



15 FEB 2023.

Sydney's Gay & Lesbian Mardis Gras

The Deaf community is like the LGBTQIA+ community.

The LGBTQIA+ community and the disability community share some of the same challenges. LGBTQIA+ people and people with hidden disabilities have to decide whether or not to come out.

Both LGBTQIA+ children and children with disabilities face bullying and stigma, for which the consequences can literally be life and death.

Studies on healthcare access among deaf patients have cited notable barriers including communication challenges, gaps in health knowledge, and lack of provider cultural competency. Other studies within the general LGBTQIA+ population have found that LGBTQIA+ patients' healthcare access is challenged by stigma, discrimination, unequal access to insurance, and outright denials of care based on sexual orientation or gender identity. These challenges may influence LGBTQIA+ patients' disclosure of sexual orientation or gender identity to the healthcare provider. Among both deaf-specific and LGBTQIA+ specific populations, research has found a number of factors related to successful health outcomes, chiefly that of a quality relationship between the patient and the healthcare provider. When the nondisclosure of the deaf LGBTQIA+ patients' sexual orientation or gender identity is made worse by barriers to patient-centred communication care, this can create significant challenges for preventive care and treatment.

Researchers in the U.K. learned that during adolescence, deaf gay men could find they were trying hard to be something they were not: oral and heterosexual for hearing non-signing others (including heterosexual members of their family of origin). Research participants spoke of increasingly being drawn toward a welcoming signing cultural world that supported them against deaf minority stress. Coming out as gay presented not only potential family of origin difficulties, but also threatened connection with the deaf community, leaving participants intensely fearful of gay visibility and stigma.

Josh Feldman (pictured) was a deaf gay trailblazer in Hollywood. He wrote and starred in a comedy-drama *This Close* in 2018. It was the first TV show created by and also starring people who are deaf.

"For a long time, I had a difficult time both being deaf and gay, only because I was not fully out. The lack of representation in the media also affected that.

"As a young kid, I wondered who my deaf gay role models were, so that I could have an idea of what deaf gay adults could do, or what kind of people they were in society.

"We still have a long way to go on that front. I am hoping future generations of deaf LGBTQ kids will have role models they can look up to and see themselves represented in the media."

Waiting To Be Heard: On Being Deaf and Gay, Deaf LGBTQ Patients' Disclosure of Sexual Orientation and Gender Identity to Health Care Providers, Toward an Understanding of the Experiences of Deaf Gay Men, Josh Feldman, Deaf Gay Trailblazer in Hollywood, Discusses the Importance of Representation.





West Australian amateur golfer Abbie Teasdale has proven she is certainly a talent to watch. Abbie, from Royal Fremantle Golf Club had a remarkable 2022.

The 20-year-old is full of confidence after winning her first national event at the Riversdale Cup in Melbourne, then following-up with her first international victory at the English Amateur.

What was your top result/best event so far?

Winning the English Amateur was definitely my best result. Very proud of winning this event.

What do the next 12 months look like for you?

I have quite a few Aussie events – The Dunes, Vic Am, Aus Am, NSW Open and Riversdale.

I will concentrate on these and head back to the UK in March to do the summer season again.

Is there a tournament you are desperate to compete in?

The Women's Open in the UK – that would be seriously amazing.

Name an international course you want to play.

Augusta National.

What aspects of your game are you currently working on?

Distance! Working on my club head speed.

What has been your biggest challenge in the last 12 months?

My biggest challenge was going to England. It was completely different course conditions to what I am used to, and I really needed to get back into playing a lot more after Covid. The courses presented new challenges and I didn't know many of the golfers there either.

How has having your cochlear implants changed things for you?

My hearing has still got a way to go as I work to retrain my brain on how to listen. It has been a long time coming and I am learning fast. What has improved is that now I feel and hear vibrations more. I hope that makes sense; it is a new feeling for me.

By Catherine Strickland writing for Women's Golf: Summer edition 2022/23.





Audiology of the Future.

Robert V. Harrison, PhD, DSc

Imagine 20-30 years into the future when you might routinely order a whole genome sequence of a client, to provide an accurate diagnosis of a hearing or vestibular problem and guide optimal intervention. This will be the ultimate in "personalised medicine".

I am convinced that this scenario will come to pass. There are already many potential applications of whole genome sequencing in audiological areas such as neonatal screening, diagnosis of genetic causes of hearing loss, and determining risk factors (genetic disposition) for age-related hearing problems.

The total cost of generating the first human genome sequence³ was many billions of dollars (yes, billions!). The US funding contribution alone was \$3 billion. Within a decade, and with improved technology, the cost of an individual, high-quality genome sequence fell to \$14 million by 2006.

Ten years later the cost was down to a few thousand dollars, but data processing times were lengthy - days to weeks even with highly automated methods. More recently, "new generation sequencing" methods and shortcuts reduce time and costs.

It is thought that most (but not all) mutations that cause disease occur in exons, so whole exome sequencing can efficiently identify mutations that cause disease. Today, such whole exome sequencing costs a few hundred dollars and takes about 5 hours. These costs/times now make whole genome sequencing an affordable and convenient clinical and research tool.

There is no doubt that the ability to map the human genome has the promise of a new era in healthcare.

The earliest clinical applications were in detecting unknown, disease-causing gene mutations. In some cases, identification of the genes (genotype) and their biological function (phenotype) has led to successful treatment to restore normal function.

Our accumulation of knowledge about the genes mutations responsible for various diseases has provided us with gene panels that can be used in genetic screening for individual patients.

We are all familiar with certain types of congenital, genetically related hearing problems in audiology, and we presently use genetic screening panels to identify *known* gene mutations. However, hundreds (if not thousands) of rare and unknown gene mutations (single or multiple) are linked to

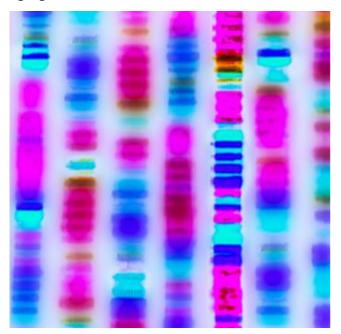




hearing loss; these can be potentially revealed by whole genome sequencing.

With the potential low cost and availability of whole genome mapping, we might well see this used for UNIVERSAL neonatal screening to complement our hearing screening. This will more immediately help to define the etiology of a hearing problem and inform optimal intervention.

Further to genome mapping for congenital hearing loss, we could move to whole genome mapping in later life to determine genetic risk factors for developing hearing loss, tinnitus, or balance problems related to noise exposure or aging.



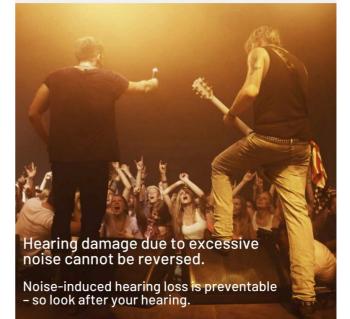
Regarding another audiology application, I recently heard a conference presentation on whole genome sequencing of a large cohort of patients with Meniere's disease. As we know, this grouping is very much a "mixed bag," and the study's intent was to define genetic subtypes with distinctly different etiology and pathological features. Such a sub-classification could be useful to finally understand the causes of the disease and define treatment options.

Clearly, human genome sequencing has much to offer the field of audiology.

By Robert V. Harrison, writing for <u>Canadian</u> <u>Audiologist</u>.

Free social media resources to promote World Hearing Day

World Hearing Day 2023



If you or your organisation would like to promote <u>World Hearing Day</u>, 3 March 2023 but lack the time and resources to prepare materials, this might help.

We have written a series of social media posts with associated images. All the materials are copyright-free so you can use them as they are, or adapt them to suit your style, or treat them as an encouragement to do your own thing.

For organisations, we have left some space at the bottom-right of each image for you to add your logo.

We hope this saves you time and allows you to help promote World Hearing Day on 3 March.

Access the words and the pictures on the Deafness Forum <u>website</u>.



Cochlear implants can bring the experience of sound to those with hearing loss, but results may vary -

here's why

Cochlear implants are among the most successful neural prostheses on the market.

These artificial ears have allowed nearly 1 million people globally with severe to profound hearing loss to either regain access to the sounds around them or experience the sense of hearing for the first time.

However, the effectiveness of cochlear implants varies greatly across users because of a range of factors, such as hearing loss duration and age at implantation. Children who receive implants at a younger age may be able to acquire auditory skills similar to their peers with natural hearing.

How does a cochlear implant work?

In fully-functional hearing, sound waves enter the ear canal and are converted into neural impulses as they move through hairlike sensory cells in the cochlea, or inner ear. These neural signals then travel through the auditory nerve behind the cochlea to the central auditory areas of the brain, resulting in a perception of sound.

People with severe to profound hearing loss often have damaged or missing sensory cells and are unable to convert sound waves into electrical signals. Cochlear implants bypass these hairlike cells by directly stimulating the auditory nerve with electrical pulses.

Cochlear implants consist of an external part wrapped behind the ear and an internal part implanted under the skin.

The external unit, which includes a microphone, signal processor and transmitter, picks up and processes sound waves from the environment. It divides sounds into different frequency bands, which are like different channels on a radio, with each band representing a specific range of frequencies within an overall spectrum of sound. It also extracts information about amplitude, or loudness, from each frequency band.

It then transmits that information to the receiver in the internal unit implanted in the cochlea. The electrodes of the internal unit directly stimulate the auditory nerve with electrical pulses based on amplitude information. Electrodes at the base of the cochlea transmit electrical signals containing high-frequency auditory information while electrodes at the top transmit electrical signals containing low-frequency information to the brain, mimicking the frequency analysis in a fully-functioning ear.

Where cochlear implants fall short

While people with cochlear implants are able to detect sounds and perceive speech in quiet environments reasonably well, they often have great difficulty understanding speech in noisy environments, enjoying music and localising sounds, that is, figuring out which direction a sound is coming from.

Cochlear implants are fundamentally limited by their poor ability to tell the difference between sound frequencies and transmit rapid variations in sound amplitude over time. For example, current cochlear implant systems use only 12 to

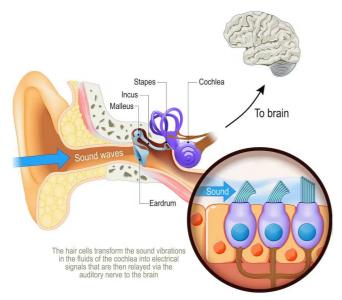




22 electrodes to stimulate surviving auditory nerve fibres, whereas natural hearing has 30,000 auditory nerve fibres to encode detailed information about incoming sounds. Furthermore, electrode stimulation inside the cochlea excites a large group of auditory nerve fibres without much precision.

These factors result in poor frequency resolution. Picture it like painting with a thick brush that can show only an overall shape without the fine details, or only blurry details.

The hearing experience from cochlear implants differs from that of natural hearing.



Sound travels through the ear canal and is converted by hair cells in the cochlea into electrical signals that enter the brain. ttsz/iStock via Getty Images Plus.

Cochlear implants work better for some

It remains difficult to accurately predict the performance of cochlear implants for each user. There are a variety of factors that can affect the number of healthy auditory nerve fibres available to transmit acoustic information to the brain. Cochlear implant users with better survival of their auditory nerve fibres may have improved frequency and timing representations of sounds represented by electrical stimulation, which can lead to better speech and pitch perception.

Neural health is not the only factor that contributes to variability in cochlear implant effectiveness. One study of cochlear implant users in 2012 found that speech recognition varied greatly, and only 22% of the difference could be explained by clinical factors like length of experience with the implant and cause of hearing loss. Furthermore, it is challenging to directly assess the effects of neural survival on the performance of cochlear implants. This suggests that other factors also play a role in determining the success of speech recognition with cochlear implants.

For instance, research has found that cognitive skills like working memory can influence the extent to which a person can understand speech after implantation. Cochlear implants increase cognitive load, or the amount of mental effort required to perform a task, as the sound quality users hear is often lower than that of natural hearing. Aging may also negatively affect cognitive processing skills, including attention deficits and slower processing speed on listening tasks.

Furthermore, most of the implant's electrode arrays don't reach the top of the cochlea where low-frequency information is conveyed in natural hearing. This leads to mismatches between the frequencies conveyed by the implant and those of natural hearing, resulting in reduced sound quality.

Read the full article by Niyazi Arslan at <u>The</u> <u>Conversation</u>.



Niyazi Arslan

Ph.D. Candidate in Speech and Hearing Science, Arizona State University

Niyazi is a third-year Ph.D. student in the Speech and Hearing Science program at Arizona State University. He is a researcher studying pitch perception with cochlear implants. Understanding the mechanics of this technology and its limitations can help lead to potential new developments and improvements in the future. https://niyaziarslan.carrd.co/#



The response of others shapes the communication success of people with hearing loss.

People with hearing loss are often adversely affected by the communication behaviours of others.

People with hearing loss are disadvantaged when other people:

- Speak too quietly, too quickly, or use unfamiliar words: this diminishes their capacity to use available acoustic information.
- Have poor visual communication skills. E.g., if they use little gesture or facial expression, turn away while speaking, or speak when they can't be seen, this limits the number of visual cues available to enhance understanding of the verbal message.
- Do not use the available surrounding context to 'illustrate' their words. E.g., standing beside a piece of equipment and explaining how to use it but not actually demonstrating the corresponding actions as they speak.
- Do not introduce the topic they are speaking about in a way that enables the person with hearing loss to accurately place the topic within the wider context of their existing knowledge, enabling the optimal use of 'thinking listening skills'. A suitable introduction will enable the person to use

what they already know to understand the spoken words.

- Change the topic too quickly without flagging the change. Indicating a change enables the listener to 'shift thinking frameworks' to place the new topic in its correct context.
- Fill the conversation with verbal asides or elaborations that are irrelevant to the main topic, making it difficult to follow the conversation and to extract the important information about the main topic.
- Speak for too long, creating the danger of 'listening fatigue', especially in regard to the listener's capacity to use the cognitively demanding 'thinking listening skills'.



Article by Damien Howard, Phoenix Consulting, a psychologist who specialises in psychosocial outcomes of people with hearing loss and auditory processing problems.

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DEAFNESS FORUM AUSTRALIA ONEINSIX

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The Wimmera Hearing Society will cease its operations at the end of March after 40 years of community service to country Victorians. The decision was made when it was clear that the organisation was unable to get ongoing funding to continue its work.

The organisation was formed in 1981 to assist deaf and hearing impaired people in the Western, Wimmera and Mallee regions of Victoria. A very small grant was gained from the Victorian Government that met the cost of volunteer insurance to then provide basic hearing assessments and support for the community.

Over the years, Wimmera Hearing Society has lobbied successfully for improved services to the Wimmera area. The organisation convinced Hearing Australia (National Acoustic Laboratories as it was then known) to open a visiting site in Horsham.

It was instrumental in establishing an Audiology department and service from the Wimmera Base Hospital, and a school-based deaf facility at Horsham 298 Primary School with a teacher of the deaf on staff and teachers of the deaf to

continue visiting remote schools across the region.

A family camp was held for 24 years at Roses Gap for families with deaf and hearing impaired members. This camp became a muchanticipated weekend for many students as in most cases they were the only students attending remote schools with a hearing loss. Many great friendships and careers have resulted from these weekends. Families travelled from across Victoria to attend the weekends as it was the only camp available to the deaf children and their families.

Members of the committee received audiology training and began providing hearing screenings first at the Wimmera Machinery Field Days in a tractor cab, and later from a caravan with a soundproof booth.

The Wimmera Hearing Society gained substantial funding in 1998 allowing the purchase of a custom renovated bus with 2 hearing booths and to meet the cost of a fulltime manager for the service. With this extra funding it was able to expand its services to the whole of Western Victoria. Over time it was able to gain extra funding to employ an extra worker to manage the office and another to be out and





INDEMAN

about with the mobile testing unit, attending field days, health expo days, schools and visiting remote rural towns that had no access to hearing services.

With funding from philanthropic trusts and donations the mobile testing unit was upgraded from a caravan to a bus to a purpose-built unit and finally to a mobile motor home converted to mobile testing unit.



The Wimmera district is part of the Grampians region in western Victoria. The district covers the dryland farming area south of the Mallee scrub, east of the South Australia border and north of the Great Dividing Range. It is the land within the social catchment of Horsham, its main settlement.

Volunteers were trained each year to keep their skills up to date – many of them completed counselling courses and noise management courses allowing Workcover hearing assessments to be conducted for local industries.

The organisation had given presentations to five National Health Conferences over the years.

But Government funding dried up in 2017.

Since then, Wimmera Hearing Society has survived on small ad hoc funding. In 2019, the mobile unit was sold to keep the organisation running – but that worked for only for a short time.

"To the mighty Sue Ward, her helpers, the committees and volunteers over the years, you are the epitome of the spirit of community service," chair of Deafness Forum Australia David Brady said. "You have been a Deafness Forum member for such a long time and we will miss you, and so too will the grateful communities of the Wimmera district."



Even in its final days, the organisation is active in serving its community. School visits and agricultural field days are booked. The office will be operated by volunteers until closing its doors for the final time on 31 March.



The sound of a motorcycle



The sound of a motorcycle is shaped by many influencing factors and to be a successful product it has to meet the requirements of three distinct and often conflicting perspectives.

Motorcycles have to meet government noise regulations; the user wants their motorcycle to generate an emotional and visceral response and the manufacture has to design a product that balances all of these often-conflicting requirements in an economically viable product.

The job of a motorcycle designer is to take the competing requirements and develop a product that satisfies all. The packaging constraints, manufacturing complexity can be staggering and not always successful. The delicate balance is many times thwarted by the end user installing aftermarket equipment.

The motorcycle exhaust system is a critical component in defining the performance, styling, and sound quality of the motorcycle. Packaging constraints, weight, styling, and cost are all considerations that are assessed in exhaust system design.

A basic muffler design may include a perforated tube and plug whereas a more complex design could include several acoustic elements along with tail pipe emission control technology.

As the size of the exhaust system increases, the relative engine performance increases and the overall sound level decreases. Noise legal highperformance motorcycles may have a minimum of 10:1 ratio of exhaust to engine volume whereas a cruiser style motorcycle would be much less. An exhaust system with good sound quality has a consistent increase in sound level with engine RPM and there are no significant resonances. The sound of an intake is usually not desirable and subtracts from the overall sound quality of the vehicle. Similar to the exhaust system the volume of an intake system does have a direct effect on vehicle performance and sound level.



The motorcyclist wants to establish an emotional connection with their bike. Each machine has its own distinctive characteristics that attract the rider. It may be the visuals or performance but for many it is the sound quality. What might be music to the ears of one can be an unnerving source of irritation to another.

Alexander BJ Jaeger, Noise News International.



New directors join the board of Deafness Forum Australia in 2023

The board of Deafness Forum Australia, elected by and representing its membership, sets the direction and policy on key issues.

The Board ensures the organisation is focused on its purpose and strategic objectives and manages its resources efficiently and effectively for the future.

The directors' various life experiences and professional expertise, coupled with the Deafness Forum's activities and consultative processes, ensure the organisation has the authority to respond to key issues common to the entire deafness sector.



Jennifer Clemesha

Jennifer is an experienced professional in the not-for-profit and public healthcare sector.

She is a qualified chartered accountant and started her career in big 4 accounting specialising in not-for-profit and middle market entities, advising businesses on audit compliance and process improvements.

Having a special interest in hearing from her family history of hearing loss, she then

retrained as an audiologist and spent 8 years working with adults and children with severe to profound deafness in some of London's busiest hospitals. Her work there inspired her to complete certificate II in British Sign Language.

She returned to Australia in 2021, and after a short stint at the National Acoustic Laboratories, now works for Cochlear Ltd.

She has two young children, one of whom is on the autism spectrum. Her personal experiences have fueled her passion for evidence-based, patient-centred, and neurodiverse affirming disability services.



Catherine Morgan

Catherine is a passionate audiologist with more than 15 years' experience in clinical practice with hearing impaired children and adults.

She has led international multicenter studies, and more recently in executive leadership of National Acoustic Laboratories' Clinical Trials business model.

"I have worked in range of industries within health operating in highly regulated areas, both for-profit listed and not-for-profit organisations."

"The role at Deafness Forum excited me both with respect to the individual challenges associated with attending to the growing issue of hearing health and wellbeing and the collective opportunity to make a difference across the wider community."





Barry MacKinnon

Barry has been actively working on behalf of Deaf and Hearing Impaired people for 30 years.



He was until recently the President of the Deafness Council Western Australia, and a chair of the state's Disability Services Commission.

Barry continues to provide advice, guidance, and policy suggestions to various Deafness Forum policy papers and positions to the Commonwealth Government.

He spent 6 years as leader of the West Australia Liberal Party and Leader of the Opposition between 1986 and 1992. In 1997 he was made a Member of the Order of Australia for services to people with hearing impairment. He also received a Centenary Medal in 2001. In 2022 he was made an Honorary Life Member of Deafness Forum Australia.

Directors continuing in their roles

David Brady is our chairperson in 2023.



Michelle Courts (SA) and Raelene Walker (WA) are vice-chairs. Rhonda Locke (NSW) is our brand and marketing adviser. Dwin Tucker (NSW) is treasurer. <u>Learn more</u> about them.



Judy, a One in Six reader, told us that some (maybe most) MacDonalds restaurants no longer have visual order number displays to show customers when their order is ready at the counter.

Trying to hear an announcement that your order is ready in a noisy environment is frustrating for the customer and the staff.

We posted an article about it on our Facebook page. 8,000 people read it and there were many comments, not all on topic.

We wrote to Macca's to explain that if there is a plan to remove visual order number displays it will displease several million Australians who have hearing issues. As for the 16-thousand people throughout the nation who communicate in Auslan, they are left high and dry. We said it's probably a breach of the Disability Discrimination Act.

We also tried out Macca's online complaints system. It was simple and fast - let's see how they go with the followup - Macc.as/feedback

Deaf Australia announces new board.



<u>Deaf Australia</u> is an organisation representing culturally Deaf people.





Minnesota becomes first U.S. state to screen all newborns for cCMV.

Congenital cytomegalovirus (cCMV) is a common viral infection that can have serious health effects for children if not detected early including hearing loss in about 20% of diagnosed cases.

Minnesota, in mid-western United States has expanded its newborn screening program to detect more conditions that can benefit from early intervention. Congenital cytomegalovirus becomes the newest addition to the more than 60 conditions for which newborns are screened.

Congenital cytomegalovirus is the most common viral infection in newborns. It occurs when the infection is passed from a pregnant person to their unborn baby and can cause a range of problems, including hearing loss. It's estimated that up to 300 babies out of 65,000 born each year in Minnesota will have cCMV.

"Adding congenital cytomegalovirus to our newborn screening program is a big advance in protecting and improving the health of all Minnesota children," said Minnesota Commissioner of Health Dr. Brooke Cunningham. "Parents of children at risk for permanent hearing loss will receive early support that can help them prevent potential developmental delays."

Most babies with cCMV have no symptoms of the disease at birth and are not expected to develop symptoms. However, about 20% of

babies diagnosed with cCMV will have symptoms either at birth or later in childhood.

Of that 20%, about half will have permanent hearing loss as the only symptom of the disease. The hearing loss may be present at birth or show up later in childhood. For this reason, it is important that children with cCMV have regular hearing exams even if no other symptoms are present at birth.

Screening for cCMV helps identify infants at risk of hearing loss and who may benefit from follow-up monitoring and early access to interventions such as sign language, hearing aids and cochlear implants.

Newborn screening cannot predict if a baby will have symptoms, which is why additional testing is important for children with cCMV. Follow-up urine testing within 21 days will determine whether the baby was infected with cytomegalovirus at birth. If cCMV is found in the baby's urine, more testing will be recommended to look for symptoms of the disease.

In Australia, healthcare providers offer free screening for newborn babies. The screening tests for certain rare genetic conditions and metabolic disorders. About 99% of babies are screened every year - more than 300,000 babies. Of the babies screened, around 1 in every 1,000 has a condition that would otherwise have gone undetected.







Anthony Albanese will be the first sitting Australian prime minister to march in Sydney's Gay and Lesbian Mardi Gras when he joins the parade at WorldPride festival this month.

The prime minister said he will be joined by Foreign Minister Penny Wong, the first openly gay woman in parliament, when he takes part in the event on February 25.

He said his government was committed to removing inequality on the basis of sexuality or people's identities.

"We speak a lot about tolerance – and tolerance is really important – but this is about a step that is way more important than tolerance," he said.

"We need to celebrate our diversity, not just tolerate it because our diversity is what gives our society strength."

The prime minister also paid tribute to protesters who marched for gay rights in 1978, many of whom were arrested when the first parade on Sydney's Oxford Street was dispersed.

From The Sydney Morning Herald.



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Drop us a line at <u>hello@deafnessforum.org.au</u>

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One in six Australians live with some form or degree of hearing loss. This may increase to one in four by 2050.

Hearing health is essential for general health and better hearing leads to greater wellbeing.

Deafness Forum Australia is the peak body representing the views and interests of citizens who live with hearing loss, have ear or balance disorders, people who also communicate using sign language, and their families and supporters. Our mission is to make hearing health & wellbeing a National Priority.