



A Learning Event for Health and Social Care Professionals

Friday 27th September 2019

Armagh City Hotel

DRAFT PROGRAMME

- 10.00am** Registration and refreshments served
- 10.30am** Opening remarks from Sorcha McPhillips, Chief Executive HDANI
- 10.45am** *Prof. Hugh Rickards: Understanding & Responding to Challenging Behaviour in HD*
- 11.30am** *Dr Emma Yhnell: The Role of Brain Training in HD Management*
- 12.15am** Q&A
- 12.30pm** Lunch
- 1.30pm** *Prof. Monica Busse: Making the most of Physiotherapy in HD*
- 2.15pm** Interactive workshop on HD management led by HDANI with input from carers and professionals
- 4.00pm** Closing remarks, photos, certificates

This is a not for profit event with a fee of £30 which includes refreshments, lunch and materials.

The event is aimed at anyone currently studying or working in the field of health or social care with an interest in Huntington's Disease. No medical knowledge of the disease is required.

Tickets may be purchased via Eventbrite <https://tinyurl.com/hdani19>

If you have any questions about the conference or would like to register

email sorcha@hdani.org.uk or call/text 079 8284 3907

For further information on Huntington's Disease visit www.hdani.org.uk

Keynote Speakers

Professor Hugh Rickards

Hugh Rickards is a Consultant in Neuropsychiatry and an Honorary Professor of Neuropsychiatry at the University of Birmingham. He has led a HD service in the West Midlands for about 25 years. His research interests include the social interaction and understanding of people with HD, and clinical trials. He is also passionate to make sure that everyone who might benefit from any new disease modifying treatment has access to it. Hugh is a trustee of the UK Huntington's Disease Association.



Dr Emma Yhnell

Emma obtained a BSc degree in Biochemistry at Cardiff University before staying on to complete a PhD in the School of Biosciences exploring Huntington's disease in the laboratory. She then obtained an independent research fellowship funded by the Welsh Government through Health and Care Research Wales. Her work looks to translate her findings on cognitive training into the patient clinic to see if computerised brain training is feasible for people impacted by Huntington's disease.



Emma is experienced in public engagement, outreach and science communication. She has presented her work in Parliament and spoken at the Hay Festival, Soapbox Science and Pint of Science and she gave the Charles Darwin Award lecture at the 2018 British Science Festival.

Professor Monica Busse

Monica Busse is a chartered physiotherapist, trials methodologist and Director for Mind, Brain, Neuroscience Trials in the Centre for Trials Research (CTR) at Cardiff University. She established the Cardiff Huntington's Disease (HD) physiotherapy research group within the Cardiff HD Research and Management Clinic.



It is her longstanding view that people with HD should be able to access high quality, evidenced-based physiotherapy services (delivered by skilled clinicians) across the spectrum of the disease. Monica's group has worked closely with service users to develop appropriate physical interventions (such as Move to Exercise, ENGAGE-HD and PAT-HD) and her work has informed guidance for physiotherapy practitioners globally.

Monica is consortium lead for the multi-national DOMINO-HD consortium that has recently been funded through the JPND research programme and includes academic and clinical sites across Europe (Ulm, Germany; Burgos, Spain; Warsaw, Poland and Zurich, Switzerland). The

DOMINO-HD programme will investigate how physical activity, sleep and nutrition impacts the disease so as to develop new ways to support them to manage these fundamental aspects of their lives.

Monica is also co-principle investigator (with Lori Quinn) in an ongoing study, Physical Activity and Exercise Outcomes in Huntington's disease (PACE-HD, NCT03344601), that is currently underway in 6 sites across the US and Europe. This study includes both a longitudinal observational study and a within-cohort randomized controlled trial of a 12-month physical therapy and exercise intervention. The intervention incorporates the use of wearable physical activity monitors as both an outcome measure and for daily monitoring of activity levels throughout the trial. Importantly, this study is conducted alongside Enroll-HD, which will provide a basis for comparative analysis on disease progression measures whilst minimising participant burden. Results of this study are due in the summer of 2020.

About HDANI

HDANI works throughout Northern Ireland providing support, information, advice and social connections to those living with the impact of Huntington's Disease. We run regional support groups, provide telephone and face to face advice and support as well opportunities for families to connect through our events and befriending services.

We also work closely with medical professionals to advocate for the most effective care for our clients and lobby the Executive for improved and efficient services. We provide training and awareness raising events and keep our members informed of the latest research and medical advances in the quest for effective treatments and ultimately a cure.

The Association is dependent on a small but dedicated team of staff and volunteers who are committed to providing the best possible outcomes to our members. The Huntington's Disease Association Northern Ireland's vision is for those affected by HD to be empowered and supported to live as normal a life as possible.

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