

CONTINUING THE FIGHT ON BEHALF OF OUR MEMBERS



2015

HDNL 2015 - Issue No 64, Q4 15

CHECK OUT OUR WEB SITE

www.huntingtons.ie
e: info@huntingtons.ie

SUPPORT MEETINGS

See dates on page 4

GENETICS

For information on Genetic testing contact the Genetics Centre -

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 info@huntingtons.ie or phone 1800 393939 for more information.

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

Enroll HD

HDAI is delighted to report that the Enroll-HD Study at Beaumont Hospital has commenced registration. This is a significant milestone for Ireland's HD community. It gives Irish families an opportunity to contribute to the world wide effort to find effective treatments for HD.

Welcome to

Enroll-HD



at Beaumont Hospital

For more information see the Frequently Asked Questions sheet enclosed and take a look at the Enroll-HD information video on our website www.huntingtons.ie and www.youtube.com/watch?v=_X7oUp5sB4M

You can express your interest in the study by emailing: enrollhd@beaumont.ie

Congratulations to Dr Niall Pender and his team on establishing this study at Beaumont.

Dr Ed Wild, (Consultant Neurologist and Clinician Scientist at University College London, Institute of Neurology and co-founder of HDBuzz) sent his congratulations via Twitter, "Congratulations Ireland, a great day for #huntingtonsdisease research" You can follow Dr Wild on Twitter @DrEdWild

HD Café Evening at Bloomfield Health Services



(L to R): Susan O'Neill, Senior Physiotherapist, Dr Andrea Higgins, Neuropsychologist, Aisling Doyle, Occupational Therapist, Michelle Lynch, Clinical Nurse Manager and Damien O'Dowd, CEO.

Bloomfield Health Services in Rathfarnham, Co. Dublin, extended a warm welcome to people with HD and family members on November 17th.

Susan O'Neill, Senior Physiotherapist gave an informative talk on Physiotherapy in Huntington's Disease (summarised below) and answered numerous questions from those in attendance.

Following the talk, Dr Jennifer Hoblyn, Clinical Director introduced herself and other members of Bloomfield's multi-disciplinary team and discussed their interest in developing additional HD services. People with HD and family members had an opportunity to chat with the MDT team over a cuppa and some very good cakes. HDAI received very positive feedback on the event and looks forward to continued collaboration with Bloomfield Health Services.

Bloomfield Health Services is an independent not for profit healthcare provider with 114 continuing care beds in their approved psychiatric centre.

Their multidisciplinary care team includes:

Psychiatry, Medicine, Psychology, Pharmacy, Physiotherapy, Social Work, Occupational therapy, Nursing Staff, Nutrition, Optician, Chiroprapist and access to SALT and Palliative Medicine.

Their HD service includes a Nurse Specialist for HD, a HD Assessment Clinic, a 16 week MDT assessment program and caregiver support and educational work-shops.

Physiotherapy in Huntingtons Disease

Physiotherapy is the treatment of physical dysfunction or injury through the use of therapeutic exercise, functional training, education and advice. Physical exercise is important for everyone's general health, but for people at risk of Huntington's Disease it is especially important for maintaining muscle strength and function.

A physiotherapist can provide important advice on how to maintain physical activity for as long as possible and how to reduce the risk of falls and injuries. Research suggests that a more active lifestyle may slow progression of Huntington's disease before symptom onset (Trembath 2008).

(continued on page 2)



Christmas Cards 2015

Thanks to all who have supported and / or sold HDAI's Charity cards.

This year we were delighted to include designs submitted by members. We welcome

Christmas themed photos or paintings for next year.

(continued from page 1)

The European Huntington's Disease Network Physiotherapy Specialist group recommend the following guidelines for a general adult population:

- Up to 30 minutes of moderate intensity aerobic activity at least 3 times per week.
- Strength training for major muscle groups twice a week.

Examples of moderate intensity endurance activities include: walking briskly, mowing the lawn, dancing, swimming and bicycling on level terrain.

Studies of mouse models of HD found that exercise delayed the onset of Huntington's symptoms and improved cognition and function in the early to mid- stages of HD. HD related symptoms such as apathy and lack of initiation can make it difficult for people to exercise. Family and friends can assist by offering to exercise or take an activity class with their loved one.

- Any amount of exercise is beneficial - try and do a little and often.
- Develop a routine.
- Choose an exercise you enjoy, because if it is stressful, you may undo the benefit.
- If you experience fatigue or pain or are worried about safety seek a physiotherapy assessment for an individualised exercise plan.

For people with significant movement impairments, small amounts of regular exercise is still beneficial and physiotherapists can prescribe exercises that are safe to perform.

Susan's mobility advice for people with HD includes:

- Avoid dual tasking when mobilising e.g. avoid carrying objects.
- Maintain a clutter free environment and remove trip hazards e.g. rugs.
- Always wear appropriate footwear.
- If you experience regularly falls use protective equipment e.g. knee pads.
- Seek a physiotherapist assessment for walking devices when necessary.

Changes to the home environment can support function and improve safety. An occupational therapist can provide advice on home adaptations, assistive aids and supportive seating.

European Huntington's Association Conference 2015, Warsaw, Poland

Thanks to Anne Lennon Bird for her report, summarised below.

Clinical trials: What does research need from HD Families? - Jean Marc Burgunder, MD, Chair of EHDN

It is very important to have as many participants as possible to better understand the course of the disease. There is hope for therapeutic benefits to be obtained from information received from the Enroll-HD study. Clinical trials need participants in order to progress. Types of trials include: Natural History studies, Prevention trials, Screening trials, Diagnostic trails, Treatment trials, Quality of Life trials. Families and researchers need to work together with mutual trust, respect and commitment.

How can the HD community contribute to Enroll-HD and Trials? - Joe Guilano

Enroll-HD is a global family study. Data and samples collected are available to HD researchers to answer important questions about HD. A unique number is generated for each participant to protect privacy. All family members are encouraged to participate. Enroll is dependent on participation from families from all countries. To date there are 7,588 participants.

PF-02545920, an investigational Pfizer compound for the treatment of HD. Ottavio Vitolo

Trials (Amaryllis Study) are currently underway in Poland, UK, Germany, US and Canada (45 centres) to assess whether this compound improves voluntary movement and overall symptoms in individuals with HD. This drug does not address the root cause of HD.

Which trials are ongoing with TEVA and what are the prospects for the near future? - Michael Hayden

Teva Pharmaceutical Industries Ltd have several ongoing research programs for Huntington's Disease. Some of these are:

- **SD-809** - Submitted for approval as a medicine for chorea in May 2015.
- **Pridopidine (Pride HD)** - Currently in phase 2/3 clinical trials for motor improvements and is expected to be ready for approval in 2017.
- **Laquinimod (LEGATO-HD)** - A clinical trial to decrease inflammatory processes that occur in the brain in HD, expected approval 2018.

Nutrition, challenges and possibilities Susan Sandler

The need for good nutrition was highlighted along with the challenges in providing it.

Research shows that having a good breakfast results in better sleep at night. Vitamin D levels should be maintained to keep bones strong. Mixing milk and dried milk together may better protect bones especially when there is a higher risk of falling.

The brains of HD patients seem to have problems making enough energy. Giving brains an energy boost might help with HD, but getting extra fuel into the brain is difficult. A group of researchers in France conducted a short limited study on the use of Triheptanoin Oil to boost brain energy. The study yielded favourable results but further research is required to determine benefits. (see <http://en.hdbuzz.net/185>)

Predictive testing: Rhona Macleod and Tijn Tendal discussed the need for good counselling and follow up regardless of the result being good or bad. Counselling prepares an individual for the outcome. People with a good result often suffer from 'survivor's guilt' and can feel like an outsider in their own HD family.

Stories about Predictive testing included:

Good Result - a young girl told of her struggles to make her decision to take the test. Despite getting a good result she discussed her difficulties in coming to terms with it and planning for her future. Although she felt very lucky, she felt her life had become empty.

Good Result, bad process - a young man accompanied his HD positive mother to her consultants visit. The consultant mistook his nerves for possible HD symptoms and referred the young man to his GP for a blood test. Two week later the young man got a good result but the whole process left him totally traumatised.

My child has been tested - a mother (Anne) explained her thoughts and feelings as she watched her daughter and son go through the testing process and come to terms with their respective results. She spoke of her feelings of helplessness, fear and terror. She also spoke of how inadequate she felt as a mother as she was not able to protect her children from the horrors of HD.

It was acknowledged that lay organisations are making a difference in supporting families going through the testing process.

Building better communication between the nursing home and the family - Saskia De Meulenaere

Saskia from Belgium spoke about nursing home care. She discussed the vital need for the resident to be the architect of their own care plan in consultation with their families.

Aggression in Huntington's Disease, Causes and Consequences - Dirk Liessens

Aggressive behaviour in HD is aggression without a plan as opposed to aggressive behaviour with a plan which is seen in boxing or football for example. Aggression is not an emotion, it is a behaviour possibly motivated by fear, anger or frustration due to sensory overload. Aggression is almost always a symptom of the disease; it is rarely an intentional act.

Change of personality; how to cope - Åsa Petersén

For families, information about symptoms is powerful. Learning as much as possible is important. Early contact with medical care providers is vital. Accepting the probability of life style changes helps family members cope better as their lives alter. There are also effective medications and treatment available that can be helpful in dealing with symptoms such as depression, anxiety and sleep problems.

Round up: Where does research stand and what will the next steps be? - Bernhard Landwehrmeyer

Twenty three years ago, the root cause of HD was identified. Understanding root cause does not mean having effective treatments. We need to understand how disease works to effect treatments. Compounds and potential drugs need to be specifically designed for HD. They need to get to where they should go, bind to what they should bind to and do what it is hoped to do.

Isis Pharmaceuticals has developed an ASO drug "ISIS-HTTRx" which targets the HD gene for silencing. The first HD patients have been successfully dosed with this drug in Phase 1 of the Isis / Roche Clinical Trial. This stage of the trial is targeting safety and tolerability as opposed to benefits.

Realistically it could take at least a decade before gene silencing therapies become a prescribed therapy.

Research trusts that things will fall into place once all HD families get on the bus, get behind the bus and help push it, even if conditions are difficult.

Fundraising

Ireland Fund De France



Ambassador Geraldine Byrne Nason and Helen Lambert (Photograph courtesy of François Goize)

Ireland Fund De France nominated the Association Médicale Hendayaise pour les Maladies Rares and the Huntington's Disease Association of Ireland as joint beneficiaries of their 2015

Bloomsday Dinner Fundraising event held in Paris on June 16th. Amongst those present were Her Excellency Geraldine Byrne Nason, Ambassador of Ireland and Honorary President of Ireland Fund De France; his excellency Jean Pierre Thebault Ambassador of France to Ireland; John Fitzpatrick, Chairman of the American Ireland Fund; the Hon. John B Kane, Board Director of The American Ireland Fund and Helen Lambert, President of The Ireland Fund of France. Anne Lennon Bird, HDAI and Dr Jennifer Hoblyn, Bloomfield Health Services kindly represented HDAI and accepted an invitation to speak on the night. The event raised a magnificent €25,000 for HDAI which will support self-management and awareness projects for the HD community in Ireland.

A special thank you to the Ireland Fund De France Board, including President Helen Lambert and Ann Garvey for their tremendous efforts in raising awareness and funds in support of people with HD in France and Ireland.

Thanks also to the generous sponsorship of the dinner and charity auction from companies including: Fior Uisce, Dunleavy Meats, Aer Lingus, Fitzpatrick Hotel Group and Oscar de la Renta. The Ireland Fund of France is part of the Worldwide Ireland Funds, an organisation dedicated to supporting initiatives associated with peace & reconciliation, charity, community and culture throughout Ireland and all over the world.

Dublin City Marathon



Sincere thanks to Ryan Toal (centre) who raised a magnificent €587 for HDAI by participating in the Dublin City Marathon this October.

Half Marathon



Josie and Sinead (left) continue to raise funds and awareness for Huntington's Disease. They

completed a half marathon in Dublin this Autumn and generated a marvelous €700 for HDAI. Thanks to all who generously offered sponsorship.



Celbridge Craft Fair

Marie and Íde Cussen (left) once again created and sold beautiful woolen handknits

with the Sinn Féin North Kildare Cumann at the annual Christmas Craft Fair in Celbridge, Co Kildare. Their crafts raised a marvellous €682 and they also sold Christmas Cards raising €104. HDAI are very grateful for their outstanding hard work and generosity.

Art for HD

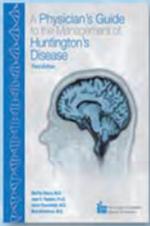


Heartfelt thanks to wonderfully creative Frankie Lundy who raised €130 for HDAI from the sale of his paintings at the Blue Bird Care Cookery Demo in the Templegate Hotel in Ennis recently.

Donations and Membership

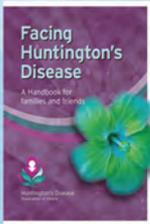
A huge Thank You to members and friends for their very generous support in Quarter 4, 2015, including: Martina and Finnola for their monthly Direct Debit donations, Patrick and Mary Alice Lennon €1,000, Moira and Aileen €240, Mick Scanlon €150, Harreds Bathroom & Tiles €233, Ward & Burke Construction Ltd and Madeline Jordan €300, Mary & Edward McNamara €100, Patrick & Teresa O'Sullivan €1,000, Caherdavin Scouts €30, Marin-Aer Ireland €500, Nonie & Seamus O'Toole €800. HDAI also received €1,450 in memory of loved ones who died recently.

Information on HD



Huntington's Disease Society America have launched a 3rd edition of the Physicians Guide available online via

HDAI's website.



The HDAI Booklet, *Facing Huntington's Disease:*

A handbook for families and friends, together

with the handbooks: *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.

EHA Congratulations

Congratulations to the European Huntington Association on the launch of their new website:

<http://eurohuntington.org>

Save The Date

Members Meeting
and Respite
Weekend Cuisle
10th -12th June, 2016

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



Huntington's Disease Association of Ireland

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In Memory



MARY CUNNINGHAM

When I come to the end of the road
and the sun has set for me,
I want no tears in a gloom-filled room,
why cry for a soul set free?

Miss me a little but not for long and not
with your head bowed low,
Remember the love that we once shared,
miss me but let me go.

For this is a journey we all must take
and each must go alone,
It is all a part of the Master's plan,
a step on the road to home.

When you are lonely and sick of heart,
go to your friends that we know,
and bury your sorrows in doing good works,
miss me but let me go.

Marie Cunningham

4th October 1950 - 9th October 2015

Sincere condolences to Frank and Family

HD 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.

Thanks to magnificent advocates Anne and Christy for championing HDAI's new **Text to Donate** facility

Text HDAI to 50300 to donate €2

100% of text cost goes to Huntingtons Disease Association of Ireland across most network operators.

Some network operators apply VAT which means that a minimum of €1.63 will go to Huntingtons Disease Association of Ireland.

Service Provider: LIKECHARITY. Helpline: 0766805278.



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.

1

Ann Hannon nominated **Nonie & Seamus O'Toole** for flowers as a Thank You for their much appreciated support over the last ten years in raising funds and awareness for HD.



Nonie & Seamus asked family and friends to donate to HDAI in lieu of gifts for their 50th Wedding Anniversary. They rose a marvellous €800 for HDAI

2



Dirk and Michelle nominated **Donna** for Flowers as a Thank You for always going the extra mile for Dirk.

Follow HDAI on Social Media

Facebook: https://www.facebook.com/pages/Huntingtons-Disease-Association-of-Ireland/121707387897701?ref=br_tf

Twitter: @HDAI_ie Thank you to our volunteers for their social media work.



HDAI Support Meetings

You are very welcome to join us at our Support Meetings from 11.00am to 1.00pm on a Saturday in Cork, Mayo, Dublin and Longford and in Limerick from 10.30am. Our Family Support Officer or a HDAI representative will host the meetings. Tea, coffee and scones are provided. Contact the HDAI office on 1800393939 for more information.

DUBLIN

Feb 6th

CORK

Mar 19th

LONGFORD

Mar 5th

LIMERICK

Jan 16th