

DONATIONS

- The Coventry Mayo Association recently donated £500stg to HDAI for our work. Grateful thanks to The Coventry Mayo Association and to Breeda for informing them of our work.
- We are very thankful to Eileen, Paddy and George for their generous donations at Cuisle.
- We would also like to express our sincere thanks to Tony & Jennifer, Brenda & Pauline for their recent donations.
- 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

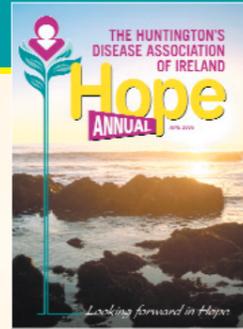
Please let us know if you need a HD Chair for a family member or if you have one that is in need of repair. Alternatively if you have one you do not need and would like someone else to make use of it we can arrange this. Please contact the office.

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.



HOPE Annual



We launched our new magazine Hope Annual at our respite weekend in Cuisle. We were very grateful to receive a kind and supportive message from President McAleese for our first edition. The magazine has personal stories, information on services, a chill out section with competitions and recipes and a young peoples section. We have posted copies to you and we look forward to receiving your feedback and your contributions for next year. Your stories and suggestions will be most welcome. Thank 's to all of you who contributed to our first publication. We have received a lot of positive feedback to date. Anne and Fionan were successful winners of the competitions. Prizes have also been sent to Niall, Kevin, Oisín, Orla and Elaine for their excellent contributions to the Young People's section.

We are considering running a short story competition (fact or fiction) with the winning story published in our next annual. Get your pens out and send us some stories!

HDAI Committee

Pat and Una resigned from the committee in June 2006. Both Pat and Una have been active and dedicated members for many years. Unfortunately, due to other commitments they need to take a break at present. They are of course welcome back after their break!

The committee and staff had an enjoyable evening in a restaurant at the end of June to thank Pat and Una for their valuable work and also to welcome

our new committee members. Anne presented Pat and Una with a gift each as a sign of our appreciation to them.

Four new members joined the committee: Mary, Eileen, Pat and Maria. We now have representatives on the committee from Dublin, Cork and Limerick. Anne Lennon Bird continues as Chairperson for the coming year. The committee meet once a month or more often if required.

HDAI Library

We send out information packs to health care professionals on request. Please advise us if you know someone who needs one. 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

Sept. 16th • Oct. 21st
December 16th

CORK

Oct. 7th • Nov. 4th
December 2nd

WEST

Castlebar - Sept. 9th
and December 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.



NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 28, Q3 06
HDNL 2006

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

Members Meeting & AGM - - held on June 10th, 2006

Our AGM/Respite weekend took place in Cuisle Holiday and Respite Centre, Dunammon Co. Roscommon on the weekend of 9th - 11th June. Approximately 65 people attended on the day with the majority enjoying the weekend there.

The committee reported on HDAI's activities over the year and presented our annual audited accounts. Members present were invited to join the new committee and we were delighted to welcome four new committee members. Following the AGM we launched our new magazine 'Hope Annual'.

Our members meeting commenced directly after the AGM. Vanessa Cloete, Senior Speech & language therapist from Roscommon County Hospital give a very practical and interesting presentation on the benefits of speech therapy including:

- **Role of Speech & Language Therapist in managing HD**
- **How HD affects speech and swallowing**
- **Tips for improving communication with a person with HD (see below)**

Fergus Timmons, Training Unit Manager from The Carer's Association gave an informative talk on the services provided by the Carers Association and outlined the training courses they run.

After the meeting, members had the opportunity to take a stroll in the garden or catch up with old friends. Chiropody, Reflexology and massage therapies were available on Saturday and proved very popular with members again this year.

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 members. The socialising lasted until the early hours!

Members had the option of a return bus service from Dublin and Cork. The team at Cuisle provided an excellent service to us again this year and we value their helpful and caring attitude.

On behalf of the Association, Anne presented Bernie Moran with a life time membership of HDAI certificate to recognise her contribution to HDAI.

We would be grateful if those of you who were at Cuisle would send us in your comments regarding the weekend. For those of you who did not attend we would welcome your suggestions on how to make this weekend more accessible to you.

Tips for improving communications with a person with HD

Presented at Cuisle by Vanessa Cloete, Senior Speech & Language Therapist from Roscommon County Hospital

TIPS FOR PERSON WITH HD

- Speak slowly
- Keep sentences short
- Describe, what you want to say, if you can't get the word out.
- Use gestures and facial expression, if possible, to aid verbal communication.
- Use an alphabet board or communication aid

TIPS FOR CARERS

- Remove distractions
- Give your full attention
- Keep questions straightforward
- Ask one question at a time
- Seek clarification if you are not sure of message
- Stay on the topic or introduce new topics

Speech & Language Therapy

The Speech & Language Therapy Service at The Midlands Regional Hospital, Portlaoise recently wrote to us advising us of their services in the Laois area (see letter enclosed). Your Public Health Nurse or your local Health Service Executive office should be able to advise you on the services available in your local area.

Think Loud - Talk Loud

Lee Silverman Voice Treatment (LSVT) teaches self-empowerment by improving the ability to communicate and thereby enhancing the quality of life. The treatment is named in honour of Lee Silverman, who was the first patient to undergo this treatment. Although the experimental data from more than 15 years research is from people with Parkinson's Disease (PD), it is now felt that other conditions respond to LSVT. Current data from treating select individuals with neural disorders other than PD e.g. Multiple Sclerosis, Cerebral Palsy, Stroke etc have documented increased vocal loudness levels following treatment with corroborating perceptual ratings of improved loudness, voice quality and functional communication. Improved speech production can lead to physiological changes (swallow, facial expression, respiration) along with neural functioning.

It has been found that the LSVT treatment effects can last for up to two years.

Problems of reduced loudness, monotone and mumbling commonly occur as a part of diseases like PD and HD. Many individuals report that they "talk less, participate in fewer activities and go out of the house less often" because it is frustrating to communicate and they lose confidence. While medicine and surgery may improve other symptoms of neurological diseases, they don't help speech disorders. The only way to improve speech is by speech therapy.

LSVT teaches people with speech difficulties, to develop the strength required, to speak at a normal vocal loudness.

LSVT is delivered intensively (individual 1hour treatment sessions, 4 days a week for 4 weeks), with a focus on increasing vocal loudness, enhancing sensory awareness of vocal loudness and "re-calibrating" the sensorimotor system for automatically producing appropriate vocal effort and loudness. Motor and sensory retraining includes patient education and carryover exercises to generalise the effects of the increased vocal loudness to daily living. LSVT exercises include three daily tasks and hierarchical speech loudness tasks.

The three daily tasks make up the first half of the treatment session and include:

1. maximum sustained vowel phonation
2. maximum pitch range exercises
3. functional phrases

The hierarchical speech loudness tasks make up the second half of the session and include working on using increased loudness during:

1. reading,
2. speaking,
3. tasks moving from simple words and phrases to spontaneous conversational speech across the four weeks of treatment.

LSVT also requires patients to participate in daily homework practice and daily carry-over assignments (patient uses new loud voice outside of the treatment room).

At the end of one month of individual treatment, most patients are able to self-generate improved loudness resulting in dramatically improved functional communication. Quality of life is considerably improved with this intensive but rather short duration, speech treatment.

The promise of LSVT is that it is "the first effective treatment established for treating the voice and speech disorders in individuals with PD and other neurological disorders"

Last June my wife Ann participated in the LSVT treatment. She was a most enthusiastic patient and enjoyed her sessions with speech therapists Noreen and Marita.

Her homework, consisting of a lot of loud "ahs" and "ees" was so effective that we worried what the neighbours thought of it all. We eventually took Ann's homework sheet with us when we went out driving.

There is no doubt in my mind that this treatment works. Ann's new found LOUD voice has taken a lot of people by surprise - even myself at times. Even before I knew that the improved speech production could lead to the physiological changes (mentioned above) I noticed that Ann did not cough and or sneeze as much at mealtime.

Huntington

by Magda Van Renterghem,
Waarschoot, Belgium. Translator:
Hannelore Michiels

*There was something about her,
something I could not recognise
not then, I was way too young
but I saw the delicate difference
that is making forty-year-olds older
even before the body is worn-out*

*There was something about her
while her steps danced softly
in slow-motion
as her arms followed uninvited
she lost direction chaotically
the grip on her movements loosened*

*There was something about her
with the hopeless intense process
still to be who she once was
bright, caring, clear-headed
until her mouth didn't follow her
words
and sentences chattered into distorted
sounds*

*There was something about her
with the years going by
braincells disappeared one by one
destroyed her body more and more
a default of the genes,
an unequal battle,
however brave it is struggled against
There was something about her
until one day she became seventy
still little sparks in her eyes
a burst of sound
who will ever know, who shall
ever measure
the dying before one actually died*

*There was something about her,
something that I will recognise now,
in the endless suffering, in the
unmasked forced introvertness
There was something about her,
something that now has got a name*

Ann is delighted to get her own voice back. She has told me in her new LOUD voice, how happy she is, that I will no longer be doing all the talking. Well, there's gratitude!!!

Please contact our HDAI office if you have any questions in relation to this. For further information on speech therapy or the LSVT treatment, please see the following websites:

www.oasis.gov.ie/health/speech_and_language_therapy_services.html

www.lsvt.org

www.ncvs.org

Fundraising Events

Dublin City Marathon

A Big thank you to Frances Woods, who ran in the Dublin City Marathon and raised an admirable €1,625 for HDAI.

Fashion Show

Muireann a transition year student from Muckross Park College was involved in organising a joint fashion show charity event between Muckross College and St Michael's College. Muireann nominated HDAI as one of the benefiting charities and we were very grateful to receive €500 as a result. Thanks, to Muireann, and to the staff and students at Muckross College and St Michael's College who helped with this project.

Muireann previously raised €198 by making and selling friendship bracelets as part of her transition year project. Thanks again for your efforts to create awareness and fundraising for HDAI.

Mini Marathon

A number of our members took part in the 2006 Women's Mini Marathon to raise funds for Huntington's Disease.

Bernie Spellman organised a whole team of participants with their combined effort amounting to a very substantial €3,049. The 'Three Degrees for HD' were part of her team and even though they were not first past the post they outshone many of the other contestants!



The 'Three Degrees' left to right, sporting high fashion: Kendra (Kieran Morrisroe), 'Noleen' (Noel Dunne) and 'Ciara' (Kieran Mc Carthy).

Special thanks to Danielle, Starlena, Betsy, Anne, Bernie, Grainne, Aisling Susan and Rosie who had a lot of fun on the day and captured it on camera.

Lorraine, Rachel and Jennifer travelled up from the west of Ireland to complete the Mini Marathon in June and succeeded in raising an excellent €468 for HDAI.

Thanks to all who took part and a special mention for The Mary Brogan Set Dancers at All Hallows College Drumcondra (pictured below) for their generous sponsorship. We know that a lot of effort goes into participating and getting sponsorship so a BIG Thanks to you all.



The Mary Brogan Set Dancers, All Hallows College, Drumcondra

Sloan Rangers Line Dancing

Many thanks to Phil for her ongoing fundraising for HDAI through her dance classes.

Balla Walk 2006

For the third year running Ann and Margaret from Mayo have worked hard to encourage their Family members, friends and neighbours to take part in the Balla 10km walk to raise funds for Huntington's Disease. The walk took place on Saturday July 29th setting off from the community centre in Balla, Co Mayo. Many people completed the walk to raise money for local and national charities.



Ann and friends walking to support HD families. Thanks to Ken Wright Photography.

Twenty-seven people walked for Huntington's Disease sporting our aluminous HD bib. This in itself is an effective way of raising awareness and shows great solidarity and support for all our families. Once again HDAI would like to extend a sincere thanks to Ann and Margaret for their dedication and hard work. Thanks also to all those who walked and those who gave sponsorship. Walkers included: Joe, Lorraine and Joan; Caroline, Eddie and Family; Madeline & Friends, Con & Bernie, Nonie & Seamus. This group have raised €3,700 so far and hope to reach €4,000 when all the sponsorship has been collected.

The Balla Community Centre provided refreshments for all who took part in the walk. Local businesses contribute by providing food and beverages. Brendan Conwall and his team work hard to organise a successful and enjoyable event.



Margaret manning the HD desk surrounded by fellow supporters - Thanks to Ken Wright Photography.