

MEETING NANCY WEXLER IN CUISLE by Sr. Bridget

A sincere thanks to our HDAI committee for inviting Dr Nancy Wexler to speak at our members meeting this year. Her presence was a unique surprise for me and her address, typical of Nancy, both scientifically and humanly inspiring. My own last encounter with Nancy goes back several years to when I worked directly in the HD field in New Zealand.

In Cuisle, Nancy outlined the process of her research. While sharing her own personal story and encounter with the disease she contributed a deeply human dimension to the large gathering. Her motivation and commitment to

ongoing research is rooted in reality. Like most similar callings in life Nancy's response involved huge generosity of heart and hard work, not an easy way to pursue! With her gifted lightness of spirit Nancy recalled some humorous incidents she experienced during her arduous research.

She sounded like a born optimist! Together with her team and many more dedicated researchers she persists to this day in working towards a cure for HD. We thank her and wish her well.

To Nancy and her sister Alice who both attended our members meeting I send this Irish Blessing:

May the road rise up to meet you
Go n-eiirl an bothar leat

May the wind be always on your back
Go raibh an ghaoth I gcónaí ar do dhroim

May the sun shine warm upon your face
Go raibh an grian ag téamh ar d'aghaidh

And the rains fall softly on your fields
Agus an bháisteach ag titim go bog ar do phairc

And until we meet again
Agus go dtí go gcasfaimid ar a cheile arís
may God hold you in the palm of his hand
Go gcoinní Dia slán ina bhois tú

DONATIONS

- Sincere thanks to Derek for his kind message of thanks and his generous donation of €200.
- Thank you to the Teachers Union of Ireland Credit Union for their generous donation of €350. We sincerely value your continuing support.
- Special thanks to George, Teresa, Jennifer for their recent 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.

Tribute to members

We would like to pay tribute, in our newsletter, to members who bravely cope with HD. Do you have a family member or friend you want to pay a tribute to? Someone who copes with HD while getting on with their daily life? If so please let us know.

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. In Dublin, meetings have relocated to a city centre hotel. 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

Oct. 20th 2007 - Carers Workshop
Nov. 17th 2007 - Support Meeting
Dec. 15th 2007 - Support Meeting
Jan. 19th 2008 - Carers Workshop
Feb. 16th 2008 - Support Meeting

CORK

Oct. 6th 2007 - Support Meeting
Nov. 3rd 2007 - Carers Workshop
Dec. 1st 2007 - Support Meeting
Jan. 2008 - No Meeting
Feb. 2nd 2008 - Carers Workshop

WEST

Dec. 8th 2007 - Castlebar
Mar. 8th 2008 - Castlebar
Jun. 7th 2008 - Cuisle



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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.



NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

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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

World Congress on Huntington's Disease 2007

The World Congress on Huntington's Disease (WCHD) 2007, took place in Dresden (Germany) from September 9 - 11, 2007. The World Congress is a joint meeting of the World Federation of Neurology (WFN) Research Group on Huntington's Disease (HD) and the International Huntington Association (IHA). The Congress in Dresden was the 22nd Meeting of the WFN Research Group on HD and the 17th meeting of the IHA. Since the 2003 Congress (Toronto) these meetings have been restructured and now form a joint meeting which goes under the name of WCHD. The WCHD in 2007 was organised in association with the clinical, scientific and patients' organisations concerned with HD.

The congress offers a scientific program open to clinicians, basic scientists and HD organisations. The scientific programme includes presentations covering: genetics, pathogenesis, clinical aspects of HD (neurology, neuropsychology, neuropsychiatry and genetic counseling), neuropathology, biomarkers (imaging and biomarkers in body fluids), drug discovery and development, clinical trial results, the latest therapeutic advances. Public policy, care and coping strategies and education

Four delegates from HDAI attended the conference and their report of the conference will feature in our next newsletter.

Woody Guthrie 40th Anniversary Dublin Tribute Night

Andy Irvine will play Woody Guthrie's songs in Whelan's, Wexford Street, Dublin on Wednesday 3rd October from 8pm. This is a Charity benefit gig and all profits will be shared between Huntington's Disease Association of Ireland (HDAI) and Focus Ireland.

Woody Guthrie (1912 - 1967) was a singer, songwriter, writer 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. His music influenced whole generations of singers and songwriters. He wrote more than twelve hundred songs including 'This Land is Your Land', 'It Takes a Worried Man', 'Hobo's

Lullaby', and 'So Long its Been Good to Know you'.

Many of his songs have been recorded by hundreds of major recording artists worldwide. Woody lost his mother to Huntington's Disease (HD) at the age of 18. Despite developing HD himself in his early thirties he continued in his personal and social struggles for many years more. Having been hospitalised in his latter years, he died aged 55 on October 3, 1967.

Andy Irvine has always been a Woody Guthrie fan and acknowledges Woody's legacy. Sincere thanks to Andy and music promoter Dereck Nally for their generous support in organising this tribute benefit night.



Promotional poster

Tribute to Milton Wexler, 1908 - 2007

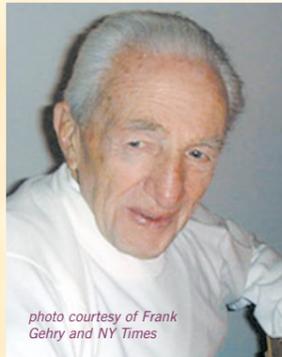


photo courtesy of Frank Gehry and NY Times

Milton Wexler was born on Aug. 24, 1908, in San Francisco, USA. He grew up in New York and graduated with a law degree from New York University but later studied for his doctorate in psychology. He met his wife Leonore Sabin, a teacher, in 1936. They married and had two daughters Alice and Nancy. The family moved to Kansas where Milton worked

with the Menninger Foundation in Topeka, specializing in research and treatment for schizophrenia.

In 1950, Leonore's three brothers were examined by a neurologist who concluded that they had developed HD, a disease they inherited from their father. Leonore was now aware of her own risk and the risk to her two daughters. In 1951 the family moved to Los Angeles where Milton established a private practice in psychoanalysis. In doing so he was able to provide financial assistance to his wife's brothers. His clients included Hollywood stars, famous artists and architects. Milton and Leonore were divorced in 1962 but remained friends. In 1968 Leonore was diagnosed with Huntington's Disease.

Milton formed the Hereditary Disease Foundation in order to find a cure for HD. He gathered young scientists, neurologists, geneticists and psychologists to research Huntington's Disease. His clients and friends helped raise funds for the foundation. He was joined in his work by his daughter Nancy a professor at Columbia University and Alice a historian who wrote "Mapping Fate" a memoir of family, risk and genetic research. In 1983 researchers affiliated with the foundation found the "marker," or approximate location, of the gene for HD. A decade later, they identified the gene.

At the age of 60 Milton began his work on HD. He was determined to highlight HD and find answers. He was

well known for his 'can do' attitude and his ability to face and solve problems

In correspondence with Bernie in 1999 Milton wrote:

"If, in some mystical way, I were to revisit the earth after my demise, I think I would love to come back as an Irishman. I love the language, the literature and the people. Despite all the troubles and the conflicts, there is something so bright, so civilized and so witty in that lush, green land, that it lifts my spirits to think about it."

Milton died on March 16 2007 at his home in California. He was 98.

His legacy to the HD community lives on.

Acknowledge Kindness

In the HD world we experience many acts of kindness and friendship from friends, neighbours or perhaps work colleagues. If you have experienced an act of kindness that is significant to you HDAI would like to offer you the chance to say thanks through our newsletter. The person receiving thanks will also receive a bunch of flowers from HDAI on your behalf. Confidentiality will be respected. Let us know if you have someone you think deserves this thanks.

THANK YOU!

Since becoming involved with HD I have been impressed with the 'family' atmosphere that exists within the HDAI and those affected by the disease. I have experienced much kindness and up to now was never in a position to express my gratitude or to highlight the kind act. There are people, kind people, who require no thanks-and may even discourage it. I would ask those to consider the benefits to those who experience or witness God using people to express his love. I appreciate the opportunity to thank two groups of people. All those who attend our members

meeting and respite weekend in Cuisle know of the magic that occurs there. This year I was talking with a group about 'absent friends'-those people we know but are now unable to make the journey to Dunamon, Roscommon. Edward and Mary were asking about Theresa Clarke and how she was getting on. Myself and my wife Ann had to point out that Theresa was in a nursing home and was not in great form. In a throwaway remark Edward and Mary said they might visit her and I thought no more about it. A couple of weeks later Ann and I were visiting Theresa in the Oaklodge Nursing Home in East Cork and we noticed a change in Theresa. It is getting harder to understand her but she made it very clear that she had received a visit from Mary and Edward-they had travelled a considerable distance to visit her. No beating of drums, no waving of flags, they just arrived. By this act they brought such genuine joy to Theresa and we are delighted with the chance to thank them publicly for this kindness. Thank you from Denis

Mary and Edward will receive flowers from HDAI on behalf of Denis.

Leisure Day

Would you like to attend a therapeutic leisure day in the Phoenix Park? This one day service allows a patient to use therapeutic facilities such as a Jacuzzi, massage, or music therapy etc. St Mary's run an enjoyable leisure day at their therapeutic centre which is located in a very scenic area of the Phoenix Park. Contact the office for more information.



Nida with Michael enjoying his leisure day in St. Mary's and (inset) Kevin & Oisín checking out the facilities

ANNUAL MAGAZINE

Congratulations to Hannah who was our 2007 quiz winner. Hannah received vouchers for her prize. Quiz Answers: Find the animals - Answers: walrus, antelope, bear, tapir, giraffe, pig, panda, anteater, wallaby, stoat and fox. 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.

Fundraising Events

Turning Trash to Cash for HDAI

HDAI are continuing to collect old mobile phones. If you have any old mobiles you no longer need we would be happy to receive them. They do not have to work and all phones are accepted. The total proceeds from the phones are given to us - 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 Dorothy, Bernie, Austin, Petra, Ruth, Josie and their friends who took part in the Mini Marathon to raise €2,028 in total for HDAI. Thanks to everyone who took part and to those who gave sponsorship.

Tesco Bag Packing

Frances, Joe, Anna, Jimmy, Betty and Jennifer with Family and friends took part in two days of bag packing at Tesco Merion in Dublin to help raise awareness and funds for HDAI. The group worked hard for two days and raised a magnificent €1700 for HDAI. We are very grateful to Tesco Merrion in Dublin 4 for giving our members the opportunity to carry out their Tesco bag packing charity event there. Thanks to all for their hard work packing bags and informing shoppers about HD. Thanks to all who contributed to HDAI.

Tesco have allocated another slot to HDAI on 21st and 22nd of December. If you would like to help raise funds by volunteering to bag pack please contact the office for details.

Sloan Rangers Line Dancing

Phil and her friends continue to donate to HDAI through their regular line dancing classes.

Balla Walk

The proceeds of the July Charity walk held in Balla, Co. Mayo were presented to Anna on behalf of the HDAI committee on Saturday 8th September at the West Support meeting in Castlebar.



Some of our friends and supporters in Balla.

Now for the fourth year our friends and supporters in Mayo have once again come up trumps for HD. Ann and Margaret with family members, friends and neighbours helped to raise a staggering €4,530. Thirty seven people walked for HDAI in the 2007 Balla community walk which took place on Saturday July 28th. We are very grateful to all who took part, for the great support and solidarity they give to HD 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.

Thanks also to Brendan Conwall and his team in Balla Community for organising this worthwhile and enjoyable event.

Support for Carers

Following on from our carers workshop in Cuisle we will host a carers only support meeting on a trial basis in Dublin on October 20th and in Cork on November 3rd.

The workshop will allow carers to share a little of their struggles in facing Huntington's on a day-to-day basis. I also hope to provide tips on how carers can start to adopt a more positive approach to looking after their own needs.

I welcome any feedback on how you found the workshop in Cuisle or any ideas that you may come up with, feel free to contact the office on Freefone 1800 393939 or myself 087 051 7772.

Elizabeth O'Sullivan
Family Support Officer

ATTENTION Young People

Activities for Young People

Are you a young person from a HD family who would like to meet up with other young people in the same situation? I would love to organise fun activities such as sailing, horse riding, arts & crafts or whatever you would like to do. Remember, in order to run these events I need to hear from as many young people as possible as we need a minimum number of participants in order to make this work. HDAI will cover the cost of the day out for you. I am open to your suggestions so please call me on 1800 393939 OR 087 051 7772.

So its over to you, all you have to do is let us know you are interested, so these is no excuse, come along and make new friends.

Call me on 1800 393939 OR 087 051 7772