

Huntington's Disease and other Neurodegenerative Disorders in Scotland New Research Summits to Climb March 2019 – Post Event Review

[NRS Genetics and Rare Disease Network](#), along with [NRS Neuroprogressive and Dementia Network](#), co-organised a research day on 28 March 2019 around inherited neurodegenerative conditions.

Titled '**Huntington's Disease and other Neurodegenerative Disorders in Scotland: New Research Summits to Climb**' it brought together Scottish Clinical Geneticists, Genetic Counsellors, Neurologists, Third Sector workers and Patient Representatives with leading national researchers.



Dr Berg (pictured right) with colleagues

Dr Ed Wild from University College London introduced the novel RNA based therapies that are being developed for a number of diseases, most **notably Spinal Muscular Atrophy and Huntington's disease**. Scotland has been very successful in opening two sites for the **Ionis-HTT study** (Aberdeen and Glasgow), the first phase 2/3 clinical trial of this approach in Huntington's disease.

Dr Stuart Ritchie, PI for both **PRECISION-HD** and **IONIS-HTT** gave a presentation in Glasgow on the current, best management of Huntington's disease in Scotland.

The **ENROLL-HD** programme is a leading exemplar for disease specific registers, having recruited close to 20,000 patients at risk of Huntington's disease worldwide. The programme has been instrumental in **developing an understanding of the disease and initiating clinical trials** and was discussed by Ms. Nicola Robertson on behalf of the Enroll-HD programme. Professor Darren Monckton from the University of Glasgow presented his work on **understanding the predictors of age of onset of Huntington's disease** that has been underpinned by Enroll-HD.

Professor Zosia Miedzybrodska, University of Aberdeen, presented work on the **frequency of Huntington's disease in the Scottish population**. Dr Suvankar Pal, University of Edinburgh, discussed his new research approach to **Motor Neurone Disease**, another research area that is active in Scotland.

Dr Oliver Quarrell, Sheffield, gave the final talk on **Juvenile Huntington's disease** and ongoing research into the presentation and progression of disease in this cohort.

Mr John Eden, CEO of Scottish Huntington's closed the session. Scottish Huntington's has been instrumental in participation in the Enroll-HD programme, a very strong exemplar for how **collaboration between NHS, universities and strong third sector organisations is key to effectively promote research in rare disease**.

We are very grateful to all the speakers and attendees, as well as the Chief Scientist Office, Scotland and NHS Research Scotland for supporting the event and Phil Brown for coordinating the day.