

Financial Advice

The Money Advice and Budgeting Service (MABS) is a free and confidential service for people with debt problems and money management problems.

They are there to:

- Help you deal with your debts and make out a budget.
- Examine your income to make sure you are not missing out on any of your entitlements.
- Contact your creditors on your behalf with offers of payment if you are not able to do it yourself.
- Help you decide on the best way to make the payments.

People usually go to MABS because they:

- Have extra bills to pay because something has happened to them, e.g., illness in the family, separation, bereavement, accident, etc.
- Can't pay their everyday bills because they are unable to manage their money.
- Have less money than they used to and can't keep up with loan repayments.
- Have been living on a low income for a long time and are getting further and further behind because of the cost of education, clothing and footwear, travel, childcare, rent, etc.
- Took out more loans than they are able to repay.

- Sometimes people go from welfare to work and find they haven't as much money as they thought they would have and need help with a new budget.

How to contact MABS:

There are 53 MABS offices in Ireland with trained Money Advisers. You can contact MABS directly yourself by phone, email, letter or by calling in person.

You can find out about your local MABS office through Directory Enquiries, Citizens Information Centres, their Web Site address at www.mabs.ie or by phoning us on 1800 393939.

The MABS service is free and you will not have to pay for any advice, assistance or information.

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.

Front of card



Reverse of card



Donations



We would like to express our sincere thanks to Sean who recently raised €500 for HDAI. We would also like to thank Ann and her friends and family for their generosity in recently donating €200 to HDAI. This money is greatly appreciated and will be put to good use. 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.

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
January 25th • **February 22nd
March 29th

CORK
January 4th • February 1st
March 1st

DO YOU HAVE ANY ARTICLES TO CONTRIBUTE OR TOPICS YOU WOULD LIKE DISCUSSED? THIS IS YOUR NEWSLETTER

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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

ISSUE NO. 14
HDNL DECEMBER 2002

Awareness for HD

- SEASONS GREETINGS**
- NEED HELP THIS CHRISTMAS?**
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

We mentioned in our last newsletter that the Fair City research team have been in contact with us lately and are considering introducing a HD story line. They have now confirmed that they will introduce this story in late December or early January. Bernie and Patricia were invited to the Fair City set and met Rachel Sarah Murphy the actress (Joe) who will play the part of being from a HD family. We were impressed by the team's researcher David O'Sullivan and their interest in portraying a realistic storyline. The research team had also been in contact with the National Genetic Centre in order to get accurate information for this story line.

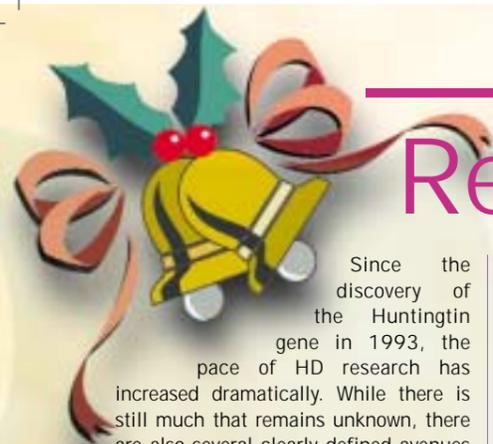
Following our visit to the RTE set Rachel called out to our office and met with some of our committee and members in order to learn more about HD and how it affects people's lives. We are very grateful to Rachel Sarah Murphy and for her time and understanding. We would also like to thank the HDAI members and committee who met with Rachel and shared their experiences with her.

We are happy to have the opportunity to highlight this traumatic disease without the need to expose families. 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.

Respite for Christmas

Do you need any financial assistance this Christmas? HDAI would like to help where possible, by contributing towards a family outing / a child's concert trip etc. Please apply in writing if we can help you this Christmas





Research Update

Since the discovery of the Huntingtin gene in 1993, the pace of HD research has increased dramatically. While there is still much that remains unknown, there are also several clearly defined avenues for research and investigation. For example in the past three years, The Huntington Disease Society of America's commitment to research funding has grown from several hundred thousand to \$3.3 million and in the next five years it is expected to grow to over \$10 million.

Current projects being funded include both basic research and clinical studies. Australia, Europe and Canada also play an important role in the global effort to discover new treatments and ultimately a cure for Huntington disease. In 1998-1999, the Huntington Society of Canada launched a new research programme, called NAVIGATOR, with a view to significantly expanding the Canadian contribution to the global HD research effort. "Developments over the past few years have left no doubt about the accelerating pace of Huntington's research. There is now an unshakeable

conviction within the scientific community that new treatments for Huntington disease are within reach, even that a cure will soon be found." Huntington Society of Canada We feel encouraged that we have made real progress - in mapping the gene for Huntington's disease, in pioneering new technologies for studying genes, and screening drugs that we hope will soon lead to effective treatments for HD and related illnesses. Milton Wexler, Ph.D. Hereditary Disease Foundation

Tips to help you cope

FEAR

The unreasonable overestimation of some threat, coupled with the underestimation of your ability to cope.

PANIC

You panic when you are anxious, depressed self critical or upset.

STOP - ask yourself...

What am I telling myself to make me feel this way?
Do I really want to do this to myself?
Do I really want to stay upset?

RELAX OR DISTRACT

Do something physical, walk, talk, read or listen to music.

QUESTION THE NEGATIVE BELIEF

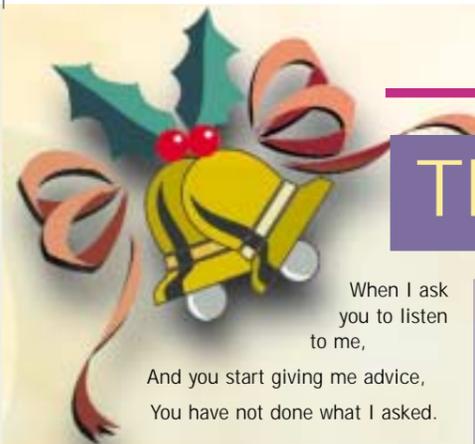
What is the evidence for this?
Is this always true?
Has this been true in the past?
What are the odds of this happening?
What is the worst that could happen?
What is so bad about that?
What would I do if that happened?
Am I looking at the whole picture?
What would I say to a friend in this situation?

WORRYING HAS NO EFFECT ON SOLVING PROBLEMS, TAKING ACTION DOES!

Books Available



The Scottish Huntington's Association have recently published these two booklets - A Guide for Children (age 8-14) and A Guide for Young People (age 14+) with an explanation of Huntington's Disease and some information about the disease. Please let us know if you would like to order either of these booklets.



The Art of Listening

When I ask you to listen to me,

And you start giving me advice,

You have not done what I asked.

When I ask that you listen to me,

And you begin to tell me why I shouldn't feel that way,

You are trampling on my feelings.

When I ask you to listen to me,

And you feel you have to do something to solve my problems,
You have failed me, strange as that may seem.

Listen:

All that I ask is that you listen,

Not talk or do - just hear me,

When you do something for me

That I need to do for myself,

You contribute to my fear and feeling of inadequacy.

But when you accept as a simple fact,
That I do feel what I feel, no matter how irrational,
Then I can quit trying to convince you,
And go about the business
Of understanding what's behind my feelings.

So, please listen and just hear me,

And, if you want to talk,

Wait a minute for your turn - and I'll listen to you.

Carers Also Need Care

Caring for a sick or elderly person can be very rewarding but it is also very demanding at times. While you may benefit from knowing you are doing something meaningful, learning to live in the present and appreciate the simple things in life, re-thinking priorities and values, and an increased insight into your own strengths and limitations, Caring can be physically, psychologically, emotionally and even financially draining.

You will experience a certain amount of stress but it is essential to avoid manage stress successfully and avoid burnout. Chronic exhaustion, Significant weight gain or loss and frequent illnesses are physical signs of high stress levels.

Frequent crying, frequent irritation, feelings of hopelessness and inadequacy and difficulty controlling ones temper are emotional signs.

In order to prevent being overwhelmed by stress you should:

- Look after your own physical health: eat nutritiously and get adequate exercise and rest.
- Take time daily to relax by doing something you enjoy for example: read something uplifting, listen to music you enjoy, take a walk or phone a friend etc
- Stay connected to friends and outside activities
- Avoid wasting time and energy on unimportant things
- Acknowledge when you need some help and ask for it!
- Find at least one person close to you who will listen and understand
- Find out about respite facilities in your area
- Take things one day at a time

Do you recognise and meet your basic needs

- Physical safety and security
- Financial security
- Friendship
- The attention of others
- Being listened to
- Respect
- Expressing and sharing your feelings
- Sense of belonging
- Nurturing
- Physically touching and being touched
- Intimacy
- Loyalty and trust
- A sense of accomplishment
- A sense of progress towards a goal.
- Feeling competent and masterful in some area
- Making a contribution
- Fun and play
- Sense of freedom /Independence
- Creativity
- Spiritual awareness- Connection with "higher power".
- Unconditional love.

If you need help or counselling or are having difficulty eating or sleeping please give us a call. If you are the spouse of a PhD you may also find counselling beneficial in helping you cope with your changed role. We could fund consultations with a counsellor in your area.

Book Update

We are updating our HD Booklet - *Facing Huntington's Disease - A handbook for families and friends*, if you would like to review the booklet and give your opinion on what could be included /updated please contact the office and we will send you a copy. If you already have the booklet we would welcome any advice you are willing to give us.

