



HDNL 2019 - Issue No 78, Q3 19

CHECK OUT OUR WEB SITE

www.huntingtons.ie

GENETICS

For information on Genetic testing, contact the Genetics Centre - Tel: **01 409 6902** and www.genetics.ie

SUPPORT MEETINGS

See dates on page 4

ENROLL HD

You can express your interest in participating by emailing enrollhd@beaumont.ie

Enroll-HD A worldwide observational study for Huntington's disease families

NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

Beaumont HD Research Study

Prof. Niall Pender and his HD research team in Beaumont Hospital have begun a new research study to investigate the cognitive and behavioural changes that take place in Huntington's Disease over time. HDAI have contributed €20,000 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 Donal Campbell at Beaumont: donalcampbell@beaumont.ie or 01 809 2223.

Beginning in the New Year, the team in Beaumont will begin recruiting for a new study evaluating the impact of a group designed to support caregivers of people with HD. This new programme, named 'Building Better Caregivers', has already been piloted with caregivers of patients with Motor Neuron Disease, and will be trialled with caregivers of people with HD in the coming months.

The study will be open to participation from friends, family members, partners, etc. who routinely care for someone with HD. To express interest in this study, or if you have any questions, please email donalcampbell@beaumont.ie

Enroll-HD: The Enroll-HD study at Beaumont now has 60 participants enrolled. Dr Pender and his team are grateful to the HD community for their participation and are committed to including interested family members as soon as possible.

European Huntington's Association Conference

The European Huntington's Association Conference 'Stronger together - Better together' took place in Bucharest, Romania from 4th - 6th October. Anne O'Shea Clarke, Anne Lennon Bird and Patricia attended as HDAI representatives and also took part in parallel meetings for HD Cope and Care HD.

The Conference commenced with a welcome address by President Astri Arnesen and EHA Board member Svein Olaf Olsen followed by an overview by Ramona Moldovan of HD Services in Romania. Presentations from the conference included:



Taking Care of HD Patients: Anne Lennon Bird together with a mother and daughter from Malta discussed the type of multi-disciplinary care and support required for a person living with HD.

How to Contribute to Research: Clinical research is an essential step in developing effective therapies for HD therefore the participation of family members is crucial. **Dina de Sousa** shared her personal experience of being involved in a HD study and **Prof. Bernhard Landwehrmeyer** discussed the importance of family member participation from a researcher's perspective.

Talking About HD in The Family: Paul de Sousa and Johan Oreel discuss the challenge of talking openly within their families about HD: Paul discussed raising children, how and when to discuss HD, other family members avoiding the subject, accepting differences, sharing information outside the family etc. Johan Oreel spoke about how attending a Huntington's Disease Youth Organisation (HDYO) camp totally changed his approach and helped him open up to family and friends.

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Christmas Cards 2019

HDAI Charity Christmas Cards are available to order this year. A pack of 15 cards still costs €8.00. Let us know if you have a local shop or Post Office willing to sell HDAI cards.

To order, email: info@huntingtons.ie

Coping with HD: Moderators facilitated separate group discussions for family members (gene positive, symptomatic, at risk / gene negative, partners) and for professionals working with HD. Presentations from HD professionals covered tips to support open discussions within families, the importance of oral care, the benefit of music therapy and sensory stimulation for HD patients, the need for professionals to listen to people living with HD and family carers and for professional carers to seek and share information on the person's interests and preferences.

Rhona Macleod, Genetic Counsellor and **Mariangels Ferrer**, Clinical Psychologist discussed supporting family members following predictive testing. A favourable predictive test result can cause survivor guilt and family tension. A short film showed a person with a negative test result discussing tensions between herself and her sister who received a positive gene test. With supportive counselling they were able to speak openly and acknowledge they both had feelings of guilt for each other. Having open discussion helped them to see that the love they had for each other was the most important thing and that HD wasn't the 'be all and end all'.



Music therapy has the potential to improve communication, reduce behavioural problems, help with relaxation and delay speech

and swallowing problems for people with neuro degenerative conditions. Vocal exercises can help to exercise speech and swallowing muscles. Music therapists **Monique van Bruggen** and **Sunniva Ulstein Kayser** (above), shared their experience of working with people with HD and suggested three basic tips to use music to improve quality of life for a person with HD: Know the person's musical taste; choose music to suit a person's mood (calm music initially to improve mood); keep it simple and encourage participation (sing along / move to music).

Research studies carried out with other neurological diseases suggest that using song and vocal training can help to treat swallowing difficulties (Kim 2010, 2015, Jomori 2010, Stegemoller et al 2017). When we sing we activate some of the same muscles used for swallowing. In addition music stimulates the brain's cerebral cortex (involved in the coordination of eating and swallowing) (Stegemoller 2017, Vega 2019 Rauschecker 2006)



Annette Carlsson is a dental hygienist working with people with rare diseases in Sweden. She discussed the importance of good oral care for a person living with HD, particularly in the early stages of the condition when preventative action can reduce future problems. It is helpful to establish a good relationship with the dentist as early as possible. The increased calorie intake recommended for HD can increase the likelihood of tooth decay, as can certain medications. Controlling the tongue to clean the teeth and mouth after eating becomes more difficult. Mouth sores, blisters and dry mouth can cause pain and difficulty eating while tooth decay and swallowing difficulties can lead to injurious bacteria reaching the lungs. The use of high fluoride toothpaste is important. Aids such as a mouth angle expander helps to keep the mouth open while brushing the teeth. Saliva substitutes or oral wipes can reduce the unpleasant side effects of dry mouth.

Non-drug interventional studies:

Members of three international HD non-drug studies gave an overview of their projects:

HEALTH-RND: This project aims to use HD to develop a multilingual e-health platform using an innovative approach to develop, apply, test and evaluate an e-health platform to improve care and support caregivers - regardless of where patients live or the distance to the nearest specialist centre. Project participants include professionals from Huntington centres and research institutions in Germany, the Czech Republic, the Netherlands, the United Kingdom, Ireland (Bloomfield Health Services) and Italy. The project will actively collaborate with the EHA to include patient and family member involvement as research partners in all phases of the project. The EHA held a patient and family meeting with representatives from the countries involved in Amsterdam in September. Anne Lennon Bird attended from Ireland.

DOMINO-HD is part of the Joint Programme for Neurodegenerative Disease (JPND) research awards. The DOMINO-HD study (Multi-Domain Lifestyle Targets for Improving ProgNOsis) is exploring how digital technologies, such as wearable fitness trackers, can be used to support

people with HD. The researchers will look at how sleep, nutrition and physical activity impact the disease so as to develop new ways to support people to manage these fundamental aspects of their lives. **Monica Busse** and her team at Cardiff University are leading the project and participants include HD clinicians and researchers from Germany, Switzerland, Spain, Ireland (Insight Centre for Data Analytics, UCD) and Poland.

CareHD is a Horizon 2020 RISE (Research and Innovation Staff Exchange) funded project investigating how the use of Connected Health technologies may support and improve the lives of people living with HD. Connected health includes wireless, digital, electronic, mobile and tele health devices and services designed around the patient's needs and used in health management. The CareHD project is led by UCD (Dublin) and will include collaboration from academic and health researchers from EHDN, University of ULM (Germany), UCL (London), Beaumont Hospital, Dublin, Maynooth and Reading (UK) universities with input from the Scottish Huntington's Association and HDAl. Further info at: <http://www.carehd.eu/>

If you are interested in participating in this study please let us know.

Therapy Updates: Four companies provided information on their HD research: Roche Pharmaceuticals discussed their current GENERATION HD1 gene lowering trial. Wave Life Sciences spoke about their two gene lowering trials PRECISION HD1 and HD2. UniQure will assess the safety and ability of AMT-130, a gene therapy to lower the problematic huntingtin protein using a 'single-shot' virus delivery system and Novartis are now in the process of developing a clinical trial to study a huntingtin lowering drug.

Active HD: The conference also included organised activity sessions to promote the benefit of exercise for people living with HD and their families. HD walks and a pool session was led by **Rudy Vera**, a HD family member and physical education expert from Spain. There was also a soccer tournament for energetic attendees! Congratulations to Astri and the EHA Board for a great conference. For Presentations see: <http://eurohuntington.org>

Media and Awareness

Futureproof with Jonathan McCrea



Lauren Byrne, HD Advocate and Researcher at HD Centre, University College London was interviewed on Jonathan McCrea's *Futureproof*, Newstalk radio show in August. Lauren from Northern

Ireland, discussed the impact of HD on her family and gave an overview of research developments. Lauren also discussed the predictive testing process and her personal advocacy work to promote PGD so that HD is not passed on to future generations. The interview is available at www.newstalk.com (Futureproof Extra) and via HDAl's website.

The Independent - Woman with brain condition left in 'unsuitable' ward for 10 months

Eilish O'Regan of the Independent (www.independent.ie - 30/09/19) wrote about the frustration endured by Triona and her family who have been waiting for over 10 months for funding so that Triona can access appropriate services. Unfortunately there are many other people living with HD who are waiting on funding to receive the services they need. If you have a loved one waiting on services perhaps you can consider speaking to your local political representative to help highlight the need for specialist services.

RTE Guide

Thank you to **Dr. Eddie Murphy** who featured an article on 'The Psychological Impact of Huntington's Disease' in the October 12 -18 edition of The RTE Guide.



The Huntington's Disease Youth Organisation (HDYO) will hold their first International Young Adults Conference for 18-35 year olds impacted by Huntington's Disease, in Glasgow, Scotland from 9th - 11th May 2020. HDYO have planned three days of educational and support sessions with internationally renowned HD experts contributing. There will also be an emphasis on FUN with lots of entertainment and activities scheduled. See <http://hdyocongress.org/> for further information. If you wish to attend but cost is prohibitive HDAl may be able to make a contribution. Email us on info@huntingtons.ie

Thank You

Sligo Music Night and Coffee Morning

A big Thank You to Sue Mahon, her son Dean (DJ) and all her family and friends who supported the HD 80's themed night at The Blue Lagoon in Sligo in August. Mayor Gino O'Boyle kindly hosted a coffee morning at the Mayor's parlour, Sligo Borough Council in support of Sue and Beccy. They have raised a marvellous €3,795 for HDAl.

Jack's 282 Miles

Jack Jones has completed his remarkable year long series of events to raise awareness and funds (over €1,500) for Huntington's Disease. Thanks to Jack and to all who supported and joined him including Miriam, Cian, Emily and Lizzie.

Marathon Support



We continued to receive funds from the Dublin Women's Mini Marathon. Well done to Josie Leavy (left) €620 and Aisling €563.85.



Viking Quarter Marathon:

Thanks to Caroline Lamb (left) who once again took part to raise €202 for HDAl. **Achill 10km Run:** HDAl are very grateful to Eoin McCarney (left) who very generously ran the Achill 10km



run on July 6th and raised €620 for HDAl.

Scoil Naomh Brid

Thanks to 6th class students of Scoil Naomh Brid, Celbridge for very generously donating €600 from their annual charity jumble sale. The school's support was in recognition of Maire Cussen's beautiful hand crocheted St. Bridget's Cloak which was carried by the students in the Celbridge St Patrick's Day



Parade. Thanks to Maire for her phenomenal support and to the teachers and school Principal Delia O'Donnell.

Recently Received

Direct Debit Donations: Sincere thanks Martina, Finnola and Zil.

Horticulture Help: Dawn Little very generously sold plants in Co. Cork earlier in the summer to raise €300 for HDAl. Thank you Dawn!

PWC Ireland: HDAl was kindly nominated as one of the charity recipients for PWC Ireland's 2019 Calendar and received a wonderful €1,500.

Mount Sackville Parent's Association: Thank you to Shivaun and the Mount Sackville Secondary School Parent's Association for their very generous €200 donation.

Mick's Coin Collection: Thank you to Mick Scanlon who has once again donated his coin collection (€150) to HDAl

Leinster Cleaning: Thanks to Michael Moore at Leinster Cleaning for his remarkable support throughout the year including a recent €250 donation.

Wedding Favours: Congratulations and sincere thanks to Noreen and Eamon for their very kind gift to HDAl.

Thanks also to online donors including: Aoidin, Jacyntha & Ger, Robert Hayes and donors who wish to remain anonymous.

Congratulations

Congratulations to David receiving an award for Walking Football Player of the Week.



In Memory



Gary Costelloe died on 17th July. He was a much loved son, brother, uncle and friend. Our thoughts are with his loved ones, in particular his devoted mother Rosaleen.



Winnie Murray died on 30th June having lived with HD for many years. Condolences to her children, grandchildren and great grandchildren. Thank you to Winnie's family and friends who donated €205 to HDAI in her memory.

UPCOMING EVENTS

Celbridge Craft Fair



Íde and Máire will once again sell their splendid 'Handknits for HD' at the Celbridge Craft Fair, The Mill on **23rd and 24th November 2019**. Their highly sought after HD Snowmen will also be on sale.

Thank You

Joe Doran's HD Awareness Walk - Lough Key



Congratulations to Joe, Pauline, Anne, Joseph and their extended family and friends for another successful awareness walk in Lough

Key Forest & Activity Park, Co Roscommon in July, 2019. It was great to have family members and friends from the HD community supporting the walk with people travelling from Longford, Limerick, Leitrim, Mayo, Galway, Roscommon, Sligo, Tipperary, Kilkenny and Dublin. We had a very enjoyable Irish music performance from Elizabeth Earley and friends at registration. Thanks also to Louise and the team at Lough Key for all their assistance. The walk has raised an amazing €9,196.64.



Sunrise Up Croagh Patrick



The #Sunriseupcroaghpatrick (SUCP) 2019 event in Westport was another great success thanks to the dedicated SUCP team, volunteers and participants. Over 100 people climbed or walked to support Huntington's Disease, Motor Neuron Disease and Parkinson's Disease.

30 people attended the Dinner event at the Westport Plaza Hotel on the Saturday night. We appreciate all the HD family members and friends who came along or supported the event.

In all, over €17,000 was raised across the three charities. Transition Year girls at Holy Child School in Killiney held a bag pack at Dunnes Stores Cornels Court for SUCP. The event has raised over €7,600 for Huntington's disease. SUCP will take place on **27th June 2020**. For information see <https://www.sunriseupcroaghpatrick.com/>



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



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HDAI Support Meetings



All those impacted by HD are welcome to join us at our Support Meetings in Cork, Dublin, Roscommon and Limerick from 11am - 1pm.

DUBLIN

Nov. 2nd
Feb. 8th 2020

CORK

Nov. 30th

ROSCOMMON

Dec. 7th

LIMERICK

Jan. 11th 2020