



HDNL 2012 - Issue No 51, Q3 12

CHECK OUT OUR WEB SITE

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

OLD MOBILES?

Have you any old mobile phones? If so please send them to us. If we recycle them we will get much needed funds. Please email hdai@indigo.ie or phone 1800 393939 for more information.

YOUR NEWSLETTER

Please send us your views

Christmas Cards

HDAI are selling HDAI Charity Christmas Cards again this year.

A pack of 15 cards (175mm x 125mm) of 15 individual designs cost €8.00 per pack which includes postage.

To order you can post a cheque to the office, including your name & address or check out our website.



NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

HD Featured on TV3



Anne and Christy (pictured) courageously discussed their battle with HD on TV3's The Morning Show on August 31st.

They discussed the problems they face due to a lack of awareness and understanding of HD. They also highlighted the lack of flexibility in getting services and the burden of needing to reapply for a medical card.

You can see this feature online through this link - <http://www.tv3.ie/3player/show/155/52117/0/>

Comments received included:

"Saw Christy and Ann on TV3, it was very good, Christy is some man!" - Íde

"Really great - very moving. It covered so many key points but from a lovely calm perspective. Well done" - Kathy

"Anne and Christy were fantastic on TV3. How brave of Anne - she is amazing. Martin King was right, she is a hero! Please pass on our regards and huge THANK YOU to Anne and Christy" - Elizabeth

What an Amazing Experience

by Katie Martin

If ever there were positives to come from something as difficult as Huntington's disease it was my week at the HD international Youth Camp. I will never forget the friends I made, although the term second family seems more fitting.

We understand each other in a way only people in the same situation can. Every HD story is different but fundamentally there's a bond between us all like no other. You can read and read and then read some more about HD but until you yourself are affected by it, it's very difficult to comprehend the trials and tribulations that come with it, not only in dealing with the person with the illness but also how you yourself cope.

Before the camp in Sweden I felt alone in my struggle to be there for my mother but also in grasping and accepting what this disease meant for me as an individual. I now know I am not alone. In Sweden we were a little community all bound by the same thing: HD.

One of the most difficult aspects of the illness for me has been acceptance. I thought this was strange, HD has been a part of my life since I was born and there has always been a member of my family with it. Yet it was only as my mum started showing her physical symptoms I began to struggle. And in Sweden, among the many things I learned, this is normal! It's ok to be upset, to be angry, and to feel sad. The most important thing I learned however is that we are not alone in feeling these things.



There is support, there are ways to cope and we can live positively. We must not allow the disease to define our lives - the disease and how we live is our responsibility. I was shocked at this revelation which came from a man recently diagnosed with Parkinson's and I can honestly say he is without doubt, one of the most inspirational people I have ever been privileged enough to meet. Of course with the disease there is a loss of control but it is only one part of our lives, not our entire being.

Life is for living! Recently on holidays I met a man who has had Parkinson's for 18 years. I just so happened to sit beside him at dinner and how lucky I was! My family asked me how I could concentrate when the disease was so evident but all I heard were the many places he had visited, his love for his children and how great his life had been. He mentioned Parkinson's once. (to page 2)

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As we went to leave he told me 'do not wait for life to come and greet you, you must go and find it yourself.'

Of course there are bad days but I think if we could all incorporate the hope we felt in Sweden into our everyday lives we'd go a long way. We laughed, we cried, we felt angry, we felt sad but we felt it together. One of the main things that struck me once I was home is how many people must be in the same position I was. I'm now 20, my mum was diagnosed with HD when I was one at which point her psychological symptoms were already evident. However we did not realise that this was the affect of the disease and as I grew up my father and I wondered where the kind and loving woman we once knew had gone to.

It's only in recent years that I made the connection. I think as a child when you are too young to understand these things you often struggle with guilt when it does dawn on you. For me that was one of the hardest parts, the opportunities I felt I had wasted. Talking to other people at camp was liberating, other people felt this too. I can't explain it but it was such a relief, I wasn't a horrible daughter, I just hadn't understood at the time. I also think you grieve the person that they once were and that can be difficult for friends and family who are not in the same situation to grasp. Yes they are still here but the person that they were can seem a million miles away. I had no idea that the psychological symptoms could be so extensive. I don't think there was the same awareness at the same time as there is now. Now the likes of HDYO and the internet are only a click away which is fantastic for young people and I don't think young people can thank Matt enough!

My mum's mobility isn't good anymore and she needs assistance in walking, yet when a woman comes in and plays music in her nursing home she badgers a nurse to stand her up and she dances. Her determination inspires me and I hope I can take that and hopefully help other people in the same position as all of us. We are not alone, we all have each other and we need each other more than anything. For me the camp was help and support but also a lot of fun! From our group meetings to water sports at the beach to samba soccer and sunbathing we built friendships that will last a lifetime. There's a question of whether there will be another camp next year. We made a video in the hopes of reaching out to other young people in the HD community but also as an appeal for another camp. For many of us this is the only support we have. We all felt the same way, at home no one really understands, or talking about it is taboo or uncomfortable, or that there is an absence

of the information we need available. Many of us are at a point in our lives where we want to know more about getting tested and the processes and implications. It turns out in every country the system is different. When I speak to my friends or family they all either feel strongly for or against. For me, it is not so simple. I've lost so many people in my family to HD that at times the prospect of testing positive was terrifying. After the camp I feel differently, I feel I have the information I need but also the strength to cope with either result. Of course it's still a very difficult decision to make, but it's more a question of when rather than whether now. Am I ready, or can anyone really know if they are prepared? I like to think if I tested positive it would push me to embrace life but if I tested negative I should do much the same. Regardless, we should make the most of the opportunities given to us and I'm so glad Sweden was one of the ones I was graced with. I think there needs to be more support for people who test negative also. While they may not have the worry of developing the disease and being dependant at some point they may be the one completely depended upon and I think support needs to be made more accessible in these situations. We need more than one week a year!



All in all, this week has been a life changing experience. At the beginning, I wasn't sure about coming and on the first night all I could think was 'get me out of here', but I wouldn't change it for the world. I've met some of the most inspirational people and as a result I not only feel I have the strength to cope better but also to begin to fight for other young people like myself and the friends I've made here. We need support, we need these camps, and we need to be involved! We are the future and we need to take an active role in paving the right path for ourselves and others to come.

In May of this year I had to find a nursing home more suitable to my mum's needs. I got in touch with HDAI and they made recommendations, one of which is where she is now. They also told me about this camp. Later that week, I found out that when the Association was originally set up my mum had an active role in its founding. What we do now matters. If she and so many others had not taken that initiative, who knows if I would have had them

as a resource. Awareness, support and information are vital in coping and if I could have anything, I would wish for others to have the experience I had.

Advance Care Planning

While it can be difficult and upsetting to discuss long term care or end of life wishes, an open discussion with our loved ones on this subject can reduce anxiety and worries about the future. Advance care planning is very important for people with neurological conditions who may face later cognitive change. A person's views on potentially life prolonging treatment such as peg tube feeding, when communicated to carers, family members and relevant health care professionals, helps provide clarity to all.

Communicating successfully with people can empower them to make informed choices over their future care. It is important for people to feel that their views and preferences have been heard and understood.

Think Ahead



A *Think Ahead* initiative was launched in 2011 as a 'flagship project' of the National Council of the Forum on End of Life in

Ireland. The purpose of *Think Ahead* is to guide members of the public in discussing and recording their preferences in the event of emergency, serious illness or death.

A *Think Ahead* form is available from: <http://www.thinkahead.ie/news/>

Thinking and planning ahead can help to ease the sadness and pain of those that you will inevitably leave behind and the *Think Ahead* form can make it easy for you to capture and keep important details that may some day be needed by those closest to you. The form allows you to provide information on emergency contacts, care preferences, legal, financial and funeral and organ donor information.

Benefits of *Think Ahead*

- Encourages you to THINK about how well (or not) those close to you would know or understand your wishes if a time came when you could not speak for yourself.
- It encourages you to TALK about your preferences with you partner, a close friend, or key professional(s) (e.g. a GP, solicitor or accountant).
- It encourages you to TELL the most relevant people in your life about your wishes and to record them so that they can be available an illness or accident means that you cannot communicate with family members or carers.

For further information please visit: <http://www.thinkahead.ie/benefits-of-think-ahead/>

Fundraising

Thank You

Women's Mini Marathon

Sponsorship is still coming in from the marvelous ladies who took part in Mini Marathons earlier this year. HDAl have received over €2,000 to date. Thanks to all who participated to raise awareness and funding for HD. Since July we received the following fundraising contributions:

Nicola D €300, Katherine €75, Mary €321, Gemma H €100 and Grainne €325+

Great Ireland Run

Sincere thanks to Jennifer and Ciara (pictured below) who participated in the Great Ireland Run earlier this year and raised an excellent €307.00 in aid of HDAl.



Congratulations also on your personal best in completing the 10km race in 59 mins and 54 secs!

Castlebar Marathon



A big Thanks to Cathorina (pictured above with friends) who participated in the Castlebar Mini marathon again this year on behalf of HDAl and raised €170. We are very grateful for your continuous support.

Yoga Classes



We're very grateful to Helen Sherlock who hosted a Yoga Class in Drumcondra in early summer and raised a fantastic €521.50. Helen also supported us last Spring. Thanks to Helen, Bernie and all class participants for their generous support.

Line Dancing

Thank You to Geraldine Martin, for continuing to donate proceeds from her line dancing to HDAl.

My Charity

If you wish to support HDAl fundraisers see the link on our website or find HDAl in the list of charities on www.mycharity.ie

All Saints Jam Club

The All Saints Jam Club in Raheny, Dublin raised a whopping €1,820 on behalf of people affected by HD. A huge thanks to Valerie and all the children and parents who supported this fundraiser. We should also acknowledge Anna who works tirelessly to raise awareness for HD. Thanks to Peter Orford for his excellent photographic skills in capturing a wonderful photo in All Saints.



Doreen and Anna kindly attended the cheque presentation on behalf of HDAl.

Donations

- Thanks to Finnola and Martina for their monthly Direct Debits.
- Thanks to Lyndsey and Kevin for their generous donation of €200.

Wedding congratulations

Congratulations to Emma and Jason who got married in August. Emma and Jason generously donated to HDAl as a wedding favour for their guests.



We are very grateful for their kindness and support in raising awareness. Emma and Jason pictured with Jennifer, Anna & Yvonne.

We know that a lot of effort goes into participating and getting sponsorship so a BIG Thanks to you all.



Thanks to Brendan at C&C Cellular for another very welcome cheque of €195.88 for recycled mobiles.

Please recycle old mobiles and raise funds for HDAl.

National Carers Strategy

Ireland's first National Carers Strategy was launched on July 19th 2012.

The Strategy's vision is to:

- Recognise and respect carers as key care partners
- Support carers to maintain their own health and well-being and to care with confidence
- Empower carers to participate as fully as possible in economic and social life

The Taoiseach, Mr Enda Kenny T.D., stated that:

"The publication of this Strategy marks a watershed moment in the State's recognition of and support for carers, valuing their continued commitment and contribution to their families and to society"

<http://www.dohc.ie/press/releases/2012/20120719.html>

Ms Kathleen Lynch T.D., Minister for Disability, Equality, Mental Health and Older People states:

"The National Carers' Strategy signals the Government's commitment to recognising and respecting carers as key care partners and to responding to their needs, across a number of policy areas.

By setting out a Vision to work towards, and an ambitious set of National Goals and Objectives to guide policy development and service delivery, the Strategy seeks to ensure that carers feel valued and supported to manage their caring responsibilities with confidence and are empowered to have a life of their own outside of caring"

National Carers' Strategy

Due to current economic constraints new services cannot be delivered in the short term therefore the strategy will address actions that can be achieved on a cost neutral basis. However Minister Lynch has committed to a periodic review to provide scope for additional actions when our economic position improves.

The National Carers' Strategy is available on the Department of Health's website:

http://www.dohc.ie/publications/national_carers_strategy.html

HD Chair

Please let us know if you need a HD Chair for a family member or if you have one that is in need of repair. Alternatively if you have one you do not need and would like someone else to make use of it we can arrange this. Please contact the office.

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.

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 HDIA office and we will take it from there.

Acknowledge Kindness

Do you have a friend or neighbour who deserves a bunch of flowers or a Thank you voucher? If so please let us know.

The articles which appear in this newsletter may not necessarily represent the views of HDIA.



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Thank You to our Wonderful Next Door Neighbour



We would like to thank our wonderful next door neighbor Majella.

Knowing Majella is next door makes our lives so much easier. She has always

been a great friend over the years and has been particularly helpful and kind over the summer when Pat had to go into hospital. Thankfully Pat is home now and is doing well but I couldn't have managed without Majella who gave us great practical help and support.

Majella is the type of neighbour who if you didn't have her you would send away for her – Everyone should have a "Majella" in their lives!

Eileen & Pat

Accessible Breaks



Cuisle Holiday Centre is the Irish Wheelchair Association's national holiday centre and Ireland's leading wheelchair accessible resort. Cuisle has been providing respite

breaks and holidays to people with disabilities from home and abroad for 15 years. This resort has 34 fully accessible bedrooms and also offers personal assistance, nursing care, a wide range of aids and appliances, a restaurant and onsite bar, leisure suite with jacuzzi, sauna and gym, fishing, indoor games and a fleet of accessible transport. It is a truly unique place and the only such facility in Ireland. People with and without disabilities can holiday together at Cuisle Holiday Centre.

Check out their recently revamped website www.cuisle.com for more information on Cuisle.

Counselling

HDIA are very grateful to The Family Support Agency for their 2012 Counselling grant of €3,600. If you, or a family member, affected by HD needs counselling, please contact the office for information.

Information on HD

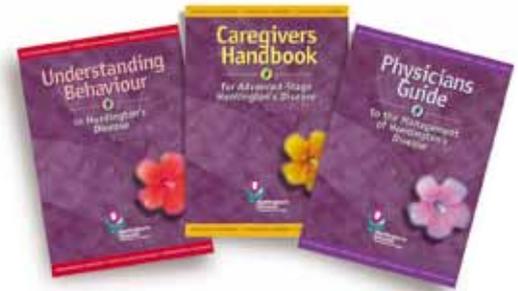


The HDIA Booklet, *Facing Huntington's Disease: A handbook for families and friends*, has been updated and reprinted in 2012.

The updated booklets are available from the Information page of the website and to

HD family members, health and social care professionals on request.

HDIA wish to acknowledge contributions from professionals in Ireland and material made available from International Associations and Huntington's Disease Association (UK) and the Scottish Huntington's Association (SHA).



The Caregivers Handbook, Physicians Guide and Understanding Behaviour Information booklets are available on our website or you can contact the office for a hard copy.

The Euro HD Network working groups are working on guidelines for **Standards of Care for HD.**

These are available from our website <http://www.huntingtons.ie/content/information-0>



Anna (HDIA), Bea (EHA President), Patricia (HDIA) and Katie Moser (USA HD advocate) at the International Movement Disorders Conference in Dublin



HDIA Coffee Mornings/Support Meetings

You are very welcome to join us at our Coffee Mornings/Support Meetings from 11.00am to 1.00pm on a Saturday in Cork, Mayo, Dublin and Limerick (dates below). Our Family Support Officer or a committee member will host the meetings. Tea, coffee and scones are provided. Contact the HDIA office on 1800393939 for more information.

DUBLIN

November 10th

CORK

October 6th

MAYO - Castlebar:

December 8th

LIMERICK

October 13th