

Donations

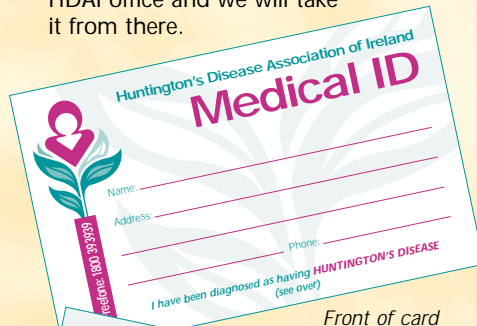
- We are very grateful to The Teachers Union of Ireland for their generous donation.
- Special thanks to Eileen Clancy for her continued support.
- We would also like to express our sincere thanks to Seamus Flood for his generous donation.
- Thank you to all those members and friends who have donated 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

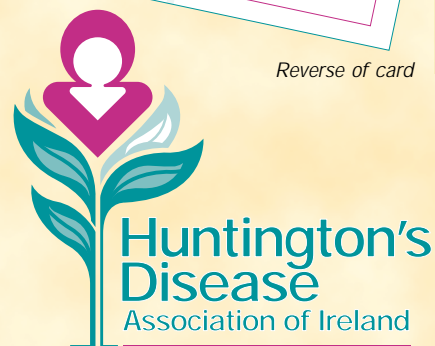
A free Huntington's ID card is available. Please send your photograph, address, phone number and an emergency contact person's phone number to the HDAI office and we will take it from there.



Front of card



Reverse of card



Support Meetings

THE WEST OF IRELAND SUPPORT MEETING

The last meeting in the West was held in Castlebar on March 11th. Members met for a chat over tea, coffee and fresh scones. Catherine our Family Support Officer hosted the meeting. Catherine was delighted to welcome five new members to this meeting in addition to our regular attendees.

The next West of Ireland support meeting takes place in Cuisle, Roscommon on June 10th.

CORK SUPPORT MEETING

Monthly meetings are held in Cork city centre on the first Saturday of the month. The meeting is usually hosted by a member of the committee or by Catherine and allows new and old members the opportunity to meet in comfortable and private surroundings.

DUBLIN SUPPORT MEETING

Our Dublin support meetings are better attended since January. We did not have a lot of feedback from members on whether they would prefer a venue or day change for the meeting.

We continue to welcome all opinions and ideas. Thanks to those of you who did give us your opinion. Please let us know if you have any suggestions on improving this meeting. Future Dublin meetings take place on June 17th, July 15th and August 19th.

Support meetings give members the opportunity to meet other people in similar situations and exchange information.

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. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information.

DUBLIN

June 12th • July 15th
Aug 19th • Sept. 16th

CORK

June 3rd • July 1st
August 5th

CASTLEBAR

Cuisle Roscommon, June 10th
Castlebar, Sept. 9th & Dec. 9th

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.



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

NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 27, Q2 06
HDNL 2006

Members Meeting & AGM - June 10th, 2006

Our AGM/Respite weekend takes place from the 9th - 11th June in Cuisle Respite Centre, Co. Roscommon. All facilities at Cuisle are fully accessible to people with disabilities. Please book now if you have not already done so. All are welcome.

We will have a number of health care professionals speaking at our members meeting on Saturday afternoon. Vanessa Cloete, Senior Speech & language therapist from Roscommon County Hospital will give a presentation on the benefits of speech therapy.

Fergus Timmons, Training Unit Manager from the The Carer's Association will talk about services provided by the Carers Association and outline the training courses they run. He will also host a discussion on any training needs our members feel they have.

We plan to have therapies available again this year as the Chiropody, Massage and reflexology therapies available last year proved very popular.

Getting to Cuisle

Please let us know if you can not attend due to travel difficulties and we will try to work something out. We provide a return bus service from Dublin to Roscommon.

The bus leaves Dublin on Friday evening and returns Sunday afternoon. We also provided a bus from Cork last year and hope to do so again if there is sufficient interest.

Please let us know if you have transport problems.

Annual Magazine

We are hoping to launch our new magazine Hope Annual which features articles from members, events during the year, members feedback etc at Cuisle this year. The magazine has personal stories, information on services, a chill out section with competitions and recipes and a young peoples section. We will post copies to all on our mailing list. We look forward to receiving your feedback and your contributions for next year.



Juvenile Huntington's Disease Meeting

We mentioned in our last newsletter that the Euro HD Network has set up a working group on Juvenile Huntington's Disease (JHD). JHD refers to anyone who develops signs or symptoms of HD before they are 20 years old.

The Euro HD Network hope that international collaboration facilitated by the Euro-HD project will allow a more detailed study of the natural history of the condition to be undertaken and for the qualitative research to be extended to other European countries. They hope that as a consequence of this

investment, services for families with JHD can be improved across Europe.

Bernie Moran represents HDAI on the JHD working group. Bernie will host a meeting at Cuisle for people affected by JHD.

Please contact us on 1800393939 if you can attend this meeting or if your family is affected by JHD so that we can learn more about the situation for families in Ireland. All information will remain strictly confidential.

Thank You God

by Angela Ssengoba

(Composed on Dec. 15, 2005 and dictated to her mom)

Thank you God

Send me your healing power from the land of love
Dress me in a beautiful gown to go back to the hot sandy beach
To feel the cool water tickle my spirit
Tickle my nose - Tickle my ears - Tickle my tummy
On a warm summer's night

Thank you God for hot summer nights

A warm breeze on my face

Let me lie down and relax on the sandy shore

Listening to the waves rise and fall

Thank you God for loving me; keeping me safe-at peace

Blessing me with courage, strength and love

Take me on a nice cool cruise

Make me as graceful as a gazelle

Thank you God for making my life a miracle



Angela passed away peacefully on December 18, 2005 after a courageous battle against Huntington's Disease (HD). Angela was born in 1965 and enjoyed a full and active life. She attended the University of Michigan where she was awarded the Hopwood Award for her poetry. She later moved to California and attended UCLA. She lived in various cities in

the Los Angeles area and continued to write poetry as well as plays, stories and movie scripts. She loved the sunshine and beaches and enjoyed reading novels, attending concerts, dancing, singing and performing in musicals. She loved a variety of types of music and hosted a reggae radio program. Over the years, Angela acquired an impressive collection of her creative writings and musical selections. She was very positive and always in good spirits. Two of our members Ann and Denis met Angela at a HD chapter meeting while visiting relatives in the US late last year. They were taken by her friendliness and welcome, in particular towards Ann a fellow sufferer.

Improving Neurology Services

The Neurological Alliance of Ireland (NAI) was established in 1998 as an umbrella organisation for groups representing the views and concerns of those affected by neurological conditions.

The NAI states its aims as informing, influencing and liaising with those responsible for maintaining and developing services and support for people with neurological conditions, their families and carers.

HDAI is a member of NAI. A HDAI representative regularly attends NAI meetings to inform NAI of the concerns of our members and receive updates on their work.

Consultant neurologist Dr Tim Lynch met with NAI in March to outline his views on the development of

neurology services and the need for a longterm brain strategy in Ireland. He spoke about the need for improvements in countrywide access to services and integration between hospital and community services. Dr Lynch acknowledged the work of NAI in highlighting the need for improvements in neurology.

There are currently 16 Adult Neurologists in the public health system located in Dublin, Cork and Galway. There are no Neurologists in the Northwest, Midwest and Southeast. There is also a substantial shortage of rehabilitation centres and multidisciplinary care teams (psychologists, speech and language therapists, physiotherapists, occupational therapists etc.) nationwide.

Funding for Neurology

The budget estimates in 2005 allocated 3 million euros for neurology and neurophysiology services across the country. The HSE in their Strategic Planning and Reform Implementation Projects for 2006, announced that three new neurology units would commence development

during 2006. These would be located in the Mid West, North West and South East with the appointment of three multidisciplinary teams made up of a consultant neurologist and support staff. We look forward to more information on this development.

Skin Conditions

We had a query from a family member on skin conditions; certain skin conditions are aggravated by stress. Your GP should be able to advise you on treatments available. Can you let us know if anyone in your family has been affected by a skin condition - Freefone 1800393939.

Coping with Change

The consequences of living with HD can be profound. Income, social status, power and social contact are just some of the factors, which may be affected. In addition to the psychological impact of giving up employment and / or homemaking the person with HD has to deal with the physical and emotional impact of living with a debilitating condition. This has obvious implications for the whole family. Change is recognised as a stressful situation. Change is less stressful if we feel we have some control and are able to manage the change. There are ways to empower oneself and deal more effectively with changes as they occur. If you need some advice or a confidential chat please call Catherine on 1800 393939

Judi Chamberlin (1999) provided the below as "A Working Definition of Empowerment"

1. Having decision-making power.
2. Having access to information and resources.
3. Having a range of options from which to make choices (not just yes/no, either/or.)
4. Assertiveness.
5. A feeling that the individual can make a difference (being hopeful).
6. Learning to think critically; learning the conditioning; seeing things differently; e.g.,
 - a. Learning to redefine who we are (speaking in our own voice).
 - b. Learning to redefine what we can do.
 - c. Learning to redefine our relationships to institutionalised power.
7. Learning about and expressing anger.
8. Not feeling alone; feeling part of a group.
9. Understanding that people have rights.
10. Effecting change in one's life and one's community.
11. Learning skills (e.g., communication) that the individual defines as important.
12. Changing others' perceptions of one's competency and capacity to act.
13. Coming out of the closet.
14. Growth and change that is never ending and self-initiated.
15. Increasing one's positive self-image and overcoming stigma.

Fundraising Events



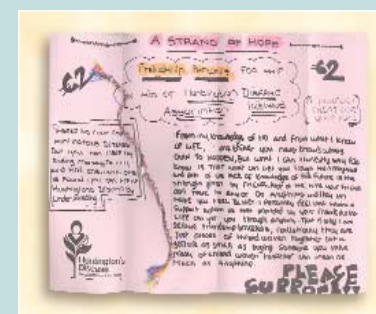
Sloan Rangers Marathon Madness

Many thanks to Phil and friends for continuing to raise funds for HDAI through dance.

"On taking part in a recent line dancing charity marathon it was decided to go that extra mile and help out the H.D.A.I. We contacted the H.D.A.I. and asked them for some sponsorship cards. These were distributed to both family and friends for collection, the generosity of people never ceased to amaze and our final total amounted to €1300. May we thank all those who donated very generously and have many blessings" - Phil.

Friendship Bracelets - A Strand of Hope Poster

Muireann a transition year student from Muckcross Park College recently raised €198 by making and selling friendship bracelets as part of her transition year project. Muireann designed an effective poster with the following touching message: From my knowledge of HD and from what I know of life, one thing you never know is what's going to happen. But what I can honestly say I do know is that what can get you through the annoyance and pain of the lack of knowledge of the future is the strength given by friends. A lot of the time your friends don't have



to say or do anything to make you feel better. I personally feel that having a support system as that provided by your friends during life can get you through anything. That is

why I am selling friendship bracelets. Realistically they are just pieces of thread woven together but a gesture as small as buying someone you value pieces of thread woven together can mean as much as anything.

Many thanks to Muireann and her family and friends for their efforts in creating awareness and fundraising for HDAI.