

Definitions Made Simpler

Adenine, A:

One of the 4 bases that makes up the rungs in the DNA ladder.

Base, bases:

Two bases join to form the rungs of the DNA ladder. In DNA the 4 bases are called A, G, C and T.

Cell:

The building blocks which make up all living things.

Chromosome:

Chromosomes are threadlike structures found in the middle of your cells that contain your genes. Humans have 46 chromosomes in each of their cells.

Code:

A code is a system of symbols or letters that represents a message. In DNA the four bases A, G C and T form a code, telling a cell how to make the proteins it needs.

Cytosine C:

One of the 4 bases that makes up the rungs of the DNA ladder.

DNA, deoxyribonucleic acid:

DNA (deoxyribonucleic acid) is the chemical that genes and chromosomes are made of. DNA is a very long molecule that is simply an acid that is found in every cell of your body which has lots of sugar groups (ribose) attached to it and each sugar is missing an oxygen (deoxy).

Gene:

a gene is made of DNA. A gene is a recipe telling your cells to make a certain protein.

Gene therapy:

adding DNA to a person with a genetic disease to try to make them healthy

Genetics:

Genetics is the science investigating similarities and differences between people and how your genes help determine these.

Guanine, G:

One of the 4 bases that make up the rungs in the DNA ladder.

Human Genome Project:

scientists all over the world are working together to write down all the bases that make up the genetic code of humans.

Inherit:

The sperm and egg cells that fused to make you both contained genes from your parents that were passed on to you. In other words, you inherited genes from both of your parents, so you may look a bit like both of them.

Mutation:

Any change in the DNA of someone

Protein:

Proteins are important substances in your cells. They make your cells look and work the way they should to make you healthy

Thymine, T:

One of the 4 bases that make up the rungs in the DNA ladder.

(taken from the gene CRC website at: <http://www.genecrc.org/index.htm>)

Donations

We would like to thank Suzanne Lyons who recently ran in the Paris City Marathon on behalf of HDAI, thanks also to Mark and Catherine who co-ordinated sponsorship, more details on the race in our next issue. Thanks to all our donors who give generously, your support is a great source of encouragement to the Committee and Staff of HDAI. Be assured the association will make excellent use of your contribution.

We have self-addressed envelopes printed to facilitate donors. Please let us know if you require any and we will post them to you.

Predictive Testing

Now that gene testing is available in the National Medical Genetics Centre many members may be trying to adapt to a changed risk. We can facilitate a support group for gene carriers if sufficient interest is available. Please contact the office if you are interested in such a support group.



How Did You Find Out?

We have heard some horror stories on how people were told HD was in their family. We know it's never nice to find out but we would like to hear how you would like to be told.

We are very keen to have your views so that we can develop guidelines for General Practitioners. Please write in or phone us on 1800 393939.

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 11.30am to 1pm on the last Saturday of the month. Contact the HDAI office on 1800 393939 for more information

DUBLIN

May 25th • June 29th
July 27th

CORK

May 4th • June 8th - AGM Cuisle,
Roscommon • July 6th

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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.

NDA Regional Consultation Meetings

See enclosed information

Companion Free
Travel Pass for
Invalidity
Pensioners - See
enclosed

My Tribute To Les

Your spirit soars in its defence
Of dignity - and in its ascent,
In your twilight world
Reminds me of the kestrel
Seen so long ago
On lonely mountainside
Before the shades of
evening fell.

It hovered in the stillness
While we gazed enraptured
by its beauty.
How like that winged
friend you are
As you survey your
life's long battles
From a distance.
Your body's shell
Enfolds a deep and
gentle spirit
Flickering in and out
of mindfulness.

Let me be privy to those
precious words
Which now you utter -
And which circumscribe
a life of triumph
over tragedy.
Let us, too, scale
the heights
Of shared and
crowning victory,
Before the darkness falls.

For my husband

NEWSLETTER OF THE HUNTINGTON'S
DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

ISSUE NO. 11
HDNL MAY 2002

AGM 2002 7th-9th June

We would like to invite you to book your place at our Members Meeting and AGM which takes place in Cuisle Respite Centre, Co. Roscommon, from Friday 7th to Sunday 9th June 2002. The AGM will be on Saturday June 8th at 1.30pm and our Members Meeting will follow at about 2.30pm.

Professor Michael Conneally, Distinguished professor of Medical and Molecular Genetics at Indiana University Medical Centre and member of The World Federation of Neurology (formerly from Co Roscommon) will address our members.

Following the meeting we will have dinner and entertainment on Saturday evening. As with all organisations we are legally required to hold an AGM and usually this takes approximately an

hour. The main benefit from this annual event is the opportunity to receive up to date information on HD and to meet other people and share experiences. Cuisle is in the grounds of Donamon Castle surrounded by open space where you can wander at your own leisure if you need a break from it all!

You are welcome to arrive on Friday night and stay until Sunday morning or join us Saturday if you prefer. We understand it is difficult for some members to attend however we think it is very worthwhile. We provide free accommodation and food so all you need to do is to turn up. We look forward to seeing you there!

Please return the booking form NOW or phone 1800 393939 to secure your place.

Sad news for the HD Community



Some of you may remember Ralph Walker founder of the Huntington Society of Canada, who spoke at some of our earlier meetings. Sadly Ralph passed away recently during routine angioplasty surgery in hospital.

Ralph was a loving husband, father and

grandfather, and has been recognized in Canada as a dedicated and generous citizen. He brought relief to thousands of Canadian families affected by Huntington Disease. His 29-year-old Canadian society, with 50 branches across the country, offers direct support to individuals with Huntington's and their families. Ralph also helped found the International Huntington Association in 1974, which includes chapters in 27 countries.

His unrelenting drive to help those affected by Huntington's was a result of watching his cousin suffer with the disease. As high school teacher and guidance counsellor, Walker also met students whose families were affected by Huntington's. He quit his career in education in 1977 to work full-time as executive director of the foundation. Ralph worked full-time with the Huntington Society of Canada until 1998, when he became executive director of the Cambridge Community Foundation, a non-profit organization that finds funding for local charities. He served in that capacity until 2001.

We are indebted to Ralph for his work with IHA which is a source of much of our information.

We will plant a rosebush in Cuisle in Ralph's honour.

Disability Database

Various Healthboards have written to us to ask us to write to our members with regard to the Physical and Sensory Disability Database. The information contained in their letter states that "The Health Boards are developing a new database for the purpose of improving the planning and provision of services for people with physical or sensory needs that are disabling. Similar types of databases in other areas have proved successful in getting funding for services. They have also improved the way in which the services are planned and provided. The new database will be a set of information on the specialist services received or required within the next five years by people with a disabling condition."

Please see enclosed an Information Leaflet from the Healthboards describing the purpose and content of the database.

You may have been contacted already by your Doctor or Public Health Nurse in relation to this Database however if not you may want to pass on your details to your healthboard.

The Disability Bill

HDAI worked hard to stress the need for protection for people with genetic conditions and were involved in consultations with the Department of Justice on the Disability Bill. While we acknowledge some changes were necessary we felt it was very disappointing that the Disability Bill is now on hold.

The present Minister for State Mary Wallace is aware of the need to ensure genetic information does not result in people being discriminated against. We sincerely hope the next Government will also be keen to protect vulnerable people at risk from genetic conditions.

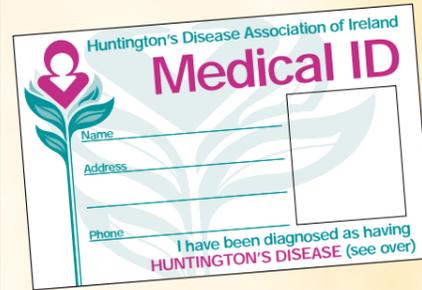
If you have the opportunity to lobby any Government representative or politician please Highlight this issue.

Medical Card Application

If you are applying for a medical card HDAI can support your application by writing a letter outlining the additional considerations for HD patients and their families. If you require such a letter please write to us or phone us on 1800 393939.

Medical ID Card

The new 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.



HDAI Office

The committee has decided to offer Patricia our office administrator a permanent position after completing her one-year contract. Bernie will continue to work voluntarily as our Development Officer with the association refunding her expenses for work carried out on behalf of our members. Our committee members, who all give their time voluntarily, meet once a month for committee meetings in addition to representing the association at various meetings where necessary.

Celebration of Life

"Live as if today is the last day of your life, and remember that someday you'll be right. Forget this nonsense about today being the first day of the rest of your life. There is no 'rest of your life'. The

future is promised to no one. Develop an appreciation for each and every person you meet, each sunset, event, rainstorm, caterpillar, seashell and everything else you encounter." Dr Wayne Dyer

Gerrit Dommerholt attended Ralph's memorial service in Canada and sent us the pamphlet "A Celebration of the Life of Ralph Walker" from which the above quote was taken.

Have we increased our influence or lost our voice?

We are all aware there are individuals representing organizations such as ours who are not being forthright with their membership. We know that in 1997 five individuals from different countries claimed to represent 50 million people in Europe with genetic conditions and were influential in getting a patenting EU Directive A4-0222/97 passed in Europe supposedly on behalf of these people.

On closer examination we discovered that while these individuals were legitimate members of charities they had no mandate and were not elected by anyone to pursue this directive, they were in fact sponsored by drug companies which stood to benefit massively from this directive.

Some of my "colleagues" in other charities are accepting sums of money in the form of public relations and hotel expenses. These bills are being paid directly by the donor so it does not go through the charities books and we must be aware that these donors are not always donating money for altruistic reasons.

For us the patient is paramount and we would not like to see any of our members taken advantage of or used to influence outcomes of drug trials. We need to be constantly vigilant.

- In the past we joined umbrella organisations to increase our influence. Should we remain members or do we risk diluting our voice to the point where our hard won expertise is lost?
- Should charities take "donations" in the form of services which are not acknowledged in the accounts or accountable to the committee?
- Should we look at the motivation of the donor? - Drug companies may have their own agenda.
- Should we ask them to sign something which ensures they know they have not bought favour from us?

What Would You Do Next ?

group adjourned to the nearby Aishling Hotel where we met with other members from the Dublin support group and enjoyed light refreshments. As always, it was a good opportunity to meet up with old friends and acquaintances and to catch up with all the news and gossip.

**If you are interested in taking part in a social event or have any suggestions for a social get-together please call the office and let us know.

Report On Outing to Farmleigh

Following on from our successful visit to Farmleigh House in the Phoenix Park last November another group from the Huntington's Association visited Farmleigh on Saturday the 23rd of February 2002.

The tour of the house was enjoyed by all and despite hail, sleet and gale-force winds the sun did shine for brief periods!! Afterwards the

We All Have a Job To Do!

Carmen Leal the author of "Faces of Huntington's" and "Portraits of Huntington's" met our members at a meeting in Dr Steevens Hospital on October 16th 2001. She has written this article for our newsletter.

I have a confession to make, and it isn't pretty. I'm directionally challenged. No matter the size of the city or whether I'm a newcomer or not-I can't get there from here. I get lost going to places I've been to countless times. Maps, to me, just look like colors and lines. For years I lived in Hawaii, where directions are given exactly as directionally challenged people need them. Instead of using north, south, east, and west, which make no sense at all to me, Hawaiians use common sense landmarks. In Honolulu, makai (ocean), mauka (mountain), ewa (toward the airport), and Diamond Head, the most famous landmark in Hawaii, helped to at least point me in the right direction. Life was simple with landmarks so large even I couldn't get lost.

Now that I travel a good bit speaking about Huntington's Disease I find myself getting lost in an increasing number of cities. Imagine my delight when I was in Dublin this October and didn't get lost! What helped me was having something to use as a point of reference, and the river Liffey, not to mention the smells of the massive Guinness brewery, made it almost impossible for even me to get lost. The 1,752 acre Phoenix Park, served as a great reference, and no, I didn't walk all those miles.

My first hours in Dublin I discovered how lovely the people are. The day was cloudy, but certainly didn't look threatening. On a walk from the hotel the heavens opened and it poured rain, and me without an umbrella. Hoping to purchase one I entered a shop where I was told no, they didn't sell umbrellas and there probably weren't any shops nearby that did either.

Another customer asked how far I was going and offered to give me his umbrella as he was close to his destination. His kindness set the tone for my three days in Ireland. I didn't meet all of the approximately 1.5 million people there, but those I did meet were wonderful.

One of the highlights of my trip was a trip to Tullamore with Bernie Moran. Bernie, I have a bone to pick with you. I bought a bottle of Irish Mist as a gift but somehow it never got to the intended recipient once I took a sip and found out how smooth it is. I should have had that sample at the heritage center and I would have bought some for myself. Oh well, I got it and my friend didn't. Their loss.

Of course the real reason for the trip wasn't the Irish Mist or the double decker red bus tour. It wasn't the Duck or St. Patrick's Cathedral or any of the other lovely sights.

The reason for my trip was to speak to a group of families who are all in some way dealing with Huntington's Disease. Of all the people I met in Ireland this fall, none were more delightful than those Huntington's families I had the opportunity to meet. I wish I could have met everyone in Ireland involved with Huntington's.

Many lived too far away to attend the evening meeting, but thanks to the Huntington's Disease Association of Ireland, no one has to be alone as they fight Huntington's, no matter what their role or where they live. With everyone working together, every member of our community can become a better person through their struggles and can have the sort of hope that looks to the good instead of the bad. My talk was entitled We All Have A Job To Do. That doesn't just mean me or Bernie or Patricia or the board members. That means everyone. I shared that each of us needs to discover what we can do to make a difference instead of focusing on what we can't do and to look at problems as opportunities. When we find the very best in ourselves and others is when

we will have the best level of care and find a cure.

Each of us is called to do a specific job in finding the cure. From raising money, to participating in studies, to creating awareness, to saying prayers. No matter what that job is, we need everyone to do their job well.

Dublin was my last stop on a three country speaking tour and I absolutely fell in love with the city and the wonderful Irish people. I felt energized and hopeful knowing finding the cure is so much closer than ever before. Knowing excellent care is available gives me hope and helps me continue on.

I learned the Irish people are concerned about family. They love to laugh and have big hearts. They are hard workers and are able to fix their eyes on the goal and fight to the finish. Gee, they sound just like the people in my county!

Wherever I speak, no matter how large or small the group, I realize we are all one big family fighting for care and cure. We all have a job to do and most of the time we have multiple jobs. One of my jobs is writing books and speaking about Huntington's Disease. What is your job?

I will never forget my wonderful trip to Ireland this fall and the special people I met. I know each day more and more people will do their jobs in a way only they can do. When we all do our jobs we all are closer to our goal of helping those we love.

Carmen Leal is the author of Faces of Huntington's and Portraits of Huntington's. She is also a speaker and singer. The combination of her writing, speaking, and singing allows Carmen to be used in a variety of forums. Since publishing Faces of Huntington's in 1998, Carmen has spoken at conferences and workshops to over 100,000 people throughout the United States, Canada and Great Britain.

The 8 Minute Relaxation Plan

Minute One - In a quiet room and a comfortable chair, assume a restful position and a quiet, passive attitude. Take four deep breaths. Make each one deeper than the one before. Hold the first inhalation for four seconds, the second one for five seconds, the third one for seven seconds. Pull all the tension from all parts of your body into your lungs and

exhale it with each expiration. Feel more relaxed with each breath.

Minute Two - Count backwards from 10 to 0. Breathe naturally and with each exhalation, count one number. Feel more relaxed as you approach zero. With each step, you descend a relaxation stairway and become more deeply relaxed until you are totally relaxed at zero.

Minute Three to Seven - In your mind, go to a place that you find particularly

pleasant and restful. Stay there for about four minutes. Using all your senses, try vividly but passively to capture the feelings of that place and time.

Minute Eight - Bring your attention back to your self. Count slowly from zero to ten. Energise your body. Feel the energy, vitality and health flow through your system. Open your eyes. Feel alert and ready to resume your activities.

Acknowledgement: Carers WA - Summer 2001 Edition