pie recipe (2006 Hope Annual) at our Christmas meeting. Do you have a recipe you would like to share with us for our 2008 Hope Annual?