



HDNL 2012 - Issue No 49, Q1 12

## CHECK OUT OUR WEB SITE

[www.huntingtons.ie](http://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](http://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 [hdaï@indigo.ie](mailto:hdaï@indigo.ie) or phone 1800 393939 for more information.

## YOUR NEWSLETTER

Please send us your views

## SHARE YOUR SKILLS

If you have time and energy to contribute, or if you know of a friend or family member who has, please consider joining our committee. All queries welcome.

## CYCLE FOR HD

HD Alliance are organising a

### LONDON TO PARIS FUNDRAISING CYCLE

for 26th - 30th September 2012

If you are a keen cyclist wanting to have a Tour de France adventure while raising funds for HDAl please contact us for more information.

## NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

# Hope

IRELAND

## Members Meeting & AGM June 9th, 2012

Our AGM and Members Respite weekend takes place from the **8th - 10th June** in Cuisle Respite Centre, Co. Roscommon. Dr Timothy Counihan, Consultant in Neurology, Galway has kindly agreed to be our guest speaker. All facilities at Cuisle are fully accessible to people with disabilities. **Please mark these dates in your diary.** We will be sending out information and booking forms shortly. If you cannot attend due to travel difficulties we will try to work something out. We provide a return bus service from Dublin and Cork to Roscommon.

## HD Alliance Survey

The UK and Ireland Huntington's Alliance is a partnership between the four charities that support people living with Huntington's disease in the U.K. & Ireland. The Alliance works together on common goals - like awareness raising and highlighting important issues that affect the people we support.

The Alliance is currently hoping to collect information about the difficulties members have in negotiating their way through the welfare benefits system so that we can raise the issues with elected members of parliament and with the relevant Government Departments.

If you are living with Huntington's disease in your family we would value your views. We are not collecting any personal information about you or your individual circumstances, but we do need to gather evidence that reflects the issues for people living with Huntington's Disease as a group. Please see cover letter and survey enclosed.

We would **prefer** if you could complete the survey **on-line**, because it will greatly speed up the process of collecting the information. If you do not have online access, please complete and return before June 30th. To do this, type the following link into the address bar of your browser:

[www.surveymonkey.com/s/589Y6LN](http://www.surveymonkey.com/s/589Y6LN)

## Neurological Briefing

Four representatives from HDAl took part in the Neurological Alliance of Ireland (NAI) briefing for TDs and Senators in

Leinster House on February 23rd. In all, 13 neurological support groups were present with their representatives. 45 TDs and Senators either attended or were represented at the briefing.

*Key messages of the day were:*

1. *Funding cuts to neurological charities are having a serious impact on frontline neurological care services*
2. *Implementing the recommendations of the National Rehabilitation Strategy is essential to address the crisis in rehabilitation in this country and make better use of the health spend*

HDAl would like to thank all of you who gave your support by contacting your local TDs and Senators and asking them to attend. Many of you also mentioned your own personal issues in living with, or caring for, people affected by Huntington's Disease.



John O'Mahoney T.D., talking to Rosemary and Patricia

We had a lot of correspondence from TDs and Senators and it all helps to create awareness. A special thanks to Anne, Denis and Rosemary who attended on behalf of HDAl and discussed issues for those affected by HD.

## Brain Awareness Week

Brain Awareness Week took place from 5th - 11th March. HDAl hosted a Carers Workshop in Cork and a Support Group meeting in Cork and in Mayo to mark Brain Awareness. The NAI Annual conference was held on 6th March "Securing Resources for Neurological Care and Rehabilitation in a Recession". HDAl hosted an information stand at the conference. Opening the conference, Mr Chris Macey, Chair of NAI, spoke of the effectiveness of non statutory organisations as advocates for change, as service providers and as key partners in transforming neurological care services.

(continued on page 2)

## Brain Awareness Week

(continued)

The morning session on Service Planning and Development included an update from the four Clinical Care Directors of the National Strategies on:

*Rehabilitation*: Dr. Aine Carroll, *Epilepsy*: Dr. Colin Doherty, *Neurology*: Professor Tim Lynch, and *Stroke*: Dr. Joe Harbison.

Dr. Aine Carroll spoke about the benefit of rehabilitation in improving quality of life and reducing disability and shortening hospital stay. Currently there are 6 Consultant Specialists in Rehabilitation in Ireland which falls far short of the minimum international recommendation of 27 for our population size.

**Aims of the Rehabilitation strategy include:**

- *Developing regional networks, local rehab teams and associated protocols and pathways*
- *Developing four regional specialist inpatient and outpatient units*
- *Defining an enhanced model for community based rehabilitation services (in association with other programmes)*

The afternoon session "Securing Resources and Investment for Neurological Care" focused on supporting non statutory organisations in lobbying and campaigning with presentations from Karol Balfe. Amnesty International (Ireland) discussed "Advocacy for Mental Health Services in Ireland" and Nicole Matthews, Alzheimer Society of Ireland discussed "Campaigning effectively for Alzheimers Disease".

Two NAI member organisation service users gave an account of what their support organisation means to them. Mags Rogers, Development Manager, NAI, summarised key learning points for support organisations.

For more information on the conference see <http://www.thinkingahead.ie/blog-articles/137-nai-conference-warmly-received>

HDAI hosted an information stand at the conference.

## HD Research

Professor Robert Lahue was interviewed on RTE's Morning Ireland, (22nd Feb 2012) regarding his research into HD. There were also features in The Irish Times 22/2/2012 and The Irish Times Health Plus (28/2/2012). Professor Lahue has kindly provided a description of his research below.

### Lahue Lab Research Description

**How can we slow down the progression of Huntington's disease?**

*That is the central question being addressed in the research lab of Prof Robert Lahue, Centre for Chromosome Biology at National University of Ireland, Galway.*

Huntington's disease is caused by inheritance of a defective copy of the HD gene. During a patient's lifetime, the HD defect actually worsens in the brain, which is thought to accelerate how fast the disease progresses. More genetic mutations at the HD gene result in faster decline of the patient, like a runaway train. Prof Lahue's research group seeks to slow down the runaway train by blocking key target enzymes that make the HD defect worse. These target enzymes are like the fireman in the old steam-engine trains; hindering the fireman slows down the engine.



Professor Robert Lahue (front left) with members of his research group

The NUI Galway group recently found a previously unknown target enzyme called HDAC3, or histone deacetylase complex 3. Slowing down HDAC3 in laboratory cells hindered the type of mutation seen in HD. Additional targets are being sought to broaden the possible range of approaches that are feasible by this strategy.

This research is at an early stage, and the findings need to be carefully evaluated by other research labs and in pre-clinical settings before any potential therapy is possible.

The research in Prof Lahue's lab is supported by Science Foundation Ireland, Health Research Board, Irish Research Council on Science, Engineering and Technology, and NUI Galway.

## Rare Disease Developments

The Minister for Health established a National Steering Group in 2011 to develop a five year National Plan for Rare Diseases. The group consists of representatives from the Department of Health including Dr. John Devlin, Deputy Chief Medical Officer, representatives from the Health Service Executive, the Health Information and Quality Authority, the Irish Medicines Board, the Institute of Public Health in Ireland, the Health Research Board, the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI), The Genetic and Rare Disorders Organisation (GRDO) & the Medical Research Charities Group (MRCG).

A Rare Diseases Taskforce has been established by MRCG, IPPOSI and GRDO with a number of patient organisations including HDAI to ensure that the needs of Rare Diseases stakeholders are represented in the National Plan.

*"The key principals governing the plan will be those of patient centeredness, quality, care and equity of access to treatment. It is recognised that the impact of a rare disease goes beyond the symptoms experienced by the person affected and involves the whole family, healthcare professionals and the broader health system."*

Dr. John Devlin, Deputy Chief Medical Officer Department of Health.

### Survey on the Experiences of Those Affected by a Rare Condition

GRDO released interim results from a recent survey they conducted on the experiences of those affected by a Rare Condition. Huntington's Disease is a Rare condition as it affects fewer than 1 in 10,000 people. Common issues include delay in diagnosis, delays in referrals to specialists, lack of knowledge among health and social care professionals etc. The survey results are being used to support the National Rare Diseases Taskforce in making submissions to inform the steering group in developing a National Plan for Rare Diseases. HDAI is a member of the Taskforce.

Of the 116 responses to the survey to date, one quarter (25.9%) are directly from patients who have a rare disease. 75.9% of responses are from those who describe themselves as "caring for someone with a rare disease". 15 respondents also describe themselves as family members or "at high genetic risk of developing a rare disease."

**When given choices about changes in the health system that would make a great difference to them responses included:**

**82%** "The establishment of a National Centre for Rare Diseases in Ireland"

**73%** "More information about my condition"

**67%** "Easier / quicker access to financial support and benefits"

**61%** "Shorter waiting time for referral"

**55%** "Shorter waiting time for diagnosis"

62.5% of respondents considered that patient support groups provide an "essential" service in giving information and support to those affected by rare disease, and a further 31.3% consider the service they provide either "very important" or "important".

## Fundraising

### Dublin Women's Mini Marathon

Get fit and have fun! The 2012 Dublin Women's Mini Marathon (the biggest all-women's event of its kind in the world) takes place on Bank Holiday Monday 4th June 2012. If you would like to participate and raise funds for Huntington's Disease you should:

- Register online at [www.florawomensminimarathon.ie](http://www.florawomensminimarathon.ie)
- Contact HDAI for a teshirt and sponsorship card
- Find the link on our website and create an online sponsorship page at [www.mycharity.ie](http://www.mycharity.ie)

### Tuam Charity Dance

Ann Hannon is very generously organising another Charity Tea Dance in Tuam on Sunday 29th April. The Dance will take place in the Ard Ri Hotel, Tuam from 3-6pm. Music by Tommy O Flaherty and Celtic Swing. Tickets are €7.00 and are available at the door. Dancing is good for you!

### Thank You

#### Charity Dance for HDAI

We are extremely grateful to Rosemary Higgins and her family and friends, to Aine Kelly of the Gort Lions Club and all the Lions Club members and HDAI members and friends who supported the Tuam Charity Dance in aid of HDAI last November.



(L to R): Back: Joe and Paddy. Front: Kathleen, Ann, Tara, Rosemary and Margaret

The Charity Dance raised a marvellous €2,288 towards our work. Special thanks also to Della Dolan and friends for organising the event.

#### Line Dancing

Once again Thank You to Geraldine, Martin, Phil and all your line dancing friends in Wicklow for your amazing support. Geraldine has lodged a whopping €3,385 to HDAI throughout 2011! We have also received €240 in February. Your continuous and dedicated commitment is very much appreciated.

### Liffey Descent

Sincere thanks to John Daly for participating in yet another Liffey Descent on behalf of HDAI in which he raised an excellent €600 for HDAI. Thanks John and thanks to all your family and friends for your continuous support.

### Gaelscoil Cholmcille

Ba mhaith linn buíochas mor a ghabháil do Scoil Cholmcille as ucht an síntiús flaithiúil €275 a thug siad dúinn le deanai. Míle, míle buíochas díbh go léir í scoil Colmcille

Thank you to the teachers, students and parents for your very kind support.

### In Memory of Paul

A big Thank You to Graham (left) and Jonathan Kavanagh who raised an excellent €428 by participating in the "Hell and Back 10k Challenge" in memory of their friend Paul Bowler.



*"We decided to do the run because a good friend of ours Paul Bowler died of the disease back in December and we just thought that as a young lad away with the scouts he could make all of us smile by just being there. We thought we would do something to remember him by and also to try bring another smile to someone's face for him."*

### Health Centre Raffle

A huge thanks to Aisling, Ann and friends at the Marino Health Centre for their organisation of a charity raffle which raised a fantastic €140 for HDAI.

### Yoga Classes



A special thanks to Helen Sherlock (left) who hosted a 6 week Yoga Class in Drumcondra in aid of HDAI and donated a marvelous €402 from the proceeds.

### HDAI Christmas Cards

Thanks to all who supported our HDAI Christmas cards. A special thanks to Bernie, Elizabeth, Jachintha, Kevin and Mark for their support in selling cards.



### Limerick Mini Marathon

A huge thanks to Mary (left) who participated in the Limerick Mini Marathon last Autumn and raised a fantastic €300 for HDAI.

### NUIG Coffee Morning

We are very grateful to Claire Concannon (below right - A member of Prof. Lahue's research team) for kindly organising a Charity Coffee Morning in Galway University and raising an excellent €415 for HDAI. Thanks also to Lisa Mullee and Louise Frizzel for their support.



We also appreciate your efforts in helping to raise awareness.

### Donations

Thanks to Marie Curley for her very generous donation of €300 towards therapy days for people with Huntington's Disease.

Thanks to Finnola and Martina for their monthly Direct Debits. Thanks also to Raymond & Nuala and Dessie.

### Sisters of Mercy

A sincere thanks to the Sisters of Mercy Ballinasloe and in particular to Sister Walsh and members of the Leadership Team for their very generous contribution of €1000 to HDAI.

### Bank of Ireland

Thanks to Michelle Reilly and the PB Property Syndicate, Bank of Ireland for their very generous donation of €644.15 to HDAI.

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



### Mobile Recycling C&C Cellular

Thanks to Della Dolan for her old mobiles collection. Thanks also to Joan who regularly supplies us with a box of old mobile phones. If you have any old mobiles you no longer need we would be happy to receive them.

## Seanad Debate on Rare Diseases

At a Seanad Debate on Rare Diseases on March 7th, Minister for Health, Dr. James Reilly T.D., announced his intention to develop a Clinical Care Programme for Rare Diseases. He said,

*"An integral and essential part of an effective policy framework will be the development of a dedicated HSE clinical programme.*

*I understand that a proposal has been submitted to the HSE's national director of clinical strategy and programmes to establish a national clinical programme for rare diseases. The proposal encompasses the development of a programme to facilitate timely access to centres of expertise nationally and internationally and to provide up-to-date information on new treatments and management options and on ongoing clinical trials for all patients affected with rare diseases in this country.*

*It also aims to develop a model of care designed to improve the patient experience, provide safe quality care, improve communication, education and interfaces with community partners and be cost efficient".*

For the full transcript see: <http://debates.oireachtas.ie/seanad/2012/03/07/00008.asp>

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



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## Rare Disease Day

### Joint Oireachtas Committee Meeting

HDAI were among a number of GRDO members who attended a Joint Oireachtas Committee on Health in Leinster House on Rare Disease Day. GRDO Chairperson Avril Daly and representatives from other voluntary groups highlighted common issues of concern including the lack of resources for genetic services in Ireland, the need for a National Centre for Rare Diseases, automatic access to medical cards for progressive conditions and the need for greater awareness of Rare Disease issues among health and social care professionals.

### Awareness for Rare Diseases

GRDO collaborated with European Rare Disease Alliance, Eurordis, to produce a short awareness-raising video for Rare Disease Day 2012. The video is available in 11 different languages and features six people from Ireland, each with a different rare condition.

GRDO also produced a series of postcards based on the video, which were sent to media, and Dáil and Seanad representatives.

### Carers Day

HDAI hosted a successful Carers Day for HD family carers on March 2nd in Cork. This event gave carers the opportunity to discuss the difficulties they face on a daily basis and share coping mechanisms and positive approaches to looking after their own needs.



*Carers taking a break at the Carers Day in Cork*

Carers had the opportunity to de-stress through a Stress Management & Relaxation Workshop and a Drumming Workshop. Carers could also avail of massage and reflexology sessions. HDAI received positive feedback from the day including the following quotes.

*"I had a great time and really enjoyed the drumming ... I feel that it's the getting together, in general, that's very good".*

*"The drumming was great fun .... There were lots of smiling faces to be seen throughout the session and I have my drumming tape to remind me of the experience! Great to have a day for the Carers, I believe it enriches the lives of the carers and their loved ones"*

## Information Session for Professional Carers

HDAI will host an Information session for professional carers and nursing staff on Tuesday June 12th 2012.

John Eden, CEO, Scottish Huntington's association, will be a guest speaker. If you know of nursing or home care staff who would be interested in attending this event please let us know.

## Acknowledge Kindness

I would like to send a special Thanks to Noreen for all her kindness. She has been a great support recently while I am struggling with ill health. Her kind offers of dinners and her supportive chats mean a lot to me. A friend in need is a friend indeed!

I want to acknowledge my gratitude to Noreen for her generosity, friendship and support - Denis



I would like to nominate the staff at LisBrí Unit in Cherry Orchard Hospital to receive a bunch of flowers. The staff

go to extraordinary lengths to make sure that Donal is well looked after, physically, mentally and emotionally. Nothing is too much trouble. Not only do they care for Donal, they also make sure that we (his family) are included and spoiled with a cup of tea and a biscuit. We cannot praise or thank them enough for everything they do - Anne, Aisling, Gráinne and Seán

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



## HDAI 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 HDAI office on 1800393939 for more information.

**DUBLIN**

May 12th

**CORK**

July 7th

**MAYO - Castlebar:**

Carers Workshop at Cuisle, June 9th

**LIMERICK**

April 14th