#### Inquiry into the Hearing Health and Wellbeing of Australia Submission 18

## The Standing Committee on Health Aged Care and Sport

PO Box 6021
Parliament House
Canberra ACT 2600

Dear Committee Chairperson

Submission to the inquiry into the Hearing Health and Wellbeing of Australia

I am making this submission so the devastation of hearing loss and chronic ear disorders and tinnitus can be better understood and supported in Australia.

I offer the following submission as an index of unmet need and a call for equity for every Australian who lives with hearing loss or impairment, a chronic ear disorder or tinnitus; are Deaf or deafblind; and their families.

Yours sincerely

Julie Hill

20/12/2016

# Submission to the inquiry into the Hearing Health and Wellbeing of Australia

#### Standing Committee on Health, Aged Care and Sport

#### Julie Hill

#### 20 December 2016

#### Introduction

I would like to offer comments and recommendations to this Standing Committee on Health, Aged Care and Sport Inquiry in relation to some/all of the terms of reference for this inquiry into the Hearing Health and Wellbeing of Australia.

1. Access, availability and cost of required drugs, treatments and support for chronic ear and balance disorders sufferers.

There is a lack of support services available at present for those people with chronic ear and balance disorders that are in between the hearing and deaf worlds, where we don't fit into either column. We are very isolated with chronic ear and balance disorders without treatment and required drugs to maintain some sort of existence.

Medical staff really need further training in these areas for early treatment and diagnosis. There needs to be more funding of medications and treatment options available to sufferers.

My current medications are costing me in excess of \$2000 a year on my current dosage as one of the medications is also not on the PBS (SERC). With specialists treatments, hearing tests etc my current medical bills exceed \$5000 a year. Within 12 months I will also be looking at obtaining hearing aids at a potential cost in an excess of \$3000.

These costs are rising each year and affecting other areas of my life like being able to provide the basics for my children such as rent, education expenses, electricity, clothing and food, putting me under further stress.

Without access to these medications and treatments and specialists I will no longer be able to be employed. I would be forced into disability and would be a further drain on the social services system. It would also affect my mental

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health as not being able to hear becomes very isolating, I would then also end up homeless as I couldn't afford to cover my rent on the disability pension.

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#### **Recommendation:**

I recommend that the Australian Government put SERC medication and it's generics on the PBS. There needs to funding provided to the organisations that provide support to people with chronic ear and balance disorders.

# 2. Development in research into hearing loss, including: prevention, causes, treatment regimes, and potential new technologies.

It is of vital importance that Australia is a world leader in hearing research and treatment. Meniere's disease has been known about for over 150 years, yet there is still no known reason why people suffer from this disease and still no cure. This disease is debilitating and robbing people of their lives. There needs to be a cure found or a successful treatment at the very least. Without funding Australian institutions and the work of Hearing CRC, NAL, Ear Science Institute no inroads can be made. People are dying from this disease – taking their own lives as this disease is so dreadful to live with and it's impacting our mental health system.

#### Recommendation:

I recommend that the Australian Government make research into hearing loss including prevention, causes, treatment regimes and potential new technologies a priority.

## 3. Whether hearing health and wellbeing should be considered as the next National Health Priority for Australia.

Hearing Health and Wellbeing should be a National Health priority as we have a greater burden of disease then existing National Health Priorities.

- High incidence of hearing loss compared with other illnesses that are targeted as <u>National Health Priority Areas</u> (see <u>Listen Hear -- the economic</u> <u>impact and cost of Hearing Loss in Australia</u> for comparison of hearing with other conditions.
- Need for national approach to raise awareness and to have a more coordinated approach to programs for vulnerable groups.
- A significant percentage of Australians experience hearing loss or impairment, are Deaf or deafblind; live with chronic ear disorders or tinnitus.

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- This represents a large but unaddressed burden of disease in Australia and a greater health burden than existing National Health Priority Areas such asthma, diabetes and musculoskeletal conditions.
- For the individual, their life opportunities can be seriously reduced by restricting their language development, social participation and inclusion, education, relationships and income.
- A large proportion of acquired hearing loss is highly preventable. There is a need for community education programs to help protect people from the effects of noisy occupations and recreational loud noise from personal music devices, clubs and concerts.
- What is needed is a nationally integrated policy approach to research, early interventions, holistic services, prevention, and community education.

#### Recommendation:

The Australian Government should make Hearing Health and Wellbeing a National Health Priority.

#### 4. Any other relevant matter.

- Risks with the introduction of the National Disability Insurance Scheme, people are waiting for the scheme to be introduced missing out on services they need now, in my area for example it won't be introduced until late 2019. There is also a risk there won't be enough funding left by that stage to receive the assistance we need as we are not considered a national health priority.
- Mental health issues for people with hearing loss is a major problem, people become isolated when they can't hear or have difficulty hearing or suffer with hyperacusis as they feel they become a burden for others they feel it's easier to stay at home and avoid situations as it's so difficult to communicate. It becomes a vicious cycle of depression and anxiety.
- Education is required in the hospitality industry of what a low sodium diets requires by those that suffer with Meniere's disease. It is very difficult to maintain some sort of normal life when you eat such a limited diet and then have people judging you and giving you a hard time as you require a special meal.

#### Recommendation:

I recommend that the Australian Government start a national campaign not only about the dangers of sugar but also about salt/sodium in diets. I recommend people with hearing loss get early access to the NDIS even if it's not rolled out in their area yet. I recommend that people with hearing loss/chronic balance disorders are offered support contact numbers for support agencies such as Whirled Foundation or other organisation that suits their diagnosis from their medical professional.