The UK Myotonic Dystrophy Patient Registry: facilitating and accelerating clinical research

The UK Myotonic Dystrophy Patient Registry is a patient self-enrolling online database collecting clinical and genetic information about both myotonic dystrophy type 1 (DM1) and myotonic dystrophy type 2 (DM2). The registry was established in May 2012 with support from the Muscular Dystrophy UK (MDUK) and the Myotonic Dystrophy Support Group (MDSG), assisted by the TREAT-NMD Alliance (www.treat-nmd.eu). The registry is coordinated from the John Walton Muscular Dystrophy Research Centre at Newcastle University.

A research paper on the UK Myotonic Dystrophy Patient Registry was recently published in the Journal of Neurology (April, 2017). The paper is called, “The UK Myotonic Dystrophy Patient Registry: facilitating and accelerating clinical research” and was written by Libby Wood and Professor Hanns Lochmüller both from the John Walton Muscular Dystrophy Research Centre at Newcastle University, with help from experts, scientists and clinicians across the United Kingdom. 556 patients with a confirmed diagnosis of DM1 (registered between May 2012 and July 2016) were included in the analysis. The full version of the published paper can be viewed here: www.ncbi.nlm.nih.gov/pubmed/28397002.

SUCCESS FACTORS: UK Myotonic Dystrophy Patient Registry

The UK Myotonic Dystrophy Patient Registry contains information on a diverse group of myotonic dystrophy patients which provides a unique cross-sectional snapshot of the myotonic dystrophy population in the UK.

The collection of longitudinal data over time will provide an additional resource when assessing the progression of the condition.

The contribution from healthcare professionals across the country has helped establish a virtual network of medical professionals with an interest in myotonic dystrophy and research into the condition.

The UK Myotonic Dystrophy Patient Registry has successfully supported recruitment into several academic research studies (OPTIMISTIC Pheno-DM1, and a pilot longitudinal study at the University of Nottingham).

The UK Myotonic Dystrophy Patient Registry is an example of a novel, online-based, cost-effective, and patient-driven registry. Its success can be measured by its continuous growth and utilisation.

if you have any questions about the UK Myotonic Dystrophy Patient Registry please get in touch - phillip.cammish@ncl.ac.uk
If you have any concerns related to your health, speak to your GP

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