

Cuisle 2003 - A Date for your Diary

6th - 8th June 2003



Wexford Rally

We would like to express our sincere thanks to The Wexford 100 Motorcycle Rally who recently raised €4,420 for HDAI. Philip Byrne our outgoing Chairperson was presented with a cheque on our behalf. This considerable sum of money is greatly appreciated and will be put to good use. Thanks to everyone who helped in this fundraising effort.

Donations

Sincere thanks to all those who sent in their membership forms. We would also like to extend our grateful thanks to those members who donated generously but prefer not to be named. Your support is a great source of encouragement to the committee and staff of HDAI.

Coffee Mornings

You are very welcome to join us at our Coffee mornings/Support meetings in Cork from 11am to 1pm on the first Saturday of each month and Dublin from 11.00am to 1pm on the last Saturday of the month. Contact the HDAI office on 1800 393939 for more information

DUBLIN

AUGUST 31st • SEPTEMBER 28th
and OCTOBER 26th

CORK

SEPTEMBER 7th • OCTOBER 5th
and NOVEMBER 2nd



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**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.



**IF YOU
NEED HELP**
If you require help
please apply in writing

GENETICS
Professor Andrew Green is
available at (01) 455 8111 if
you need information on
Predictive Testing. He and his
team will advise you.

**RESEARCH
ARTICLES**
See Enclosed

**WOULD YOU
TELL YOUR
STORY**
Contact HDAI if you
would like to tell your
story in the press or in
our newsletter!



Pictured (left to right)
are Professor Conneally
and ??? at the ???

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 12
HDNL AUGUST 2002

REPORT ON 11th AGM

Our 11th AGM took place in Cuisle holiday centre, Co. Roscommon on June 8th 2002. Approximately 60 members attended on the day. Our auditor John Handibode attended our AGM and assisted our treasurer in presenting our annual report.

After the official business of the AGM was completed Professor Mike Conneally gave a presentation on Huntington's Disease and a summary of research conducted on HD. Professor Mike Conneally is a Distinguished Professor at the Indiana University School of Medicine, he was a key collaborator in the identification of the gene for Huntington's, he is a member of The Hereditary Disease Foundation and part of the Venezuelan Research Team. Professor Conneally has been elected President of the American Society of Human Genetics for the year 2002. He has also been chosen to serve as Secretary General of the World Federation of Neurology for 2002 - 2003.

Professor Conneally answered many questions from members and was available to our members all day as we had the pleasure of his and his wife's company for the entire week-end. Philip our Chairperson presented Mike with a Celtic Book Stand as a token of our appreciation for all his hard work and generosity.

Up to 54 members stayed in Cuisle from Friday night until Sunday morning, this group included regular attendees, representatives from Northern Ireland and some new members attending Cuisle for the first time. The party mood commenced on Friday night with our own regular entertainer assisting the resident musician!

No prizes for guessing who - see back page!!

Our Members at Cuisle made the following comments:

"A wonderful weekend: ideal place for a meeting - great to see so many old friends."
Mike Conneally

"Had a great time everyone was wonderful. Hope to see you all soon again."
Mary & Eddie

"Had a great time, everything was great".
Margaret & Ann

"A great sense of being together with people who have the same level of HD. A great sense of camaraderie with all including speaker".
Patrick

"Fantastic, see you next year, Please God"
Patty

"Great place, super people"
Bridget

"This was my first time to attend this lovely meeting and gathering of family and friends of HD. I hope to be here again next year. A great experience to talk with and chat with people who care".
Anonymous

"Thanks a million for opening the door for me and many others in future".
Olive

"Thanks for the tea! This was a lovely weekend, met loads of nice people. Hopefully everyone will be here next year again. Thanks to HD Ireland for all the support".
John & Family

"A wonderful weekend and a fantastic opportunity to meet up with Alex".
Roseanna

"Seriously, a wonderful weekend and a fantastic opportunity to meet up with old friends and to make new ones. As always the staff were friendly, helpful & efficient. We'll definitely be back next year. Loved the shower!"
Denise, Damien, Laurence, Donal & Anne

".....woman, drink, great weekend".
Mark & Catherine

"A beautiful weekend and the craic was great".
Doreen

"Thank you for organising such a successful Huntington's AGM in Cuisle this year. We all struggle along as best we can in the shadow of Huntington's and it is wonderful to meet other families and sufferers to compare notes and chat. Mike Conneally's lecture was so interesting and the question and answer session it generated was lively and informative".
Nollaig & Family

Sponsorship & Fundraising - Paris Marathon



Here is a picture of Suzanne looking very relaxed despite having completed the Paris Marathon earlier this year. Suzanne, a friend of HDAI members Mark and Catherine, helped raise €1,283 for our Association.

We asked Suzanne to write a few lines on her experience:-

"Finally after three months of training in hail, rain and the odd ray of sunshine I found myself at the start line of the Paris marathon. People run marathons for all sorts of reasons and I was more than happy to run for The Huntington's Disease Association of Ireland.

I hope that the money raised through friends, family and especially Mark may help Catherine and others in some small way".

Suzanne Lyons

Tribute to Philip

Philip Byrne outgoing Chairperson of HDAI and committee member since 1992 resigned at our 2002 AGM. Philip has been an active and dedicated member of the committee and will continue to be a valued member of our Association. Unfortunately Philip's other commitments mean he needs to take a step back from HDAI committee work but we know Philip is keen to re-join our committee when his work-load eases and we will welcome him back with open arms.

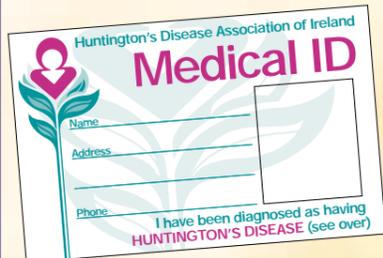
HDAI has made great progress since 1992 when we were first awarded a grant of €20,000. Before this, work was largely financed by our core founders such as Philip who has been involved in many tasks - including representing HDAI at international meetings, liaising with the press, attending committee meetings and even singing when required - see photo on back page!!

We had a delightful evening in a restaurant

on 4th July last where we made a small presentation to Philip in appreciation of his work on behalf of all members. Unfortunately Philip refused to sing on this occasion!!

Medical ID Card

A free Huntington's Disease ID Card is available. Please send your Photograph and relevant details to the HDAI office and we will take it from there.



How Do You Feel

On a good day you may feel

- Accepted
- Alive
- Beautiful
- Brave
- Calm
- Capable
- Caring
- Competent
- Friendly
- Generous
- Glad
- Peaceful
- Playful
- Relaxed
- Secure
- Trusted
- Understood
- Warm
- Witty
- Worthwhile

You may have bad days and you could feel.

- Misunderstood
- Needy
- Rejected
- Vulnerable
- Jealous
- Lonely
- Inferior
- Embarrassed
- Bitter
- Anxious

If you are having a good day let us know your secret and we can pass them on to our members, alternatively if you are having a bad day let us know if we can help.

HDAI Administrator

The following is a brief glimpse of the days tasks for the Administrator of HDAI:

- Checked Answering Machine
- Checked e-mails - replied to European Huntington's Association query on September meeting after checking with Bernie (who is the current EHA president)
- A Public Health Nurse called requiring information on HD. Prepared information pack to send to her.
- Opened post.
- Checked monthly bank statements and wrote up financial report to be checked by Treasurer and committee.
- Received a call from a member of a HD family who is concerned about the communication and emotional problems within the family. Referred the call to Bernie who made a return call to the member to discuss these problems. Advised member of monthly support group meetings and sent information in the post.
- A member called requesting respite for a family break. Informed Chairperson and Treasurer of request for their approval in principal (members details treated as confidential)
- Called the secretary of HDAI to discuss next committee meeting.
- Worked on next newsletter
- Sent out post including information to queries above and payment of invoices.
- Scanned through other organisation's newsletters received today.
- Member called to advise of article relating to HD in magazine.
- Created HDAI ID card.

From time to time I attend meetings, conferences and training courses during working hours therefore if your call is not answered please leave a message on our answer machine (confidentiality is assured) and I will call you on my return.

Last year I attended a Teaching Stress Management Skills Course which helps me cope with stressful situations. This taught me to take regular breaks and to find solutions for stress where possible. I advise you to do the same. We are here for you - Let us know if we can help.

A Member's Experiences

Some of you have already met Bridget Shannon at some of our Dublin support meetings and our AGM in Cuisle. Bridget contacted us on her return to Ireland to offer her voluntary help to HDAI. Bridget a social worker in New Zealand was involved in setting up the Auckland HD Association and worked closely with HD families there. Judith Baker a colleague in the New Zealand HD community says,

"She was highly thought of by everyone she came in contact with".

Bridget shares her experiences with us below - if you have a story to tell please let us know:

During our recent AGM weekend in Cuisle, Bernie from HDAI encouraged us to share our stories. I appreciated those few days immensely where both sadness and lightness held their place.

Personally I found listening to Professor Michael Conneally took me down memory lane. Familiar names and faces revisited me. Names like Marjorie Guthrie, Michael Hayden, Ralph Walker, Nancy Wexler, Dr. Bird and many others associated with HD over the years. I recall how much these people inspired me in taking a proactive stance in this field. HD was poorly understood in it's symptoms, treatment and effects. It is now, due to the collective approach of families, sufferers and specialists over the past twenty-five years towards this genetic, inherited disorder that our modern insights have evolved.

Near the late seventies I met my first HD patient during my employment with Auckland Area Health Board. Robert was in his early thirties married with two young children. His onset was rather rapid. Typically his diagnosis was slow. It was an uphill struggle for his family and extended family to accept what was happening. Robert's strong Baptist faith obviously sustained him. He chided me firmly when I encouraged him to take his medication and wear his medic-alert bracelet saying "I do have faith Bridget and I pray". Sobering, spontaneous words in face of a condition he inherited from his mother.

There was little known about HD even in the health field itself but this was soon to change. Plans were made for the first Australasian conference in Melbourne. In addition a new HD care and respite centre was due to open there. Three delegates from New Zealand attended including myself. Specialists came from Canada, US and Holland sharing their research and findings. Families and other participants experienced new hope and support.

On my return to Auckland I suggested to the AHB the need for a family support group. No obstacles were put in my way. I invited a NZ retired teacher to join me in initiating the project. Cathy had just returned from a similar HD conference held in Oxford. Already in her own personal experiences of HD she saw the devastating effects of ignorance and prejudice. This could happen among her friends and neighbours. She was

determined to change this by bringing knowledge of HD into the open.

Our monthly support group meetings were very successful. People were ready and waiting for an opportunity to come together in a relaxed and informative way. A retired GP, who happened to be Irish, volunteered to be liason person between the group and the NZ Medical Journal. Education and networking were priorities. In time, young people at risk formed their own support group. Gradually there were Regional support groups with input from International Newsletters. In many ways, isolation became something of the past.

The unpredicted finding of the gene marker in 1983 was very exciting for everyone. Later on, Auckland introduced its own protocol for predictive testing. I was privileged to be a member of the panel. At times, it felt almost unbelievable that people were indeed choosing this new technology with it's precise knowledge of the HD gene.

Last year my time came to return home to Ireland. I was curious in surfing the internet re HD. Phenomenal advances were obvious. Now with our own Michael Conneally at the forefront of international genetic research our direction looks positive for further advances especially for families. I hope my own interest in HD will continue even though my contribution may be less.

Bridget Shannon LSA

Book Sponsorship

In May 1983 Deirdre McGrath, Willie Kelly and Bernie met with Dr. Dick Bates to seek advise on establishing a HD Centre in Ireland. At this time Alison Leonard, a social worker in the UK was also meeting with Dr Bates to research her novel Tinker's Career.

Tinker's Career is a fictional teenage novel about a girl who lost her mother to Huntington's Disease and her efforts to unlock family secrets. By coincidence Bernie met Alison recently and she offered to partially sponsor the cost of her books for our library.

On hearing of this coincidence Carys a HDAI member offered to sponsor the remaining cost. Many thanks to Alison and Carys for their kindness.

Please contact the office if you wish to receive a copy of this novel.

The book (pictured opposite) **Prenatal Testing for Late-onset Neurogenetic Diseases** by Evers-Kiebooms, Zoetewij & Harper is now available in the HDAI library.

