HDAI BNA 2019 Event

The British Neuroscience Association - in partnership with Neuroscience Ireland (NI) and the British Society for Neuroendocrinology (BSN) - is hosting the international Festival of Neuroscience 2019 in Dublin in April: http://meetings.bna.org.uk/bna2019/

As part of the public festival of events, the Huntington’s Disease Association of Ireland will host an event on the evening of Saturday April 13th: Huntington’s Disease: Hope For A New Decade, with guest speakers Professor Bernhard Landwehrmeyer Ulm University Hospital, Germany and Professor Orla Hardiman, Trinity College Dublin. This is a free event but registration is essential. Numbers are limited - contact info@huntingtons.ie

Beaumont Research Study

Prof. Niall Pender and his HD research team in Beaumont Hospital are currently beginning a new research study to investigate the cognitive and behavioural changes that take place in Huntington’s Disease over time. HDAI have committed €20,000 over two years to contribute to this valuable study in order to highlight the burden associated with management of cognitive and behavioural changes in patients and to recommend interventions to reduce this burden.

Individuals who are part of a HD family are eligible to participate in this study. Like Enroll-HD, if you have a diagnosis of HD, are at risk of the HD gene, have tested negative for the HD gene, or are a spouse of someone with HD you are welcome to take part. Participants will be asked to complete thinking and memory tests and some psychological questionnaires for research purposes. Please let us know if you are interested in contributing to this research by emailing us at info@huntingtons.ie or contacting Michaela Hammond at michaelahammond@beaumont.ie

Enroll-HD

The Enroll-HD study at Beaumont now has 50 participants enrolled. We know there is a long waiting list but the team there are working hard to see everyone as soon as possible. Each participant enrolled in the study will have an annual appointment.

GENERATION HD1 Study

The HD Clinical trial GENERATION HD1 enrolled its first participants in the USA and Canada in January. This trial will investigate the efficacy and safety of the huntingtin lowering drug RG6042, formerly known as IONIS-HTTRx. This is a Phase III study, meaning that it is designed to determine whether RG6042 is safe and effective. We are all hoping that this drug will “slow down” the progression of the disease and have a positive effect on symptoms.

HD Cope

The Huntington’s Disease Coalition for Patient Engagement (HD-COPE) held a meeting in New York in February. Anne Lennon Bird attended as Ireland’s representative. The group had an opportunity to meet with representatives from Roche, Wave Life Sciences and PTC Therapeutics. Dr Ed Wild gave a talk on bio markers. The group had an opportunity to visit the Huntington’s Disease Society of America and CHDI offices in New York.

(Continued on page 2)
National Brain Awareness Week

To mark Brain Awareness Week 11th - 17th March, the Neurological Alliance of Ireland (NAI) have launched their latest research on living with neurological condition in Ireland. The findings from their survey, based on responses from over 600 individuals with neurological conditions and family carers, highlight a “cascade of challenges” from long waiting times to get a diagnosis, struggling to access ongoing care and dealing with the impact of their condition on work, to financial wellbeing and family relationships.

Less than half of respondents were in receipt of home care support. Of these, almost a third of respondents (27%) reported that they had access to home care but that it was not appropriate to the needs of the person they care for. The majority of respondents (64%) reported that the family income had fallen significantly since the onset of their family member’s neurological condition.

For further information see the full survey report on the NAI website at https://bit.ly/2H2QYjP

Neurology Campaign

The Invest in Neurology campaign met with Michael Harty TD on December 13th in Leinster House. Representatives from the NAI, HDAI and Epilepsy Ireland briefed Deputy Harty on growing waiting lists for neurology and the urgent need for investment in neurology services.

National Neurorehabilitation Strategy

A long awaited implementation plan for the National Neurorehabilitation Strategy was published in February. The three-year framework outlines a ten-step plan to develop neurorehabilitation services at hospital and community level across the country. Local implementation teams will be responsible for developing community neurorehabilitation services within each Community Health Organisation (CHO).

The NAI established the “We Need Our Heads Examined” campaign in 2016 along with its member organisations (including HDAI), to call for action on neurorehabilitation. While welcoming the publication, NAI warn that unless the plan is accompanied by dedicated investment it will do nothing to improve access to neurorehabilitation for people in need of services.

Rare Disease Day 2019

Bridging health & social care

Rare Disease Day is held on the last day of February to raise awareness for rare diseases and improve access to treatment, services and supports for individuals with rare diseases and their families.

‘Bridging health and social care’ was the theme for Rare Disease Day 2019. An all-Ireland conference was held in Dublin on February 28th to highlight the importance of joined-up hospital, primary care and community services for people with rare diseases.

For most people living with a rare disease, as well as their family members and carers, the reality of daily life can be challenging. A lack of coordination across services means having to repeat the same information over and over again. Communication between different services needs to improve so that services are delivered efficiently to meet patients’ best interests.
**St. Andrew’s Christmas Draw**

Thanks to Ann Maher and her colleagues at St Andrew’s Resource centre for supporting a Christmas draw for HDAI raising €215. Special thanks to Paddy McGauley who generously donated a hamper for the draw.

**Celbridge Craft Fair**

Maire and Ide Cussen hosted another very successful ‘Handknits for HD’ stall at the Celbridge Craft Fair at the end of last year. Proceeds from the fair and the sale of their beautiful hand knits and very cheerful snowmen raised an excellent €985 for HDAI. We are very grateful to Maire and Ide for their great talent and continuous dedication.

**Jack’s 282 Miles for HD**

Jack Jones has committed to a huge challenge of running, cycling, kayaking and swimming to raise funds for HDAI in support of people affected by Huntington’s disease.

“Having seen the affects of Huntington’s on individuals and families, I wanted to raise money to aid in the awareness, research, treatment and care of the disease. Fund raising has been going well and I have now hit my goal of £1,000, I hope to double the initial target by the completion of the events later this year. People have been extremely generous. I am 3 events down with my first biggie in Dublin on the 23rd of this month, Gaelforce Dublin, which is a 49km event that crosses the divide between city and country, it will involve trail and mountain running, cycling and a 1.5km kayak”.

Jack plans to participate in 11 events in total during 2019. So far he has raised a phenomenal £1,286. You can track Jack’s progress and support him at: https://www.justgiving.com/fundraising/jack-jones30

**Donations**

Recently received donations include:
- Martina, Finnola and Zil's monthly Direct Debit donations.
- Ger & Jacyntha
- Donation received in memory of Thomas Downes €561.12
- Leinster Cleaning Services €1,250
- The Cremin family €715
- Pearse College Porter’s Cabin €35.65

**Thank you**

**Toonagh Walk**

The 2019 Annual Charity Walk in Toonagh Co. Clare was held in aid of HD. Denise Whelan and friends organised a very successful walk and raffle on Sunday January 13th. There was excellent support from the Toonagh community with over 350 people registered to walk. Local papers featuring photos and articles included The Clare Echo, The Clare Champion and The Clare People.

The walk has helped to raise important awareness in addition to €8,250 to assist HDAI in providing services and supports to people impacted. Sincere thanks to all who participated, donated, raised sponsorship and volunteered on the day.

**Toonagh Hunt**

A big thank you to all the riders (and horses) who took part in the Toonagh Charity Hunt, Co Clare which was in aid of HD this year. The event raised a marvellous €2,000. Many thanks to all involved.

**Christmas Cards**

Thanks again to all who sold HDAI Christmas Cards. Proceeds received since December included €92 from Life Pharmacy Santry and €272 from Ann Hannon and friends including Euro Saver, Claremorris and Ann Long Hennessy at Centra, Ballindine.

**Upcoming Events 1**

**Fairyhouse Racecourse HD Featured Race**

Congratulations to Rachel Blackmore (above) for her recent success at Cheltenham. Our fundraising and awareness event, in collaboration with Fairyhouse Racecourse, takes place on **Sunday 7th April, 2019**. There will be a HD featured race on the day. We are offering a table for ten people which will include:
- Admission Tickets and a Race card per guest
- 4 Course Meal
- Pre-race celebrity tipster to guide you on the best bets
- Designated area reserved for the day with direct access to the Stand

Tables are selling very well thanks to the great efforts of Ide Cussen and Bernhard Caldwell. There are also some individual seats available at tables so please get in touch before March 29th if you are interested in coming along.

Thanks to Leinster Cleaning Services and other generous donors, we have received some great raffle prizes which include vouchers from the Kilronan Castle Hotel & Spa and the Rathfarnham Golf Club.

If you know any racing fans or if you have contacts in companies who may like to sponsor a table or a raffle prize please let us know.

**Dublin’s VHI Women’s Women’s Mini Marathon**

This event takes place on **Sunday 2nd June at 2pm**.

Entries are now open [https://www.vhiwomensminimarathon.ie/](https://www.vhiwomensminimarathon.ie/)

If you would like to participate on behalf of HDAI we can provide t-shirts and sponsorship forms.
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.

Acknowledged Kindness
Helena, Activities Coordinator at Fairview Community Unit pictured with flowers received in thanks for her kindness to Bernie, Michael, Kevin and Oisin.

Thank You Máire
As a Celbridge HD family member, I want to acknowledge the wonderful work of Máire Cussen in raising awareness. So impressed to see her fabulous ‘Handknits for HD’ on sale in Celbridge and her St. Bridget’s Cloak in the St. Patrick’s Day Parade. A big Thank You from Anne and family xx.

Joe Doran’s HD Awareness Walk at Lough Key - Saturday 13th July
Joe’s Annual Walk takes place at Lough Key Forest Park (between Carrick on Shannon and Boyle) on July 13th this year. Thanks to Louise and the team at Lough Key for their kind support in facilitating our annual walk in a fabulous location. Joe and his family have contributed hugely to the success of this annual event which raised a remarkable €11,000 for HDAI in 2018. We also appreciate the participation of many HD family members and friends who support the walk every year.

Sunrise up Croagh Patrick - Saturday 29th June
The 5th annual #SunriseupCroaghPatrick event takes place on 29th June 2019. This is an annual get-together of friends who gather to climb Croagh Patrick or walk beneath it to raise funds for charities supporting people affected by Huntington’s Disease, Parkinson’s Disease and Motor Neuron Disease. The event is organised by a dedicated team of volunteers including John Kelly and friends. Last year our amazing team of walkers and climbers raised almost €9,000 for HDAI.

A video with highlights from last year’s event is now online at www.sunriseupcroaghpatrick.com and on YouTube: https://youtu.be/ UWrRtbTSh2M

You can register for this year’s event at: https://www.eventbrite.ie/e/sunriseupcroaghpatrick-registration-58268282000 or contact us at info@huntingtons.ie and see: https://www.sunriseupcroaghpatrick.com/

The Sunrise Up Croagh Patrick team are running a bag pack collection in Dunnes Stores Cornelscourt on Friday May 3rd, 10.00am to 4.00pm. TY girls from Holy Child School, Killiney, will very kindly help by manning the checkouts. Proceeds will be divided between the 3 charities.

HD Awareness Week
HDAI’s 2019 Awareness Week takes place from 13th to 17th May. #LightItUp4HD is one of our annual events where we join with other HD organisations around the world by asking iconic buildings to light up in purple to raise awareness for HD. To date the following buildings and organisations have agreed to support us: The Mansion House (13th May), Dublin City Council Civic Offices, The Rock of Cashel (15th May) and Carmichael Centre, Dublin.

Upcoming Events 2

HDAI Support Meetings
Support meetings are held regionally on a Saturday morning from 11.00am to 1.00pm. Dates subject to change - contact the HDAI office on 1800 393939 for confirmation and location.

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<tr>
<th>LOCATION</th>
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<th>TIME</th>
<th>LOCATIONS</th>
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<tbody>
<tr>
<td>DUBLIN</td>
<td>May 4th</td>
<td>11.00</td>
<td>Caragh Centre, Centre for the Elderly, St. Mary’s Hospital, St. Joseph’s Hospital, Mater Misericordiae Hospital</td>
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<tr>
<td>CORK</td>
<td>Mar. 23rd</td>
<td>11.00</td>
<td>St. Vincent’s Hospital, St. John’s Hospital, St. James’s Hospital, St. Olaf’s Hospital</td>
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<tr>
<td>WEST</td>
<td>Cuisle June 8th (Carers Meeting)</td>
<td>11.00</td>
<td>St. Mungo’s Hospital, St. Mary’s Hospital, St. Joseph’s Hospital, St. Vincent’s Hospital</td>
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<td>LIMERICK</td>
<td>April 13th</td>
<td>11.00</td>
<td>St. John’s Hospital, St. Olaf’s Hospital, St. Mungo’s Hospital, St. Mary’s Hospital</td>
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