

## **INQUIRY INTO HEARING HEALTH IN AUSTRALIA**

Submission from Meniere's Australia Inc.

### **WHAT IS MENIERES DISEASE?**

Meniere's disease is a debilitating progressive condition of the inner ear. It produces a triad of symptoms - vertigo, tinnitus and hearing loss and feeling of pressure or fullness in ears. There are also a range of associated secondary symptoms which combine to have a significant impact on the sufferer and their carers. Although not life threatening, the disease can be life destroying.

There is a great deal of fear and uncertainty which may accompany the symptoms. A sufferer can appear well but may be unable to stand up straight, unable to hear properly or be coping with severe and uncontrollable ringing or roaring noises called tinnitus.

This may result in problems with employment, financial hardship and difficulties with family and friends because of the condition. Whilst Meniere's disease can be alleviated to a certain extent by medical intervention, it is normally progressive and irreversible.

Its fundamental cause/s remains unknown. The anxiety this provokes, together with the unpredictable and sometimes dramatic nature of active Meniere's attacks, creates a sense of stress, suffering, and helplessness.

### **Meniere's Australia Inc**

Meniere's Australia (MA) was established through the auspices and support of key members of the Meniere's Support Group of Victoria, who believed a National Meniere's service is required to extend services Australia wide and to cooperatively use and share scarce resources.

Meniere's Australia Inc was registered and incorporated in August 2007 with the objective of working to improve the diagnosis, treatment and management of Meniere's disease. It is now the National body for Meniere's with over 2000 members.

### ***Our Vision***

Meniere's Australia believes that all Australians suffering Meniere's disease should have equal, easy and consistent access to information, support and assistance.

This encompasses a variety of activities including offering personal support to sufferers and their carers, raising awareness within the medical profession and within the wider community as well as aiding scientific research.

## **The extent, causes and costs of hearing impairment in Australia;**

Meniere's disease falls between the cracks of the current health care system. Sensory hearing loss has been identified as one of the worst consequences of Meniere's disease.

However there is the chronic illness component associated with the vertigo attacks and vestibular impairment that is not addressed by Australian Hearing or the state and Federal Health departments.

Meniere's Australia supports the submission and recommendations made by Deafness Forum of Australia - the peak body for the Deaf, hearing impaired and those who have a chronic disorder of the ear.

**Listen hear!: The economic impact and cost of hearing loss in Australia** published in 2007 identified productivity loss related directly to hearing impairment accounts for well over half (57%) of the total financial costs – or some \$6.7 billion a year. It is well documented that hearing loss represents a real financial cost to Australia of \$11.75 billion per annum or 1.4% of GDP according to the research study by Access Economics.

However the focus of this paper will be on Meniere's disease and the extent, causes, and costs (financially and personally) of living with hearing loss in conjunction with the vestibular component.

Before you can address the impact of hearing loss there needs to be **national census** of the Australian population identifying the **incidence and prevalence of the different conditions that cause hearing loss**. It is imperative that we know the true indications to develop programs, services, resources, support and research.

There are differing estimates of the number of Australians with Meniere's disease ranging from 0.1% of the population and one in 2500. These estimates are based on figures from overseas.

However if you accept the figures from the ABS Australian Population Health Survey 2005 **one in 606 Australians** have Meniere's disease.<sup>1</sup>

There is potential for data collection at the entry point with a national register of patients presenting with the symptoms of hearing loss, vertigo and tinnitus at ENT and neurologist clinics and hospitals across Australia.

**The Meniere's Support Group of Victoria Membership Survey 2006 Report** prepared by the Chronic Illness Alliance outlines the some of financial and personal costs of living with Meniere's.

- Meniere's disease may occur at any age but is usually diagnosed between the ages of 30 and 50. This is the 54% of the survey participants were aged within the working age period.

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<sup>1</sup> Meniere's Support Group of Victoria Membership Survey 2006 by Dr Christine Walker and Jo-Anne Tamlyn Chronic Illness Alliance

- 21% reported they had to leave paid employment because of their Meniere's disease.
- 16% had to reduce the hours they worked

Australia's Health 2006 (AIHW 2006:148) reported that neurological and sense disorders account for some 19% of Years Lost to Disability (YLD) with hearing loss is seen to be one of the most important factors in limiting activities.

When people consider hearing loss they tend to consider complete or partial deafness to be the most significant aspects.

Meniere's disease contributes to the incidence of hearing loss in Australia, affecting approximately 40,000 Australians.

The implications of hearing impairment for individuals & the community is outlined in Harvey Dillon's **Hearing Loss: The Silent Epidemic - Who, Why, Impact and What we can do about it** –

Mental health issues of stress, anxiety, depression are compounded when significant hearing loss and the vestibular component of Meniere's disease are combined.

There is insufficient counselling services and support for people with hearing loss and even for people with Meniere's disease

### **The adequacy of access to hearing services, including assessment and support services, and hearing technologies;**

The current health system is unable to adequately support people with the symptoms of Meniere's disease. Hearing Loss – low frequency fluctuating; Recruitment, Diplacusis (pitch change); Vertigo and Tinnitus.

- Need for research into the cause and potential cure of Meniere's. The Meniere's Research Fund recently funded and established a Meniere's Research laboratory in Sydney.
- Further research is required into the needs of people with Meniere's disease

### **Managing hearing loss and Meniere's disease and in Australia requires:**

- Better identification and diagnostic skills of GP's with regards to hearing loss and disorders of the ear.

#### **Some of the effects of Meniere's & deafness on my life!**

*Meniere's and its accompanying problems have had a disastrous effect. I have no hearing in my right ear. Very little hearing in my left ear with the help of a strong (expensive) hearing aid.*

*I find people in general do not understand my many problems which also include constant dizziness, wobbly slow walking even with my trusty stick.*

*Hearing loss and Meniere's is isolating, frustrating, embarrassing, tiring and very hard to cope with.*

Royce Goodall

- Increased content regarding hearing loss and disorders of the ear in curriculum and professional training programs via the Division of General Practices
- Better referral networks to audiologists who specialise in Tinnitus, Meniere's disease and other disorders of the inner ear as well as other organisations.
- Recognition and financial support of the role organisations such as Meniere's Australia, Better Hearing and State Deafness organisations in service delivery, providing peer support, counselling and case management.
- Recognition & support from Federal and State Governments of organisations transitioning from self help groups to service delivery and Government utilising the proven expertise of Allied Organisations.

### Example

#### **Meniere's Support Group of Victoria Survey of Community Health Services**

Aim: to identify if the Victorian Community Health Services (CHS) were able to meet the need of people with Meniere's disease (Hearing loss; Vertigo and tinnitus)

136 Victorian Community Health Centres sent a survey  
42 responded (approx: 30.9%)

#### **Does your centre have the resources to assist clients with ongoing management of Ménière's disease?**

Yes: 11  
No: 29

#### **Would you be willing to refer clients with Ménière's disease to the Ménière's Information and Resource Centre?**

Yes: 40  
No: 0

The results of this survey indicated that although the Victorian CHC was identified by the Minister of Health as an avenue for people with Meniere's disease to obtain health services, the reality was that CHS did not have the knowledge and resources to provide that service.

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