

Dublin Bus Community Support Programme

HDAI were delighted to receive a €2000 grant from the Dublin Bus Community Support Programme (CSP). The programme, now in its third year, awarded €350,000 to 210 local, non-profit organisations based in all parts of Dublin and the greater Dublin area. It started when Dublin Bus decided to award money from unclaimed bus passenger change receipts. An Taoiseach, Bertie Ahern, TD presented the Dublin Bus CSP awards at a ceremony held in Dublin. He said the award ceremony was a great opportunity to showcase the work of the organisations and the volunteers who keep them going.

DONATIONS

- Thanks to Celbridge Classic Bike and Car Club for their very generous donation of €1,425.
- 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.

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.

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.



Niall Quinn, Patron of Dublin Bus Community Support Programme said "I am proud to act as patron of a Programme that recognises so many charities and non-profit groups for the invaluable work that they provide in their local communities..."

We had applied to CSP for a grant towards our 2007 annual magazine and were delighted to receive €2000. Catherine and Patricia attended the event and took the opportunity to give Niall Quinn our current magazine. We also got an autographed photograph from Niall, which we will offer as a spot prize for contributions to our 2007 Hope Annual magazine.

HDAI Library

We have a stock of relevant books in our library. These are available to our members on request. Is there a book you know of that you would like us to add to the library? If so please let us know.



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 and Dublin from 11.00am to 1.00pm 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. Catherine our Family Support Officer or a committee member will host the meetings. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information.

DUBLIN

Dec 16th • Jan 20th
Feb 17th

CORK

Jan - No Meeting
Feb 3rd • Mar 3rd

WEST

Castlebar - Dec9th and
March 10th

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.

Respite for Carers

HDAI RECEIVES SUPPORT FROM THE COMMUNITY FOUNDATION FOR IRELAND

The Community Foundation for Ireland provides a channel for organisations to undertake effective community based charitable giving. They favour projects which lead to the social inclusion of people who have been excluded due to circumstances such as geographic location, age, disability, family circumstances, race and poverty. HDAI were successful in their application to The Community Foundation for Ireland to provide a respite grant to carers who seek our support. We received €1,000 towards this project. This grant is for the primary carer of a HD patient. It must be used towards the cost of relaxation therapies or counselling. For further information on this grant please contact our office in writing or by telephone: 1800 393939.



RESPITE FOR XMAS

DO YOU NEED ANY FINANCIAL ASSISTANCE THIS CHRISTMAS? HDAI WOULD LIKE TO HELP WHERE POSSIBLE, BY CONTRIBUTING TOWARDS A FAMILY OUTING OR A CHILD'S CONCERT TRIP ETC. PLEASE LET US KNOW IN WRITING IF WE CAN HELP YOU THIS CHRISTMAS.

CHECK OUT OUR WEB ADDRESS

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

THIS IS YOUR NEWSLETTER. PLEASE SEND US YOUR VIEWS

RESPITE FOR CARERS - SEE PAGE 4

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 29, Q4 06
HDNL 2006

EHA CONFERENCE

The 11th bi-annual European Huntington's Association (EHA) meeting took place in Blankenberge - Belgium last September 13th - 17th. It took for its title 'Looking back to the future' and it was held in conjunction with the 3rd plenary meeting of Euro Huntington's Disease Network (EHDN). This latter organisation is a privately funded grouping of scientists and researchers drawn from universities and research centres across Europe and actively seeks a cure for HD. Three of the five delegates who attended from HDAI were funded by EHDN (as they are registered participants in working groups) and one of the other delegates was self funded.

The conference began at 1.30pm on the 13th September and this first half day was taken up with discussion relating to the Business of EHA. We had reports from the President, Secretary and Treasurer. Each member country association gave a short report the nice thing here was listening to reports from newly arrived members from Eastern Europe such as Poland and Russia.

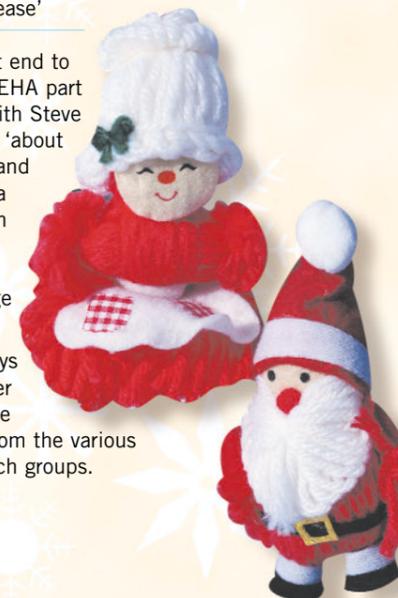
There was a lively discussion on whether/how we should co-operate with the scientific grouping (EHDN) who were hosting the final two days of the conference. The final outcome was agreement that we should cooperate but guard our independence, as we need to have some input into / influence on the research. Christiane Lohkamp was unanimously nominated as EHA representative on the executive committee of EHDN. The business meeting ended with agreement that the next EHA meeting would take place in Portugal in 2008 and possibly Northern Ireland in 2010.

The next day (14th) began with a welcome from Beatrice De Schepper, President of EHA and vice-president of the Belgium Huntington Liga vzw (Flemish section) We then had talks from:

- **Prof. Patrick Cras**, Department of Neurology, University Hospital of Antwerpen, on treatments for Huntington's disease
- **Tanja Beeckman** and **Katja Batens**, on speech therapy and HD
- **Dr. Dirk Liessens**, Psychiatrist, U.P.C. St. Kamillus - Bierbeek on the relationship between lay-organisations and professionals.
- **Prof. Gerry Evers-Kiebooms** and **Dr. Marleen Decruyenaere**, on 'Predictive, prenatal and pre-implantation genetic testing in Europe, present and future'
- **Professor René Dom**, Department of Neurology, U.K.U. Leuven addressed 'Bridging medical science and the lay organisation: a mutual obligation in the care of patients with Huntington's Disease'

There was a pleasant end to this day (and to the EHA part of the conference) with Steve Smith playing music 'about Huntington Disease and Woody Guthrie' and a talk from the Flemish Minister for Welfare, Public Health and Family - Minister Inge Vervotte.

The following two days 15th - 16th September were given over to the EHDN and reports from the various scientific and research groups.



EHA Conference (continued)

There were also reports from a number of EHDN working groups which are involved in drawing up benchmarks and standards for dealing with HD patients and research into the illness itself. Bernie is working hard with the group dealing with juvenile HD while Catherine and Anne are playing a major role in the group dealing with Quality of Life issues.

Much of the detail in reports from the research groups was difficult for us lay people to follow - but we did note the

breadth and scope of the research and this was heartening to see.

When one thinks of the amount of research already being undertaken by the Hereditary Disease Foundation in North America and couple this with the quality of research reported on in Belgium last September we are left with a great sense of confidence that the scourge of HD will soon be comprehensively consigned to history.

Self Esteem

In times of stress and work overload our self-esteem can take a nosedive. Having high self-esteem is a healthy psychological state and we need to protect it. People with high self-esteem are generally calm, relaxed, purposeful, positive and expressive.

When our self-esteem is low we become fearful, negative, passive, tense, indecisive and unmotivated. As well as affecting our happiness, low self-esteem also impacts on our work and relationships.

Below is a quick fit list to help lift negative feelings and revitalise the body and spirit in spite of external pressures.

- Take a walk or a run in the park.
- Have a long hot bath by candlelight with aromatherapy oil. (Lavender or geranium oils are very relaxing.)
- Have a fast bracing shower.
- Do some leisurely gardening.



- Have a swimming race with a friend.
- Have an early night with a great book or a great person.
- Watch your favourite comedy
- Buy yourself or somebody else flowers
- Start a savings plan for 'rainy day' treats
- Have a take away dinner by candle light listening to your favourite music.

Young People in HD Families

We would be interested to hear from young people in HD families in Ireland. We realise that growing up in a HD family can add significant pressures to young people at a time when they may have pressures from school, sporting activities or studying for exams and making decisions about their future career. Our annual magazine has a young people's section and we hope in future this will provide a forum for young people to share their views and concerns.

At the present time the committee are considering producing our own booklet on informing young people about HD and the implications for the family. Do you have a view on how this subject should be approached or what you feel should be included? We value all feedback.

If any family members or friends would like information on this subject please contact Catherine through the HDAI office.

Scottish Huntington's Association Youth Service

The Scottish Huntington's Association has a well established Youth Service which has been funded by Children in Need for nearly five years.

Their stated objectives for 2006 include:

- To increase young people's knowledge of HD by providing information in a suitable format for children and young people.
- To empower children and young people to increase their confidence and self-esteem.
- To build on the number of children and young people involved with the project.
- To increase professional knowledge of HD and the issues and challenges facing children and young people.
- To involve children and young people from HD families in group activities, which can build their confidence and self-esteem, and enable them to meet people from similar backgrounds.
- To secure funding for YP and parents to produce a DVD about growing up with HD and 'how to tell the children'

Fundraising Events

Recognising Voluntary Fundraisers

President and Dr. Mc Aleese held a reception in Aras an Uachtarain to recognize the valuable work done by charitable organizations, for older people and people with an illness or disability, to whom the President is Patron. Each organization was invited to nominate five voluntary fundraisers to attend the reception on their behalf. We compiled a list of our regular fundraisers and drew out five people. Anna, Ann, Bernie, Frances and Phil were selected to represent HDAI on the day. They received a warm welcome and all enjoyed the event.



Meeting President and Dr. McAleese.

Sloan Rangers Line Dancing

In addition to their regular fundraising dance classes, Phil and friends held a line dancing "hoedown" for HDAI on 30th September. They also raised money through auctions and raffles. The night was very successful and raised approximately €2000 for HDAI. Thank you to everyone who helped out with this event including Waterford Crystal, Fairyhouse Race Course, Wexford Race Course and Leopardstown Race Course for their gifts for auction. A special thanks to Phil and her friends for their ongoing help and support.



Liffey Descent

Sincere thanks to John Daly who took part in the 'Liffey Descent' (a canoe race on the river Liffey) earlier this year and raised a very impressive €980 for HDAI. Thanks also to Betty and John for their support and kindness.



Mini Marathon

Mary and friends took part in the 2006 Limerick mini-marathon and raised a very impressive €1,200 for HDAI. Mary, Ciara, Maria, Ann and Helen successfully completed the mini marathon and were featured in The Irish Examiner's reporting of the event. HDAI are very appreciative of your support. Thanks to all those who sponsored Mary and friends.



Mary, Maria, Ann, Ciara and Helen.

Balla Walk 2006

Sponsorship from the 2006 Balla Walk continues to come in. The final tally now amounts to a staggering €5,195 (cheque being presented below). A reception was held in Balla to celebrate the achievements of all the walkers who participated and raised money for various charities.



Fundraising 50th

Congratulations to Michael on being 50 years young! Michael generously forfeited presents, instead he suggested to friends and family invited to his party, to make a donation to HDAI. HDAI are very grateful to Michael and Bernie for their thoughtfulness and generosity. Michael would like the €2,315 raised as a result of his party to go towards support for carers.

Thanks to everyone who contributed to HDAI on behalf of Michael.