

DONATIONS

- Sincere thanks to Wexford 100 Motorcycle Rally for their very generous contribution of €2,500 raised from their recent annual bike rally.
- DCC were again generous to HDAI with a contribution of €250
- Thank you to Marin Air for their generous donation of €500. We appreciate your continuing support.
- We received a generous contribution of €1,090.43 (£750) from the Hospital Saturday Fund.
- Special thanks to Maria, Jim, Joan and Teresa, for their recent very generous donations.
- We are very grateful to our members for their 2007 membership contributions. Thanks also to all our members and friends who have donated recently. Your support is a great source of encouragement to the committee and staff of HDAI.

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.



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. In Dublin, meetings will be held in a city centre hotel from September onwards. We will

host a carers workshop in October in Dublin and November in Cork. 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. Our Family Support Officer or a committee member will host the meetings. Tea, coffee and scones are provided. Contact the HDAI office on 1800 393939 for more information.

DUBLIN

July - No Meeting
 August - No Meeting
 Sept 15th - Support Meeting
 Oct. 20th - Carers Workshop
 Nov. 17th - Support Meeting

CORK

July 8th - Support Meeting
 August 4th - Support Meeting
 Sept 1st - Support Meeting
 Oct. 6th - Support Meeting
 Nov. 3rd - Carers Workshop

WEST

Sept 8th - Support Meeting
 Dec. 8th - Support Meeting



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 North Brunswick Street,
 Dublin 7.
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 Fax: 01 872 9931. 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.

WOODY GUTHRIE 40th ANNIVERSARY GIG

Woody Guthrie was a writer, singer and political activist. He had a huge influence on American folk music. He is also considered to have paved the way for singer-activists such as Bob Dylan, Pete Seeger and Bruce Springsteen. He died on October 3, 1967 as a result of HD. He had written more than twelve hundred songs including "This Land is Your Land" and "So long, It's Been Good to Know You".



Errol from the Northern Ireland HD Association (pictured singing a song at Cuisle) is organizing a Woody Guthrie 40th Anniversary gig on Sunday 7th October in the Empire Music Hall in Belfast to commemorate the work of Woody Guthrie and to raise funds for the NI Association.

TO DATE THE BILL INCLUDES:

- Juliet Turner - winner of Irish Meteor Music Award in 2005 for best Irish Female Performer.
- Bap Kennedy (Brian Kennedy's brother) - Bap has written for films and made several critically acclaimed albums).
- Arty McGlynn and his wife Nollaig Casey - Arty is well known in the traditional music world, he also played with the likes of Paul Brady and Van Morrison. Nollaig has played with the national orchestra and also joins in with Arty in the trad world.
- Brian Houston - An up and coming Belfast songwriter with a healthy following.
- Ronnie Greer Blues Band - Hot stuff on the blues circuit in Belfast.
- The Delawares - (hotly tipped new band).
- Maeve Dunphy - (talented Omagh songbird with her new band).

If you are interested in attending or buying a ticket please contact Errol at 00 44 7718910423 or email address, errol@laganboatcompany.com

The tickets will be available from Ticketmaster by August.



NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 31, Q2 07
 HDNL 2007

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

Our AGM and Members Meeting took place from the 8th - 10th June in Cuisle Respite Centre, Co. Roscommon. The members meeting was attended by sixty six people with most staying in Cuisle for the weekend.

Anne as Chairperson thanked members for attending and introduced Elisabeth our new Development & Family Support officer. The committee reported on HDAI's activities throughout the year. The treasurer presented our annual audited accounts which were approved by members present. D.F. Byrne was appointed Auditor for the coming year. Anne thanked the present committee for their voluntary work throughout the year. She also reminded members present to consider joining the committee and contributing to the work of HDAI.

Our members meeting began with Carole Clayton, Clinical Nurse Specialist in Huntington's Disease and Manager of the Leicestershire Huntington's Disease Service in the UK, who gave a very interesting presentation on cognition and the care of people with Huntington's Disease. She provided lots of practical examples of misunderstandings that can arise in the care of HD patients and how they can be avoided.

Alice Wexler, author of Mapping Fate, spoke about HD and her family's experience of HD. She

spoke about her father Milton who died earlier this year aged 98. At the age of 60 Milton began his work on HD. He was determined to highlight HD and find answers. Alice spoke about his 'can do' attitude and his ability to face and solve problems.

Nancy began her presentation by giving us a background of her father Milton, her sister Alice and her own work on HD. She spoke about her research project in Venezuelan and how a boy with an abnormally high CAG repeat provided insight into the mystery of the condition which helped find a marker for the gene. Nancy has high expectations that the latest research into RNAi will eventually result in a cure for HD. She pointed out that was one of the last subjects her father discussed with her before he passed away.

Anne gave Alice, Carole and Nancy a Celtic broach each as a token of our appreciation for their time and expertise.

Our 2007 Hope Annual was launched and copies given to members present. Afterwards

Anne thanked Catherine, on behalf of members and the committee, for her expertise and valuable support as Family Support Officer and wished her well in her retirement. She presented Catherine with book tokens as a gift (pictured below) from the association and welcomed her back as a valued committee member. Anne thanked Patricia for her work throughout the year and gave her a bunch of flowers on behalf of the members.



Nancy and
 Alice Wexler
 with our
 Treasurer
 Pat Griffin



Members Meeting & AGM (continued)

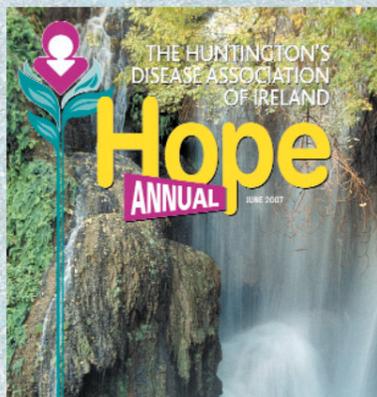
Therapies including Chiropody, Massage and reflexology were available to members on the day. Elisabeth delivered a caring workshop for carers.

After the meeting, members took advantage of the sunshine and caught up with old friends. We celebrated our year's work over dinner on Saturday evening, followed by music and dancing. Joaquim, our regular entertainer at Cuisle shared the stage with Lisa and Errol. Phil gave a line dancing class to the brave among us and had a floor full of dancers before too long. As usual 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.

Annual Magazine

We launched our second edition of Hope Annual at our Members Meeting. We were very grateful to President Mc Aleese for another kind and supportive message this year.



Thanks to Anna and Bernie for their work on the magazine and to all who contributed personal stories and chill out articles. A big 'Thank You' to Adam, Claire, Eve, Grainne, Niall, Oisín, Shauna and Kevin who contributed to the Young People's section or sent in photos. Ashling won our short story competition with a short story titled "Precious" and copies are available from the office for any budding writers who may be interested in reading it.

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.

We look forward to receiving your feedback.

COMMENTS ON THE WEEKEND INCLUDED:

A very enjoyable weekend. Nice food, nice company, weather beautiful. Will come again!

"Most enjoyable weekend, lovely to meet new friends. Join a club and learn more line dancing" - Phil.

A great weekend. I think it was the best ever. A lovely crowd - Doreen.

Fantastic week-end, really enjoyed everything, weather, speeches and food was brilliant. Staff also were so helpful, much appreciated.

Lovely weekend, great company, guest speakers excellent and staff very kind.

Great to meet such lovely people. I felt very relaxed and comfortable and had a great laugh too! We'll be back - Susan.

Wonderful weekend! Great to meet all the Southern family for the first time.

Terrific information from Alice, Nancy and Carole - so helpful and hopeful! Fantastic opportunity to relax and bond with people, to really get to know people. Thank you all so much from the Belfast Posse! Love too from those who couldn't make it - Errol.

Lovely weekend, met some lovely people. Hope to be invited back someday - Ken.

An extraordinary weekend. Great privilege to be here - Alice.

ATTENTION Young People

You may have read in Hope Annual that Elizabeth, our Family Support Officer, is hoping to organise activities for young people.

The idea is to allow young people to meet up with other young people who are in the same situation and get some peer support while also having some fun. Elizabeth will be organising fun activities such as sailing, horse riding, arts & crafts or whatever you would like to do. HDAI will cover the cost of the day out for you. Elizabeth is open to your suggestions so please call her on **1800 393939** OR **087 0517772**.

So it's over to you, all you have to do is let us know you are interested. There is no excuse, come along and make new friends.

Support for Carers

At this year's AGM I decided to run the first workshop solely for the carers. Although I have only been in the post of Family Support Officer for a short space of time, I have been struck by the day-to-day strength that family members and caregivers have shown whilst facing Huntington's Disease. Carers often go unheard and forgotten, one of my aims will be to address this issue and offer more direct support to both the carers and the Huntington's patient.

The carers workshop I ran in Cuisle was very well attended, and although it was intended to run for just over a half an hour the level of need and interest in this safe space meant the workshop went on for significantly longer. The workshop allowed people to share a little of their struggles in facing Huntington's on a day-to-day basis. It also highlighted how carers can start to adopt a more positive approach to looking after their own needs. The next step we would like to take will centre around the monthly support mornings, adapting it in some form to allow this space to continue. We plan to hold a carers only meeting on a trial basis. These will take place initially on October 20th in Dublin and November 3rd in Cork.

I welcome any feedback on how you found the workshop or any ideas that you may come up with, feel free to contact the office on Freefone 1800 393939 or myself 087 0517772.

Elizabeth O'Sullivan, Family Support Officer

Fundraising Events

Turning Trash to Cash for HDAI

HDAI received €2,099.16 from Brendan Chambers of C&C Cellular for 232 old mobile phones which a number of our members had collected. C&C Cellular and Shared Vision began the concept of 'Givers Gain for Charity' in 2006. C&C Cellular are based in Mayo and wanted to give something back to the local community. They raised over €28,000 for local Mayo charities last year. This year Western Care and Mayo Cancer Support are the charities chosen to benefit from the C&C Cellular collection.

Two of our members Ann and Doreen met Brendan at the Balla Walk presentation last year and 'sweet talked' him into also helping Huntington's by converting our old mobiles to cash. These old phones would normally go into landfill but are now recycled. The phones do not have to work and the more modern they are the more money they generate. All phones are accepted. The total proceeds from the phones are given to charity - there are no administration costs. If you or your friends have any old mobiles you would like to recycle HDAI can earn money from them so please send them to us or call the office if you would like to organise a collection in your area.

Mini Marathon



Thanks to all who took part in the Mini Marathon to raise funds for HDAI. Well done to Bernie (pictured left receiving a HDAI memento from Anne for her committed fundraising work), Austin and friends, to Petra, to Dorothy, to Josie and her friends and to all who braved the wet June bank holiday weekend in Dublin to take part in the Mini Marathon to raise awareness and funds for HDAI. This event has so far raised €1,622. Thanks to everyone who took part and to those who gave sponsorship.

Wedding Gifts

Special thanks to Sinead who asked her wedding guests to make a donation to HDAI in lieu of wedding presents. Congratulations and Best Wishes to Sinead and Patrick.

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.



Sloan Rangers Line Dancing



Phil and her friends continue to donate to HDAI through their regular line dancing classes. They held another dance marathon in March and raised over €1,200.

Anne presenting a HDAI memento to Phil at Cuisle, with thanks for her committed fundraising work.

Rang a 6



Thank you to Kevin in Rang a 6, Gaelscoil Colmcille (pictured left with Muinteoir Keith) who celebrated his confirmation earlier this year. Kevin's class very generously donated some of their

confirmation money to three charities. Kevin nominated HDAI as one of the chosen charities and we received €210.00 as a result. Special thanks to Kevin's class and to Muinteoir Keith for organising this.

Sponsored 'Hair Do'



Frank raised a few eyebrows at Cuisle before we found out his unusual hair colouring was all for the good of HDAI. Many thanks Frank for your sporting attitude and for the money raised.

Future Events

- BALLA WALK - BALLA, CO. MAYO - 28TH JULY 2007
- AUCTION OF ALL THINGS HORSEY - CO. WICKLOW - 21ST SEPTEMBER



Signed Jockey Silks, Horse-drawn Caravan Holiday, Polo Lessons, Riding Lessons and many unique items to be auctioned for HDAI in Woodenbridge Hotel, Co. Wicklow on 21st September 2007.

Denis donating a saddle to Phil for her September auction