Ménière's Society – Research Projects

Meniere's Disease Registry

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I am a Consultant ENT Surgeon at the Norfolk & Norwich University Hospitals NHS Foundation Trust. Together with Prof Peter Rea (University Hospitals of Leicester NHS Trust), Prof Louisa Murdin (Guy's and St. Thomas' NHS Foundation Trust), Mr Jonny Harcourt (Imperial College Healthcare NHS Trust), Prof Lee Shepstone (University of East Anglia), and Norwich Clinical Trials Unit (University of East Anglia), we have been funded by the Ménière's Society to develop a national Ménière's Disease registry.

What is Meniere's Disease?

The answer here might seem obvious: Ménière's disease is a condition that affects the inner ear and is characterised by recurrent episodes of spinning dizziness (vertigo), fluctuating hearing loss and ringing in the ear (tinnitus), often with a feeling of fullness in the ear. However, this is merely a description of a constellation of symptoms. We still don't know the identity of the fundamental processes that underpin these symptoms. More to the point, there is mounting evidence that Ménière's disease is not the consequence of a single disease process; and that Ménière's disease might very well be the end result of a number of individual conditions that affect the inner ear. Understanding how Ménière's disease might exist as a cluster of separate clinical entities (clinical subtypes) is key to allowing further research into its underlying mechanisms and the targeting of specific treatments; as well as allowing a better understanding of the how the inner ear malfunctions in other conditions that cause dizziness.

Why a registry?

Clinical subtyping is a process that has acquired increasing attention over the last decade and is necessary for individualising the practice of medicine. Clinical subtyping is a process by which lots of information are collected and analysed to identify whether specific pieces of information are associated with the outcome of a disease. Information collected can often include physical symptoms, clinical course, objective test results, treatment responses, genetics, environment, and lifestyle. Clinical subtyping has benefited the study of a variety of conditions, including cancer, autism, autoimmune diseases, cardiovascular diseases, and Parkinson's disease. Work to define clinical subtypes of Ménière's disease is important to gain a better understanding of key biological pathways and to ultimately lead to tailored treatment strategies and to provide information regarding the likely disease outcome in the future. One method to achieve this goal is to gather a broad range of information from a large number of patients with Ménière's disease to identify clusters and common themes.

The use of national registries has many advantages over conventional data collection methods. When implemented correctly, national registries can allow the appraisal of a more representative sample of the target population. Furthermore, a national approach broadens the opportunities both for participation among the patient population to be served by such a venture, and for public engagement and dissemination activities. A national registry allows the identification of features at presentation that predict disease course and long-term outcome, improving our understanding of disease progression, treatment response, and underlying causes.

Additional benefits of a Ménière's disease registry

A national Ménière's disease registry would also provide a resource for broad and far-reaching research into Ménière's disease beyond that of defining clinical subtypes. Registries offer other benefits to patients, carers (including partners and family), researchers, clinicians and other individuals that are involved with the provision of services for those affected by the condition being studied. Individual hospitals and the NHS as a whole can use registry data to improve the services they offer. Individual patients and carers can use registries to learn more about their condition and this can lead to a better understanding of how people's lives are affected.

Short term goals

This project will provide the initial necessary steps to set-up a UK Ménière's disease registry, by primarily investigating a single clinical subtype of Ménière's disease: bilateral disease – Ménière's disease affecting both of the ears. The development of bilateral Ménière's disease has significant implications for short and long-term opportunities for treatment and rehabilitation; this in turn has significant implications for communication and employment. Previous literature on bilateral disease has offered widely ranging estimates of the likelihood that it will occur in cases when unilateral Ménière's disease is confirmed, and no clear predictors have been identified. It is hoped that one of the first set of questions that our registry answers, will be around the incidence of bilateral Ménière's disease, together with some understanding of predictors for developing bilateral Ménière's disease.

Long term goals

The longer terms goals of this project will be to establish the best means to recruit large numbers of representative patients with Ménière's disease. This work will be essential to aid the expansion of this project throughout the United Kingdom to allow us to answer a greater range of questions regarding Ménière's disease.

Current status

At the time of writing, we have recruited over 250 patients to participate in this project. Our initial goal is to recruit 400 patients, before determining the necessary steps to expand this project further.

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