

Donations

We would like to express our sincere thanks to companies who recently made donations to HDAI these included: Computershare, Anglo Irish Bank, Bank of Ireland and Coca Cola. Thanks also to a HDAI family member who generously donated €500 and to a Doctor who made a donation after receiving our information pack. Thanks to all of you 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.

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



Brainwaves

IMAGE

"Keeping clean is as much about hope as it is about hygiene".

WORRY

"it is not work that kills, it is worry. Work is healthy, worry is rust upon the blade"

CONFLICT

"there are usually three sides to a controversy. Yours, the other persons and the right side"

BEREAVEMENT

"Bereavement can include a loss of dreams. The death of the future you expected. Take time to grieve"

ACTION

There are three kinds of people. Those who make things happen, those who watch things happen and those who don't know what happened.

GENETICS

Life is a hereditary risk.

EQUALITY

You are unique....just like everyone else

SELF TALK

"human beings are the only creatures on earth that can talk themselves into trouble. Be careful what you tell yourself"

ANGER

Are you angry with others...or yourself. You may be right but do you want to be right or do you want to be happy?

TALK IS CHEAP

A man was showing his new hearing aid to his friend. "It's the most expensive I've ever had" he said. "It cost me Fifteen Hundred Euro". "What kind is it" his friend asked. "Half past four" he answered.

POSITIVE THOUGHTS

Take time to think of what went right. Chances are you already know what went wrong.

PRESSURE

Today you have different pressures and they require a different response.

CARING

It's not feasible, desirable or fair to expect carers to continue without help. ASK FOR HELP.

SWITCH OFF

"Before you go to bed, make a list of the things you can do tomorrow. Then make a list of the 5 good things that happened today. Do 5 more good things tomorrow. Sleep tight.

SILENCE NOT SECRECY

Sometimes we need a calm silent environment to find peace. *"The most important thing is silence. Souls of prayer are souls of deep silence. That is why we must accustom ourselves to stillness of the soul. In silence we find a new energy and a real unity"* - Mother Teresa

Silence can be found in the library, the park, the church or the spare room. Find a corner where you can be yourself and get the peace you need to rest and refuel.

There is no cost involved.

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

MARCH 29th • APRIL 26th
and MAY 31st

CORK

APRIL 5th • MAY 3rd
June - No Meeting

CUISLE - 6th - 8th June 2003 (All welcome)

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: <http://indigo.ie/~hdai/>

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.

CUISLE 2003

Our AGM/Respite weekend takes place from the 6th - 8th June. Please mark these dates in your diary. All are welcome. We will be sending out further information nearer the event.



Pictured from left to right are Catherine, Minister Martin, Bernie and Rachel.

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 15
HDNL 2003

Raising Awareness

Bernie, Patricia, Catherine our Chairperson, committee representatives and some HDAI members met with Michael Martin in Cork on Saturday January 25th 2003.

We have enclosed information on TDs within your area, please contact them to ask for better service for HD patients. Let us know if you need more information.

Before we met the minister some of our Cork members met Sarah Rachel Murphy the actress who plays Joe in Fair City. Rachel herself a Cork woman was interested in meeting members from Cork.

Topics discussed at the meeting included: the reasons for and against taking a predictive test, the early symptoms of the disease, mechanisms to cope etc

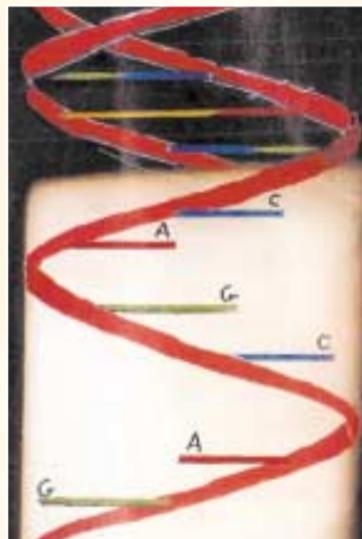
Following the Huntington's Disease storyline on Fair City and a number of radio interviews we received many calls some from people who were concerned about their own risk, and a couple from people who were members of HD families but who were unaware of our Association. After the story's introduction we received a call from one of our members who was very distressed at HD being aired in a soap opera as she felt it would not be able to portray adequately the effects of HD on a family. She also felt it would cause distress to HD family members. We regret the distress this may have caused to some members but we feel it is important to raise positive awareness.

This provides a great opportunity to highlight this traumatic disease without the need to expose any one family. Most of the feedback we received was positive, one family member reported that because they were aware of HD through Fair City her health centre encouraged the family to apply for a medical card which was granted despite the family failing on the means test. Rachel herself received a card from one of our members thanking her for her work,

"I was almost afraid to watch, well now I'm glad I'm watching. You are doing an absolutely brilliant job, thank you so much....I don't know if you realise how helpful to people like us doing this part is. It is so difficult for us to tell our story - thank you again for doing the part so well"

GENETICS

Genetics can determine eye colour and other traits passed from one generation to the next. Genetics is the study of heredity and the variation of inherited characteristics. It is not just about Dolly the sheep. It is about the origin of thousands of conditions that affect everyone. You probably know a lot more than you think about it. You may have studied the form at greyhound or horse races. You may have expected a young man to play football well because his dad had lined out for the county. You may have expected a child to play music, dance or sing like their parent or grandparent. You may have recognised a child because she had her mother's eyes. You may even have judged an in-law based on their pedigree!! Genetics is used as the excuse or the reason behind many of our quirks. We knew about genetics but we didn't know its language. How did it get its message across?



Just as a knitting pattern provides the code for an Aran sweater our genes provide the code for our shape. House plans and recipes are all "codes" predicting a specific outcome. The gene is the recipe telling your cells to make a protein. Proteins make your cells work. The cells are the blocks that create all life.

Crick and Watson cracked our code 50 years ago. They discovered DNA (deoxyribonucleic acid) the chemical that genes and chromosomes are made from.



Pictured (left) A healthy brain and (above) a HD brain

It has four bases as follows:

- A - Adenine
- G - Guanine
- C - Cytosine
- T - Thymine

Two bases form each rung of the DNA ladder.

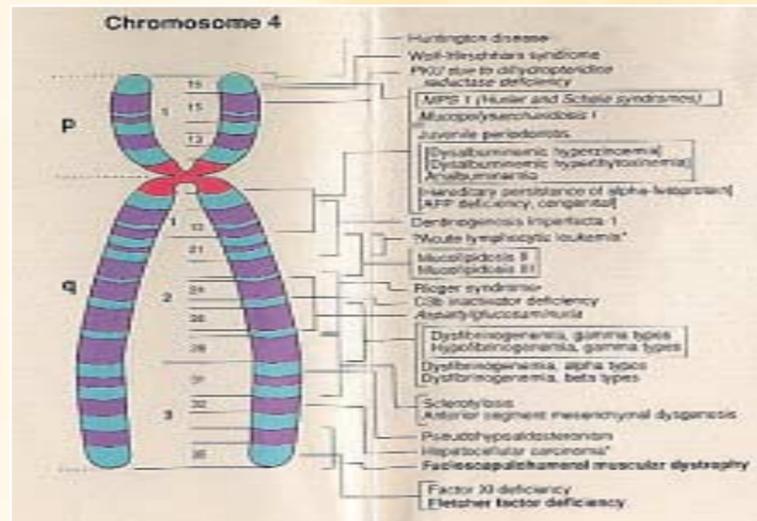
Genetic information is packaged in Chromosomes. Humans have 23 pair of chromosomes in each cell. The HD gene was found in 1993. A mutation is any change, good or bad, in DNA. The mutation on chromosome 4 that codes for HD is a CAG repeat. It creates a protein. No one is entirely sure what this "dropped stitch" in our genetic "pattern" is doing. This protein (Huntingtin) is now being studied by researchers all over the world. You are born with 23 pairs of chromosomes holding all your code. You are lined out and ready to play the game of life with all the strengths and weaknesses you inherited from your parents, grandparents etc....

This does not control the weather or the traffic!

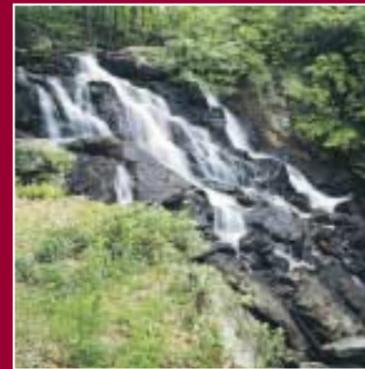
Many environmental factors will also influence our "game".

Is the cloning debate about nature versus nurture?

An identical set of genes may not create the same result second time around. Environmental factors need to be considered. What if the cloned Bertie didn't like sports? Oops... One Big Stadium too many!! Could Shergar be cloned so we could enjoy a happy ending to that story? What horse, greyhound, singer, politician, footballer or hurler would you clone and why? Would Charlie Haughy have any advice for his clone? How would you advise your clone? What distraction was not available to you but could change the course of their future? They say its not what we stand for that makes life difficult but who we fall for. Would Gay Byrne's identical genes have the same result if he had eloped with an American tourist he met in O'Connell Street when he was 17 yrs old? Let us know your views.



Take the Line of Least Resistance



Be gentle with yourself. You may be under pressure living with HD. This can be a large "withdrawal" from our emotional "bank account". We must make "lodgements" so we are not "overdrawn".

What did you do recently to rest your nerves? Did you worry and draw further hardship on yourself by having to undo mistakes? - more haste less speed? Did you react rather than decide? Could you have walked away? Could you have taken a few minutes to gather your thoughts? Could you

have asked for help? Did you behave in a way that made you dislike yourself?

The easy flow of water around a rock, while slowly wearing it away reminds us that the path of least resistance is one possible way forward. Bamboo bends in the wind to avoid snapping. That reminds us that there is wisdom in not being too rigid in our views. Maybe we need to bend a little, change our standards to accommodate our changing needs so we can avoid stress related illness.

ONE VOICE

New legislation in Europe could make research into HD very lucrative. This is great if we keep an eye on it. Exploitation is possible when big business meets vulnerable people. We police our police, our politicians and our priests. We should police our Patient groups. The Voluntary Sector (Charity Industry) is not regulated. Some people have accepted flights

and headed notepaper from sponsors who stand to gain from this lobby. Be on guard. We want to have our voice heard. We are not willing to be "Lobby fodder" for big business. Please report any unusual activity, financial or otherwise to our office so we can alert the International Huntington Association.

Disabled & Proud

Some people are shocked to hear this slogan. To some people this phrase can seem like a contradiction. Many HD patients suffer anxiety and shame. They blame themselves for their condition. It is time for all of us to convince the pHD that they

can be proud. It is not their fault. They can be proud of how they manage despite the illness. If you are a carer and you blame the pHD you need to get help. It is not fair on anyone. No one should have to live in a hostile environment. *"It is important that the kind of care a sick person receives is not dictated by the fears or the convenience of others"* From a letter from the Irish Bishops

Radio Interviews

Pat Kenny Live - Bernie our Development Officer and Philip our former Chairman were interviewed on the Pat Kenny Radio Show on Monday 27th January 2003. The storyline in Fair City was discussed and Bernie and Philip provided general info on the disease and it's implications. This interview can be downloaded from our website.

East Coast Radio and Limerick FM also interviewed Bernie and Rachel. As the media continue to show an interest please let us know if you are interested in telling your story to the press.

At the recent European Huntington's Association conference in Zurich Professional speakers from both Switzerland and Scotland highlighted the problems for families in both countries facing discrimination as a result of the disease.

It can be wise to restrict the amount of people knowing about the disease as people at risk could be discriminated against be it through financial discrimination, employment, insurance etc. HDAI hope that through greater awareness and better legislation we can fight discrimination.

Remembering Maria

Maria with her beautiful black hair, sharp wit and happy smile has left this world for a better place. Throughout her illness she showed great determination, strength and will. Maria got great pleasure from the simple things in life, she loved walking with her faithful dog Cindy, fishing in Co. Donegal and sizzling fresh mackerel on the pan! Maria had a particularly strong bond with her family. We all miss this beautiful person, always such a pleasure to know. Maria is now in a happier place watching over all her family and friends until we meet her again.