

Balancing Everything Out

Fifteen years of research into dizziness, balance
and the pathology of Ménière's disease



www.menieres.org.uk

Index of References and Sources

Further details of the reference sources and research projects discussed in this paper can be found at the following locations:

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Foreword

Linda Luxon CBE, Emeritus Professor of Audiovestibular Medicine and Consultant Neuro-Otologist

Ménière's disease is a complex condition to diagnose and its impact can be deeply debilitating to sufferers. The complexity of the condition sometimes makes it difficult for researchers to secure funding from bodies for which Ménière's is a small part of their specific focus.

The Ménière's Society's policy of funding cross-disciplinary research makes it a unique and valuable resource for those working with the condition. I am grateful for its existence and pleased to offer a foreword to this review of recent research.

As a clinician and a researcher, I have benefited from projects supported by the Ménière's Society. I was co-sponsor of a project funded by the Society. More often, I have used the results of research run by others.

I very much hope that readers will be encouraged to support the valuable work of the Ménière's Society through making a donation to their Research Fund.

Introduction

Humphrey Bowen, Trustee for Research, Ménière's Society

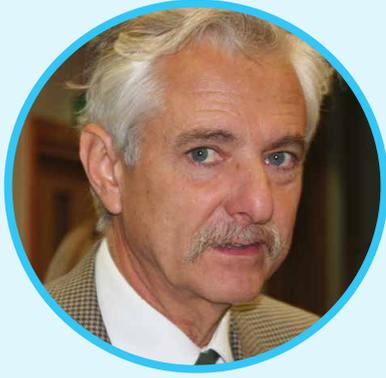
It is fifteen years since the Ménière's Society started its Research Programme. In that time, we have been fortunate to build a positive reputation across the community of researchers, clinicians and patients with an interest in Ménière's and vestibular disorders. Our programme is recognised both for the quality of research it supports and for its policy of focusing solely upon Ménière's and related disorders whilst encouraging research into every aspect of these conditions.

I am very proud that, as a result of nearly £0.5 million invested in research, we now have, or are moving towards:

- Better understanding of the psychology of Ménière's disease
- Better tests to identify and monitor the condition
- Better, less destructive treatments for severe cases.

This paper describes some of the projects which we have supported in the search for new ways to make things better for people with dizziness and balance disorders.

Ménière's disease is a debilitating condition with no known cause or cure. Please support us in investing to make it better.



Ménière's disease, an overview

Adolfo Bronstein, Professor of Clinical Neuro-Otology,
Imperial College London

Ménière's disease is characterised by long-term hearing and balance symptoms: episodic attacks of vertigo, fluctuating hearing loss, tinnitus and aural fullness. The diagnosis of Ménière's disease is presently made by clinical history and results from a hearing test. Current treatments are aimed at suppressing the attacks of vertigo. There are presently no established treatments for hearing restoration, stopping tinnitus or reducing aural fullness. Ménière's affects men and women equally and can occur at any age. Familial occurrence has been noted in about 10% of patients. Ménière's disease becomes bilateral in around half of patients. There is currently no known cure.

What causes Ménière's disease?

The cause of Ménière's disease is unknown but there appears to be a relationship between presence of hydrops in the cochlea and vestibular apparatus and loss of hearing and balance function. Hydrops might increase pressure of the endolymph fluid causing damage to the surrounding membrane. Other theories include allergic reactions, familial inheritance and other factors.

How are sufferers affected?

A vertigo attack is typically associated with a pre-warning: an increase in tinnitus, aural fullness, hearing loss or changes in balance. Vertigo attacks typically last 20 minutes to multiple hours during which a person can experience nausea, vomiting, sweating and imbalance. Whilst the attack is on-going sufferers are forced to lie motionless until the symptoms subside, as any head movement makes them worse. A single attack can leave a person feeling groggy and unsteady for several days and attacks can occur multiple times per week or lie dormant for several years.

Hearing and balance symptoms can vary over the course of the disease and each sufferer can be affected very differently to another. In the latter stages of the disease, hearing loss can be severe and a person may be quite sensitive to loud noises. Permanent damage to the balance organ can result in daily or periodic dizziness symptoms.

Ménière's disease is a progressive and incurable condition with an unknown cause.

Better Diagnosis

VEMPs - a simple, non-invasive test of balance function

Diagnosis of Ménière's disease is notoriously difficult. The American Academy of Otolaryngology states that "certain" Ménière's disease can be confirmed only by autopsy – not an ideal situation for sufferers.

In practical terms, the diagnosis is arrived at by elimination of other possibilities and by testing, and tracking, of the known symptoms. Testing for progressive hearing loss is easiest and the most common test performed. Testing, and then tracking, the patient's balance function is more problematic. The popular caloric test is time-consuming for both clinician and patient. As it involves pouring liquids into the affected ear, it is frequently an unpleasant experience for the patient. As a consequence, the balance function is often measured only at the outset of diagnosis (if at all) and no measurement is taken of on-going degradation or stabilisation of the condition.

The Society has funded two research projects into an innovative approach known as the VEMP test. VEMPs (Vestibular Evoked Myogenic Potential) are electrical signals that can be recorded in certain muscles when the balance organs are stimulated by sound. By placing electrodes on the patient's neck or below the eyes, these signals can be measured and, in turn, the functioning of the saccule and utricle (part of the balance system) can be determined. A test based on measuring VEMPs in patients would be non-invasive and quick to perform. This could lead to greater patient comfort and to the possibility of repeating the test periodically in order to record changes in the patient's balance function over time.

In 2004, the Society awarded a research grant to Dr Borka Ceranic, Clinical Lecturer in Audiological Medicine and Professor Linda Luxon, Professor of Audiological Medicine, Department of Neuro-otology at the National Hospital for Neurology & Neurosurgery, London. Dr Ceranic and Professor Luxon's project evaluated the use of VEMPs tests as a means of diagnosing Ménière's disease.



VEMPs offers hope of a simple, non-invasive test that can be repeated as a regular tracking tool.

In 2009, this work was furthered in a research project by Dr Jas Sandhu, Clinical Scientist at Leicester Royal Infirmary. Dr Sandhu's work supported earlier findings but also found suggestion that the optimum frequency to elicit a response in the tests was different for sufferers of Ménière's disease compared to the rest of the population. This indicates a possible test for diagnosing as well as monitoring the progress of the condition. This research has been continued as an NHS approved research study to determine if these results occur in other vestibular conditions or if they are unique to Ménière's.

A genetic cause for some cases of Ménière's?

The Society has a policy of encouraging research along all possible lines of inquiry, subject of course to clear guidelines and peer review. In 2003, the Society provided research funds to Andrew Morrison FRCS, Consultant Otolaryngologist for an investigation into possible genetic predisposition to Ménière's disease. The results laid a clear path for future research in identifying an area of chromosome 14 that may predispose carriers towards development of the condition. Mr Morrison subsequently secured funding from other sources for a follow-on project.

The Society has also recently approved a request for funds from Dr Jose Antonio Lopez-Escamez, at the Centre for Genomics and Oncological Research in Granada, Spain for a project considering the identification of rare allelic variants in familial Ménière's disease. This should lead to a better understanding of the genetic cause of some cases of Ménière's disease.



The optimum response frequency in a VEMPs test appears to be distinctly different for Ménière's sufferers than others.

Better Treatment

Steroids versus gentamicin for transtympanic injection

For cases of Ménière's that do not respond to dietary or medicinal treatments such as betahistine, the next medical option is often transtympanic injection (injecting a drug through the ear-drum). The two drugs used for transtympanic treatment are gentamicin and steroids.

Gentamicin works by selectively destroying the vestibular system in, and therefore the poor balance information coming from, the treated ear. The treatment is highly effective and is routinely used throughout the UK. However, it can have some negative side-effects including a decrease in hearing for about one in ten patients and temporary vertigo.

Steroid treatment does not suffer these negative side-effects and there is even anecdotal evidence of an improvement in hearing in some cases. However, most of the studies into the use of steroids in the treatment of severe Ménière's over the last ten years have not been carried out in a controlled way so that there is no clear evidence as to the true effectiveness of this treatment compared to the use of gentamicin.

In 2008, the Society agreed to fund an important clinical trial into the use of steroids versus gentamicin in unilateral refractory Ménière's disease. The specific aim of the trial is to determine which drug is better at controlling vertigo. The trial is also monitoring the other symptoms of Ménière's disease to identify any changes.

This ambitious, multi-disciplinary study under Professor Adolfo Bronstein, Professor of Clinical Neuro-otology at Imperial College London, includes two year, post-treatment follow-up and measurement of hearing, balance and tinnitus in order to provide a comprehensive comparison of all aspects of each treatment over a reasonable course of time. The trial is a randomised double-blind trial so that neither patients nor the study team know which patient receives which treatment until the trial is over. To be statistically valid, the trial requires 60 patients. The trial is now fully recruited and to-date 29 patients have completed the trial.



The use of steroid in place of gentamicin would be less destructive and carries the potential to improve hearing in some cases.

Until the results can be un-blinded at the end of the trial, no conclusion of the relative effectiveness of each treatment can be made. Results so far are, however, encouraging. They demonstrate the validity of the trial's protocol and the overall impact of both treatments with clear improvement in hearing in some cases.

This is an important study that will lead to better understanding and treatment of the condition. Researchers, clinicians and the Society keenly await the final results of the trial.



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The Meniere's Society has been immensely supportive during the course of the clinical trial. Their funding and support has enabled us to undertake this crucial study

Professor A Bronstein

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Better Understanding

Having a poorly understood condition that is chronic, incurable and progressive can take a toll on individual sufferers. However, a number of research projects funded by the Society have helped to develop a better understanding of what this really means for patients, what help can be provided and how patients can take control of the condition and help themselves.

Central to this research have been Professor Lucy Yardley and Dr Sarah Kirby of the Department of Psychology, University of Southampton.

Understanding levels of distress and anxiety in Ménière's sufferers

A study by Professor Yardley and Dr Kirby found that the incidence of post-traumatic stress disorder (PTSD) and health anxiety is much higher than in non-sufferers.

Nearly one in eight people with Ménière's were found to meet the criteria for full PTSD, compared to the general population where just one in sixty has PTSD. The high levels found in Ménière's sufferers are comparable with those found among people who have suffered a stroke, heart attack or heart surgery.

Similarly, levels of health anxiety and depression were found to be much higher in Ménière's sufferers. Nearly half of Ménière's sufferers have high levels of anxiety compared to around a quarter of non-sufferers. Just over a quarter of sufferers have high levels of depression compared to just one in twelve of non-sufferers.

Understanding these high incidences of stress and anxiety helps clinicians to look for appropriate signs and to ensure patients receive appropriate support.

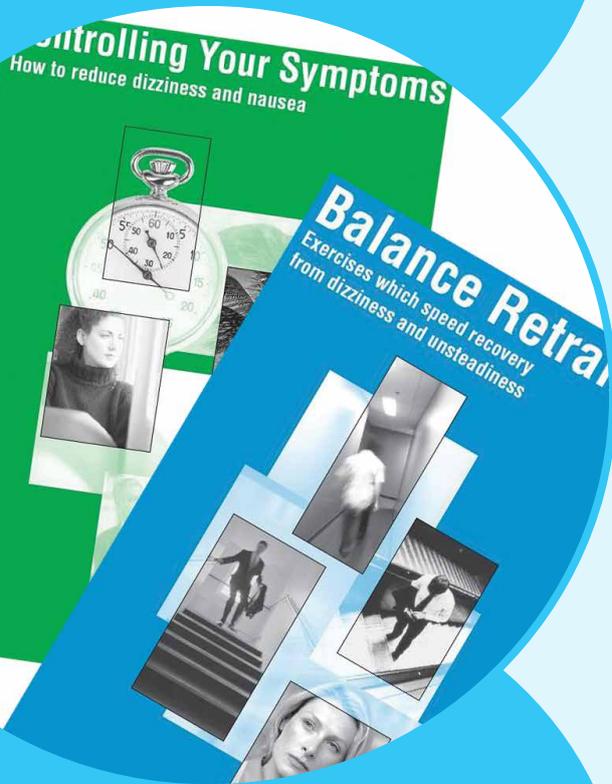
Ménière's and the built environment

A separate study by Dr Kirby identified those aspects of the built environment that most often cause difficulty for Ménière's sufferers. For example, 100% of survey respondents have difficulty in supermarkets or shopping malls; 50% find patterns on flooring difficult while 31% experience problems in different kinds of artificial light. In an article for the Society's magazine Spin, Dr Kirby described the eight most common environmental problems, explaining why they cause issues so that sufferers can understand and make accommodation for the condition.



1 in 8 Ménière's sufferers show signs of full post-traumatic stress syndrome compared to just 1 in 60 non-sufferers

Ménière's Society self-help booklets have a significant impact upon how well patients feel



To date, the Society has distributed over 10,000 copies of the booklets to patients and professionals worldwide

Taking control: self-help booklets for sufferers

In another important project, Professor Yardley wrote two self-help booklets for sufferers of Ménière's disease and other vertigo related conditions. She and Dr Kirby conducted a trial to measure the impact of these booklets on the symptoms and levels of anxiety in 358 patients.

After twelve weeks, over a third of those who had received the booklets reported feeling better compared to just one fifth of those who had not (the control group). After six months, 40% of those using the booklets felt better compared to just 16% of the control group. The booklets are a clear benefit to sufferers.

The study showed a marked decrease in anxiety levels for those patients who had used the self-help booklets (from 56% of participants before the trial to 48% afterwards).

The study also identified predictors of anxiety and means of reducing the levels of anxiety experienced. In general, patients who suffered more severe physical symptoms were more likely to also experience anxiety. Patients who felt they did not have a good understanding of their condition also experienced higher levels of anxiety.

The booklets - Balance Retraining and Controlling Your Symptoms (which gives advice and exercises to control stress and anxiety) - have proved to be useful in helping patients understand their condition, control their symptoms and reduce their overall levels of anxiety. Both booklets are available from the Society. This study was also published in the British Medical Journal and by Evidence Based Medicine.

Future Results

The Society is awaiting results for five further studies currently in progress. These cover topics from further psychological aspects of the condition through to investigations into different aspects of the balance function.

At the time of writing, the Society has a further four requests for funding at different stages of assessment.

Help us Make it Better

The Ménière's Society is looking to boost its research reserves so that we can continue to support leading, cross-disciplinary research into Ménière's disease and other balance-related conditions.

Ménière's disease is a capricious, debilitating condition that, as Professor Yardley's research has shown, takes a mental toll on sufferers as well as bringing its physical symptoms of vertigo, hearing loss, tinnitus and aural fullness. Poorly understood and unpredictable, with no known cause or cure, those experiencing an attack feel wretched. They simply want to be better.

The Society is proud to have furthered understanding of this complex condition. Our focus on Ménière's disease and, more recently, all balance-related conditions has enabled us to support research across a number of disciplines.

At the same time, the Society has built a reputation within the research community as a supporter of valuable research. This has encouraged researchers to approach the Society with innovative and potentially valuable research proposals.

However, the Society's reserves are limited. Success has consequences and the Society now receives more valid requests than we have funds to support.

This year, we have set ourselves an ambitious target to raise £50,000 specifically for research funding. We hope - now that you understand more about the valuable research we support - that you will help us with a donation.

To contribute to the valuable work of the Ménière's Society, visit www.menieres.org.uk/research



£40,000 allows us to fund a PhD student for two years

About the Ménière's Society

Helping people with dizziness and balance disorders

The Ménière's Society is a UK registered charity dedicated solely to supporting people with Ménière's disease and other vestibular disorders that cause dizziness and imbalance. The Society provides information to patients, carers, health professionals and the general public. It also supports and encourages research into Ménière's disease and related conditions.

With over 25 years' experience supporting those affected by vestibular disorders, the Ménière's Society helps people source specialists in their local area, publishes a quarterly magazine (Spin) and factsheets on a variety of subjects (e.g. driving, surgery and vestibular rehabilitation). The Society also provides a confidential telephone information line during working hours.

The Ménière's Society is a registered charity, no. 297246.

History

The Meniere's Society was founded in 1984 by Mrs Marie Nobbs MBE to support people with Meniere's disease and related disorders, and those who care for them. The Society acquired charitable status in 1987. With increased publicity about Ménière's disease and the improved services the Society offers, membership is now around 5,000. The Society's members are found in all parts of the UK and across the world, in countries including Ireland, Spain, Australia and the USA.

To learn more, visit www.menieres.org.uk

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Over the past 15 years, the Ménière's Society Research Programme has awarded nearly £0.5 million in grants supporting valuable, cross-disciplinary research into Ménière's disease and related conditions



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