



## Tinnitus game-changer?

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## It's all in the delivery

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## Deaf representation: Disability Royal Commission

In a fine example of citizen advocacy, the Deaf Hub Bendigo provided 200 hours of stories featuring Deaf people's experience of violence, abuse, neglect and exploitation.

## Study shows promise for the development of gene therapies to repair hearing loss

In developed countries, roughly 80 percent of deafness cases that occur before a child learns to speak are due to genetic factors. One of these genetic components leads to the absence of the protein EPS8, which coincides with improper development of sensory hair cells in the inner ear.

Currently **one in six** Australians suffer from some form of hearing loss. This may increase to one in four by 2050. *Access Economics 2006*

Deafness Forum Australia is a Voice for All. It is the peak body representing the views and interests of the 4 million Australians who live with hearing loss, have ear or balance disorders, people who also communicate using Australian Sign Language, and their families and supporters. Our mission is to make hearing health & wellbeing a national priority in Australia.

# Can it take off here? Google Maps adds loops

From [Hearing Tracker](#)

Google Maps is now including hearing loops in the accessibility information on its website, which should prove useful for users of hearing aids, cochlear implants, and other listening devices that employ a telecoil.

It represents good news for people who are hard of hearing and use hearing aids and other devices that employ a telecoil, according to the



Hearing loops, in their simplest form, are a thin copper wire discreetly placed to encircle a room and are connected through an amplifier to the room's public address system. The amplifier feeds the sound from the PA system to the loop wire that then transmits it as a silent electromagnetic signal to receivers called telecoils that are available in many hearing aids and cochlear implant processors.

To check if a particular venue offers hearing loop communication access, the [Google Maps](#) website can be visited via a computer, a tablet, or a smart phone:

On a computer, users enter the name of a venue in Google Maps and be taken to a street map showing the location of the venue. A box to the left of the map contains information such as the phone number, street address, etc. In that same space, directly below a row of blue circular icons, is a brief description of the venue with a "continued arrow" link like this > on it. Click on that link and you'll find "Assistive hearing loop" if one is known to be present, plus applicable accessibility information pertaining to wheelchair access and other accessibility-related accommodations.

Using an app with a smartphone or tablet, this information is found by clicking on "about."

This is an ongoing project to seek out and verify hearing loop installations throughout the country, says Loop New Mexico. The listings are interactive so individuals can lend a hand in maintaining their integrity. At a venue's Google listing there is a "suggest an edit" link or, with the app, an individual can click "update this place." There are also links to add a photo and/or post a review.

Installers and others can use an online form to provide the committee with the needed information to update the listing for a venue or to add listings to the Google site. For more information, send any inquiries to [GITHLinfo@hearingloss.org](mailto:GITHLinfo@hearingloss.org)

# Kiwi researchers claim breakthrough in management of tinnitus

Auckland University researchers say they have had a breakthrough in the management of tinnitus that they hope will be rolled out worldwide.



Associate Professor Grant Searchfield said their new method used a combination of counselling and a phone game.

People with this common condition hear ringing or other noise when there is no outside sound. It can range from mild, to severe and disruptive. There is no cure but there were techniques to lessen the impact.

University of Auckland audiology associate professor Grant Searchfield said its new method, using a combination of counselling and a phone game, worked for more people and in a much quicker timeframe than others.

There were already phone apps but the difference in the study was that participants also had counselling, and the games were then individually tailored, he said. It helped to rewire the brain.

"Over time peoples' focus on the tinnitus changes, declines, and it fades in the background where people just don't notice it," he said.

"It becomes just another sound in the background, not worthy of attention."

Everyone in the study had to have moderate to severe tinnitus to take part, he said.

Sixty-five percent of those using the method noticed an improvement within 12 weeks, where other methods often took about a year, he said.

Some participants said it was life changing.

Dr Searchfield hoped the method would soon be able to help more people cope better with their tinnitus.

"It can mean that they return to work sooner, it may mean that their relationships improve, it's likely that their sleep improves. Typically a reduction in tinnitus will also be associated with a reduction in any depression and anxiety as well," he said.



# Long-term funding needed for Government hearing services for vulnerable Aussies



Deafness Forum Australia has highlighted to the new Government the importance of committing to funding the services delivered by Hearing Australia for children, young adults, adults with complex needs and Aboriginal and Torres Strait Islander peoples.

In our view, Hearing Australia is key to the Australian Government's goals of improving the hearing health of First Nations children and preventing avoidable hearing loss in the whole of the population.

We are concerned that there is no long-term Government funding commitment to these services:

- Funding expires in mid 2023 for the [Hearing Assessment Program — Early Ears](#) (HAPEE) program focussing on hearing loss in children aged 0-6
- The [Community Service Obligations Program](#) (CSO) contract with Hearing Australia is due to finish in mid 2024.

We believe that putting long-term funding contracts in place for the HAPEE and CSO programs is a priority for this Government.

## Sue Jo Wright: Dinner Table Syndrome



Dinner Table Syndrome is an [exhibition](#) by Sue Jo Wright on display in the Object Space window gallery at Australian Design Centre at Darlinghurst in Sydney.

'Dinner Table Syndrome' is a term used to describe the alienation deaf and hard-of-hearing people experience at every day social gatherings, such as at the dining table. This isolation often undermines a deaf person's connectedness and self-esteem.

Sue Jo Wright is a Sydney-based artist working primarily with photography, video, and textiles, which explore her identity as a Deaf person.

# Review of Disability Standards for Accessible Public Transport



The Disability Transport Standards are currently being reviewed by the Australian Government's Department of Infrastructure, Transport, Regional Development, Communications & the Arts.

We prepared a submission to the Review through the lens of our involvement in the Transport for NSW Accessible Transport Advisory Committee, of which we are a long-standing member, represented by Ms Christine Hunter.

NSW Opal travel cards data shows there were 20 million Opal card trips in the month of June 2022, implying that 3.3 million passengers per month could have had hearing loss.

In our research we found that [Transport for NSW](#) had made commendable efforts to increase the accessibility of its services for people with hearing loss, by installing hearing loops. Unfortunately, however we know that its efforts are not reaching as many people with hearing loss as needed, especially in circumstances of disruptions to commuter rail services.

On this basis, Transport's strategy for supporting passengers with hearing loss needs to include multiple forms of one-to-many real-time communication, such as text-based visual signage.

Deafness Forum Australia found that a combination of aural and text based real-time information would better meet the needs of passengers who are living with hearing loss.

Read the [Deafness Forum Australia Submission to Stage 2 Reform of Disability Standards for Accessible Public Transport 2002](#) that was prepared for Transport for NSW by our Consumer Advocate and Transport Adviser, Ms Christine Hunter.

## A Personal Experience

Most people with hearing loss would be able to relate stories of difficulty during disruption of transports services. One member of Deafness Forum reported the following incident:

She has severe hearing loss and relies heavily on high quality hearing devices. Recently she was on a train journey that was experiencing an extended delay. There were audio announcements on the train but this time it was unintelligible, largely because the sound system on that carriage was faulty. The real time station signage on the train could offer no information on the delay and was not visible from the vestibule of the carriage.

On arrival at the next train station there was unclear advice about the need for passengers to disembark and the amplified message on the station was little better. The station master was also speaking quickly, complicated by a lot of background noise. This led to much confusion for many.

She had little idea of the alternative arrangements and resorted to asking a complete stranger where they had to go and whether or not other arrangements were being advised.

Fortunately, this incident did not threaten her safety, but it was certainly frustrating and inconvenient. It also reminded her forcefully of her disability and that under these circumstances she was not able to act independently as she normally does when travelling.

The incident is not the only time that the transport system's communication strategies during disruptions have not met her needs.

In this situation, the isolation and helplessness felt by this person would have been typical of people who have hearing loss and, considering the analysis above, there could easily be many people, both those using hearing devices and those who were not, experiencing similar difficulties on a daily basis during public transport journeys.

## **Our Findings and Recommendations**

A reliance on T-coil technology is not sufficient to meet the needs of the majority of passengers with hearing loss.

Ideally, there needs to be clear real-time text-based messaging that can back up any announcements made. For example, in trains where there is rolling overhead real-time signage indicating the train route and upcoming stations, consideration should be given for updates from Rail Operations Centre to be displayed, if only to advise passengers to alight and wait for further official advice in times of delay.

Real time electronic signage should also be clearly displayed at railway stations and other transport terminals. All written and graphical transport related stand-alone signage (including maps and directions) on stations should be clearly visible and able to be understood by all commuters.

There are real-time communication apps available on smart phone devices (e.g. Tripview) which provide excellent timetable and travel information. This is a great way to access real-time information regarding timetabling and if there are delays or disruptions to services. However, given that a large percentage of the people with hearing loss who are aged over 65 years, many may not have smart phones or be able to manage this facility, particularly if they have dexterity issues or have no access to smart technology.

Current disability training for staff and operators is very general, not disability specific.

For hearing loss, the training needs to be more specific. Customer service staff and operators need to understand that it is less about speaking louder and more about ensuring that there is clarity in communication.

Unfortunately, the more recent wearing of face masks has made lip reading impossible and therefore much harder to understand face to face conversation as the sounds are also more muffled.

# All in the delivery: midwifery to speech therapy

Amidst a global pandemic, 19-year-old Siena moved out of home for the first time, settled into life at university college, and started studying to become a midwife.

Ultimately working towards the goal of undertaking medicine and training as an obstetrician, Siena's current studies have given her invaluable experience of life on a busy maternity ward. It's been a demanding time by any standards, but it's a chapter Siena said she has relished.



"I'm now in my second year of a Bachelor of Midwifery and absolutely love it. I'm very passionate about women's health," said Siena.

"I have delivered six babies so far on my university placements, with another one due this week!"

It was also during the peak of coronavirus last year that wearing masks in hospitals was made compulsory. Siena, who was diagnosed with hearing loss at three years old and wears hearing aids, said she found it difficult not being able to see their faces. It meant extra effort was needed for conversations with staff and patients, and she was constantly left feeling exhausted at the end of each day.

Siena came to Hear and Say for a series of specialised speech therapy sessions (known as [auditory learning](#)) to help make listening less draining and get the most from her hearing aids .

"When my hearing loss was first diagnosed when I was three years old, I did playgroup at Hear and Say. It was great to then go back last year and do some speech therapy which helped me with 'listening fatigue' when I'm at my hospital placement," said Siena.

"In sessions with my listening and spoken language specialist, I would practice things relevant to my work as a student midwife, such as listening in noise or from a distance, following a small group conversation of people wearing masks, and understanding and answering questions a patient might ask.

"Being able to clearly listen and speak has made the world of difference to me. From all the dancing I did growing up, to playing the piano, to the critical need for communication skills now in my career, it's really allowed me to follow my dreams."

From [Hear and Say](#)



# Deaf Hub Bendigo supplies 200 hours of stories to Disability Royal Commission



The Royal Commission's Peter Murphy (far left) and Mohamed Mustapha (far right) met with Deaf Hub Bendigo's Lem Rourke (2nd from left), Shanleigh Meldrum (3rd from left) and Elise Stewart (2nd from right).

The Disability Royal Commission has acknowledged advocacy organisation Deaf Hub Bendigo for providing 200 hours of stories featuring Deaf people's experience of violence, abuse, neglect and exploitation.

Peter Murphy and Mohamed Mustapha branch along with interpreter Nicole Clark met with the crew from Deaf Hub Bendigo in person to acknowledge the huge contribution.

"The information contained in these accounts will help us better understand the personal experiences of Deaf people in regional Victoria," said Peter Murphy from the Royal Commission's engagement branch.

The stories, which are in Auslan and recorded on video, will be translated by qualified Auslan interpreters.



## **Very little is known about how young people with disability view their wellbeing.**

We need a good measure to see if Australia is making progress in supporting young people with disability.

Monash University, the University of Sydney and Flinders University are collaborating to design a Disability Wellbeing Index about what is important to young people with disability.

The research team wants to recruit young people aged 15-29 years who are hearing impaired/ deaf and visually impaired/ blind. Communication supports will be provided. Receive a \$100 voucher.

For more information, please contact Kim at [kim.bulkeley@sydney.edu.au](mailto:kim.bulkeley@sydney.edu.au)

[University of Sydney Human Research Ethics Committee Project No. 2022/318]



# Research revolutionising treatment for hearing and vision impaired children

Researchers are working on a way to re-grow tiny hair cells in the ears of children with a rare syndrome that causes the loss of both hearing and sight.



Dr Elaine Wong, Adjunct Senior Research Fellow at The University of Western Australia and Ear Science Institute Lead Scientist, is heading a team to help children with Usher Syndrome.

"If they are not born deaf or with partial hearing then children with Usher Syndrome start losing their hearing and aspects of their vision from about ten years of age," Dr Wong said.

Dr Wong said the syndrome had a significant impact on their language and social development.

"The hearing loss experienced by these children is caused by the failure of the tiny hair cells in the cochlea and once they are lost, they don't regrow," she said.

"For the past five years Ear Science researchers have been working on a solution to regrow hair cells in the ear."

Dr Wong's work in treating Usher Syndrome-related deafness has recently been helped with a grant from the Channel 7 Telethon Trust.

"Our starting point in this ground-breaking work has been to take skin cells from people with Usher Syndrome and then, in the laboratory, change them into pluripotent stem cells which can develop into many different types of cells or tissues in the body," she said.

"Other techniques then transform them into cells with the characteristics of those we find in the cochlea, called inner ear organoids."

Dr Wong and her team's research has led to an international patent, and they are ready to proceed to research using organoids on a larger scale.

"The aim is to finally be able to test a sample of drugs that have shown promise in treating Usher related deafness by arresting the loss of hair cells. We want to also develop methods by which these drugs can be safely and effectively delivered to the cochlea."

From [The University of Western Australia](https://www.uwa.edu.au/news/2018/05/ear-science-researchers-working-on-a-way-to-re-grow-tiny-hair-cells-in-the-ears-of-children-with-a-rare-syndrome-that-causes-the-loss-of-both-hearing-and-sight/)

# I thought needing captions meant I was getting old. Turns out it is all the rage among the kids.

[Arwa Mahdawi](#) writing for [The Guardian](#)



Apparently four out of five viewers between 18 and 25 put subtitles (captions) on – but it is not for the reasons you might think

First there were the creaky knees and a newly sprouted chin hair (her name's Gertrude). Now, my journey from carefree youth to cranky middle-age has taken on a new element: I've started to watch TV with subtitles on. I don't know whether it's my ageing ear, sound mixing or modern acting techniques, but actors seem to mumble a lot these days. And the background noise is often way louder than the dialogue. Not as loud as the ads, though. Those are, by design, significantly louder than the shows.

Turns out I'm not quite over the hill yet: my TV-watching habits are all the rage among kids these days. A study [last November](#) found that four out of five viewers aged between 18 and 25 said they use subtitles "all or part of the time" compared with only a quarter of those aged between 56 and 75. There are various reasons for this, including the fact that the likes of Netflix have opened up the availability of non-English-language programming (which is one of the best things about streaming services), and have helped normalise subtitles for people who aren't hard of hearing.

There is also, of course, the fact that many of us now watch television while simultaneously staring at our phones. As one young person stated, in a recent piece titled ["How generation Z became obsessed with subtitles"](#), captions allow people to "flick their eyes up and read ahead, then take in the whole scene quickly, and look back down at their phone". I'm not a gen-Zer, but I'm guilty as charged.

Subtitles are also starting to become a creative medium in themselves, as the [much-memed captions](#) for Netflix's [Stranger Things](#) demonstrate. The team behind descriptors such as "tentacles undulating moistly", "wet footsteps squelch" and "unearthly susurrations", have said they worked hard to give hearing-impaired audiences a more [immersive experience](#) – but they've also added a fun new dimension for everyone else. Which is a good reminder that increasing accessibility is a win for everyone.



Members of the **Hearing Health Sector Alliance** met in Canberra to discuss areas of government policy that are of mutual interest. Pic: Deafness Forum's Steve Williamson is at far left and David Brady at far right. The Alliance comprises national representative peaks across four cohorts in the hearing sector. Its founding members are:

- Citizens representatives - Deafness Forum of Australia and Better Hearing Australia
- Hearing Health Professionals - Audiology Australia and Australian College of Audiology
- Service Providers/Business - Hearing Business Alliance and Hearing Care Industry Assn.
- Researchers - Ear Science Institute, National Acoustic Laboratories



**Introducing Hear With Us!** Formed in April 2022, Hear With Us is a centrally Brisbane-based organisation that meets every 3 months at a central location, and also meets outside the three-month timeline on the weekend to enable those working to attend a meeting. The organisation aims to provide education, information, and support about hearing loss issues. It also aims to also hear, listen, and be heard. Contact the [secretary](#).



### **Come to the next Soundfair Social**

Find other hard of hearing and D/deaf people to have enjoyable, meaningful conversations with, online. It is a monthly public event for people who are interested in discussing what it's like to live with hearing conditions. Sessions have closed captions and Auslan interpreters are provided upon request. [RSVP here](#)



# Auslan storytellers building accessibility

By [Celina Lei](#) for [Arts Hub](#)

**What I Wish I'd Told You** is an exhibition that has recently opened in Melbourne. But more than that, it's a national project using decolonising strategies and truth-telling to empower and affirm experiences of Deafhood.

Led by Deaf artist Chelle Destefano and Deaf advocate and artist Claire Bridge, the project engaged more than 70 Deaf storytellers and hearing allies to pave a new path of accessibility which centres autonomous storytelling over interpreting.

An important context to the exhibition examines audism, a form of discrimination which prioritises hearing people and oppresses those who are d/Deaf.

Bridge explained: "Audism is the notion that hearing and spoken languages are superior, and that being able to behave as if you can hear and speak is superior and preferred. Audist colonisation is the domination of Deaf people and the control over and erasure of d/Deaf bodies, minds, language, culture, spaces and knowledge."

This can be seen through the closing of several Deaf schools in Australia, where now only one remains, and many Deaf clubs where community gather were also sold off. Even in the everyday, audism can take the form of denying Deaf people the right to use sign language or interpreters and excluding Deaf people in conversations and as contributors.



Claire Bridge and Chelle Destefano, Simple English, with Chelle Destefano in What I Wish I'd Told You, 2022, multi-channel video projections with audio, video still. Image supplied.

Destefano added: "The Deaf storytellers in the exhibition celebrate Deaf pride, Deaf language, Deaf culture and maintaining our identity as Deaf people. The show also gives Deaf people the opportunity to see how much power we do have to stand up and ask for our rights for access and equity.

"Deaf culture goes hand in hand with Auslan. Our stories are empowered voices, with our own agency, being heard and having our Deaf experiences known," Destefano wrote.

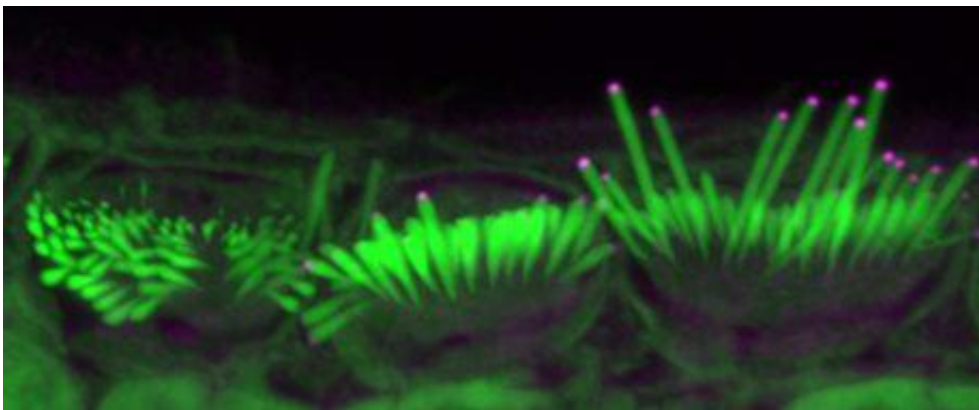
[What I Wish I'd Told You](#) runs until 28 August at Footscray Community Arts. The exhibition will later tour Victoria and NSW in 2023.

# Discovery advances the potential of gene therapy to restore hearing loss

LA JOLLA—Scientists from the Salk Institute and the University of Sheffield co-led a study that shows promise for the development of gene therapies to repair hearing loss.

In developed countries, roughly 80 percent of deafness cases that occur before a child learns to speak are due to genetic factors. One of these genetic components leads to the absence of the protein EPS8, which coincides with improper development of sensory hair cells in the inner ear. These cells normally have long hair-like structures, called stereocilia, that transduce sound into electrical signals that can be perceived by the brain. In the absence of EPS8, the stereocilia are too short to function, leading to deafness.

The team's findings, published in *Molecular Therapy – Methods & Clinical Development* online on July 31, 2022, show that delivery of normal EPS8 can rescue stereocilia elongation and the function of auditory hair cells in the ears of mice affected by the loss of EPS8.



From left: Short, intermediate and long hair stereocilia (green) of the inner ear that transduce sound in mice treated with increasing levels of EPS8 (magenta). The addition of more EPS8 results in stereocilia elongation. Credit: Salk Institute/Waite Advanced Biophotonics Core

"Our discovery shows that hair cell function can be restored in certain cells," says co-senior author Uri Manor, assistant research professor and director of the Waite Advanced Biophotonics Core at Salk. "I was born with severe to profound hearing loss and feel it would be a wonderful gift to be able to provide people with the option to have hearing."

The cochlea, a spiral tube structure in the inner ear, enables us to hear and distinguish different sound frequencies. Low-frequency regions of the cochlea have longer stereocilia while high-frequency regions have shorter stereocilia. When sound travels through the ear, fluid in the cochlea vibrates, causing the hair cell stereocilia to vibrate. These hair cells send signals to neurons, which pass on information about the sounds to the brain.

Manor previously discovered that the EPS8 protein is essential for normal hearing function because it regulates the length of hair cell stereocilia. Without EPS8, the hairs are very short. Concurrently, co-senior author Walter Marcotti, professor at the University of Sheffield, discovered that in the absence of EPS8 the hair cells also do not develop properly.



Uri Manor. Credit: Salk Institute

For this study, Manor and Marcotti joined forces to see if adding EPS8 to stereocilia hair cells could restore their function to ultimately improve hearing in mice. The team found that EPS8 increased the length of the stereocilia and restored hair cell function in low-frequency cells. They also found that after a certain age, the cells seemed to lose their ability to be rescued by this gene therapy.

"EPS8 is a protein with many different functions, and we still have a lot more to uncover about it," says Manor. "I am committed to continuing to study hearing loss and am optimistic that our work can help lead to gene therapies that restore hearing."

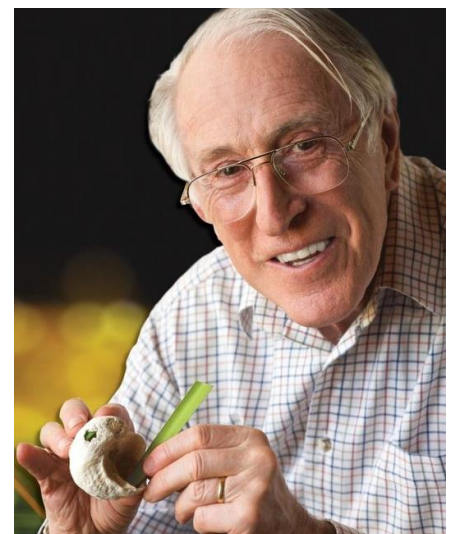
From [Salk](#), DOI: 10.1016/j.omtm.2022.07.012

**Happy 87th birthday, Professor Graeme Clark**, inventor of the multi-channel cochlear implant.

You never know where inspiration will come from. Professor Clark was walking on the beach when a seashell and a blade of grass offered the inspiration needed to navigate the cochlea with the first multi-channel cochlear implant.

That was 45 years ago.

Since then, his discovery has helped hundreds of thousands of people to hear.



**Know someone who deserves their own copy of One in Six?**

Drop us a line to [hello@deafnessforum.org.au](mailto:hello@deafnessforum.org.au)

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