



## World Report on Hearing

The first-ever World Report on Hearing will be launched in May. The Report will have 4 key messages beneath the theme "Hearing for Life" which stresses the importance of maintaining good hearing and communication across the life course.

## Beethoven's dream

Yasmin Ali writes, "Other members of the deaf community see themselves as a cultural minority, rather than as a disabled group to be 'cured'. My research aims to help those who feel disadvantaged by deafness and want to be able to hear. As Helen Keller once wrote: 'Blindness cuts us off from things, but deafness cuts us off from people'."

## Royal Commission halts public events

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has suspended public hearings due to concerns about the spread of COVID-19 coronavirus. The Commission has postponed hearings, community forums and private face to face sessions.

## Second chance for deaf pups

Sonja Coombes founded rescue organisation Hear No Evil Australian Deaf Dog Rescue in 2014 to help give deaf dogs a second chance.

## World Hearing Day & Hearing Awareness Week in Australia's parliaments

In Perth, Sydney and Canberra, parliamentarians heard the message that hearing health & wellbeing is a national priority. Chris and Bill were at the launch of World Hearing Day.

## World Report on Hearing

The World Report on Hearing will be launched on 17 May. The Report by the by the World Health Organisation (WHO) will:

- deliver a cohesive narrative on hearing loss and ear and hearing care that is based on the best available evidence
- outline the shift in the epidemiological distribution of hearing loss globally
- highlight best practices for ear and hearing care
- provide guidance to countries on recommended interventions

### **A message from David Brady, chair of Deafness Forum**

Friends,

Deafness Forum is a member of the World Hearing Forum, a group within the World Health Organization. We have been asked by the WHO to promote this first World Report on Hearing.

In Australia, we know that addressing hearing and ear care among First Nation people will make a significant contribution to Closing the Gap.

The Report will have 4 key messages within the theme "Hearing for Life" which stresses the importance of maintaining good hearing and communication across the life course:

- At all life stages, good hearing health and communication connect us to each other, our communities, and the world.
- Preventative actions at all stages of life can reduce prevalence of hearing loss.
- Interventions can reduce the impact and improve quality of life in those who have hearing loss.
- Investment in hearing health care and reduction of communication barriers is cost-effective at all stages of life for the individual, family, society, and governments.

There's more information on the Deafness Forum website and we will keep it updated:  
<http://www.deafnessforum.org.au/news-and-issues/world-report-on-hearing/>



Deafness Forum's Steve Williamson and David Brady at the World Hearing Forum in Geneva, Dec 2019.

## How can the World Report on Hearing be used?

The Report will provide governments with recommended interventions to benefit people with hearing loss in their countries. The WHO intends the World Report on Hearing to be used as both an evidence-based resource to increase understanding about hearing loss issues across the human life span and as a policy tool for guiding governments in incorporating key ear and hearing care interventions into national health plans.

## What is the geographical focus of the World Report on Hearing?

The report will be global in its reach while keeping a special focus on low- and middle-income countries where the number of people with hearing loss is not matched by the availability of services and resources.

## Who are the target audiences for the World Report on Hearing?

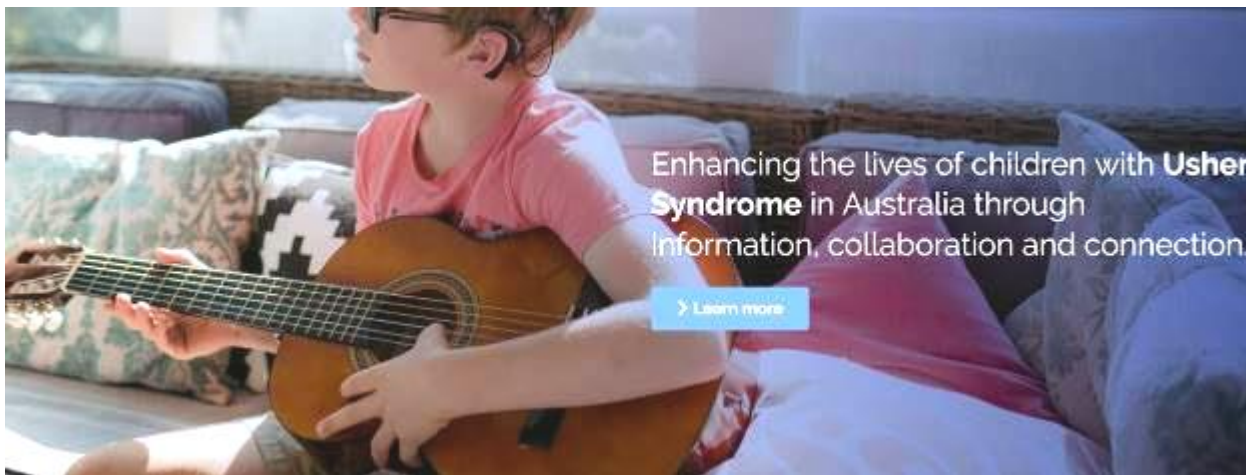
The target audiences are policy-makers and representatives of international agencies, civil society organisations, professional bodies and service providers.

## What will the World Report on Hearing say?

The World Report on Hearing features four main sections with chapters detailing the following themes:

1. Hearing across the life-course: will explain why hearing matters, the importance of communication in everyday life, and the impact of hearing loss on individuals, families and society. This section will provide a life-course perspective to hearing and outline how causative and preventative factors faced across the lifespan influence one's hearing trajectory and determine an individual's hearing capacity at any point.
2. Actions for ear and hearing care: to demonstrate that hearing loss can be prevented, and its impact mitigated. It will showcase the vast array of preventative interventions that are available. It will also outline opportunities for early identification of hearing loss at all ages and in different settings, including community-based settings. It will focus on public health approach as a means for delivering person-centred hearing care.
3. Facing the challenges: there will be a focus on epidemiology of hearing loss and its rising number in the context of ongoing demographic shifts; gaps in human resources available to provide ear and hearing care services in countries where they are most needed; and issues around access to hearing devices. It will look at challenges related to the often-complex requirements for addressing hearing loss; barriers of knowledge and awareness; and health system limitations.
4. Designing the way forward: this section will propose a package of interventions for implementation by countries to promote access to ear and hearing care. It will include health system enablers that are necessary for implementation of this package.

<http://www.deafnessforum.org.au/news-and-issues/world-report-on-hearing/>



## Usher Kids new-look website

Check out the website at [www.usherkidsaustralia.com](http://www.usherkidsaustralia.com) It's packed full of new information, including all the latest in Usher syndrome clinical research projects happening right here in Australia and internationally. There's a new resource section and updated service providers section.



### John, a Deafness Forum member writes

I always look forward to reading One in Six, which is an excellent and informative newsletter.

I was particularly interested in the article on sign language (Ed: 18 Feb 2020 edition).

The number of sign languages is much larger than identified in the article.

Many indigenous people throughout the world have developed unique sign languages that are used when tribes with different spoken languages meet.

An example is Plains Sign language in the US and Canada. There is Wikipedia article that explains the extent and use of Plains Sign Language.

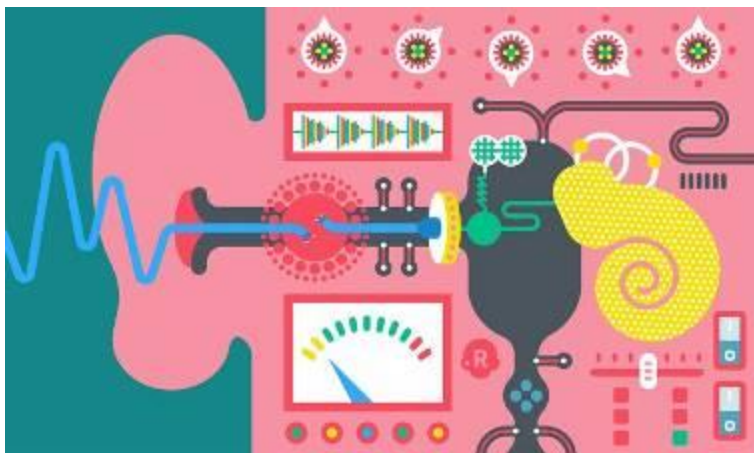
There were many sign languages in use among Australian indigenous people although most are no longer widely used and some seem to have no users. However sign language is still widely used in Kimberley Region of Western Australia when people from different tribes meet if they do not have a spoken language in common. Sign languages are also used for cultural ceremonies, which seems a major factor for the survival of the languages, and of course the indigenous sign languages are also used for hearing impaired members of the communities.

Read the original article at <https://www.deafnessforum.org.au/sign-language-around-the-world/>

## Beethoven's dream

The great composer wished for a cure for his hearing loss.

Yasmin Ali writes, research could make it a reality for my twin brother – and millions more.



In 1802, under a June Sun, a 31-year-old Beethoven paced through the countryside around Vienna. Rays of sunshine pierced through the trees, the hard soil crunched beneath his feet and birds conducted their own orchestra. But Beethoven didn't marvel at these details; he was preoccupied by thoughts of suicide. Some years earlier, he had started to lose his hearing, and although it wasn't yet severe, he was still struggling immensely with his condition. Living with hearing loss made his life a "wretched existence" that drove him into despair, he wrote. He still persevered with his work, and went on to create timeless music. But he found little joy in the process.

I observed a similar struggle at first hand, as my twin brother Islam, when we were 18 years old, started to lose his hearing. I noticed changes in his personality, too. He was always the outgoing troublemaker, but became quiet and withdrawn. Because hearing loss isn't visible, I didn't know what he was going through, which also made it difficult for me to be there for him.

Today, 466 million people worldwide have disabling hearing loss, and over 900 million are expected to have it by 2050, according to the World Health Organization. Its impact is often underestimated compared with other disabilities, but people with hearing loss constantly experience communication difficulties in their everyday lives. They often mishear speech and find it very difficult to follow conversations. These miscommunications can lead to individuals feeling isolated as they struggle to take part in social interactions, ultimately leading them to withdraw from society. As Helen Keller once wrote: "Blindness cuts us off from things, but deafness cuts us off from people."

To this day, there is still no cure for sensorineural hearing loss (the most common type, and the one Beethoven had). We have advanced technological devices that amplify sound, such as hearing aids and cochlear implants, but these still don't restore hearing. In my and my brother's lifetimes, I'd like to see research make that possible.

Sensorineural hearing loss occurs as a result of damage to the inner ear organ, called the cochlea, which has intricate sound-sensing hair cells that are responsible for hearing. In humans and other

mammals, any damage to hair cells is irreversible. Other animals, such as birds, fish, amphibians and reptiles, can spontaneously regenerate their cochlear hair cells, meaning that any hearing loss they develop is only temporary.

Scientists have been studying the regeneration process of hair cells in non-mammals, and have identified various genes and proteins that have central roles. These can be targeted to stimulate support cells in the cochlea to in turn create more hair cells and replace those that died.

Some of these cell therapies have been successful in restoring the hearing of mice and guinea pigs: a breakthrough! These advances have led to the development of more therapies, and one such therapy is now being tested for the first time in humans. The REGAIN clinical trial (REgeneration of inner ear hair cells with GAMMA-secretase INhibitors), an international collaboration led by researchers at University College London, is testing a molecule called  $\gamma$ -secretase inhibitor that could potentially restore hearing by encouraging supporting cells to transform into new hair cells themselves.

If it works, such a scientific advance could transform hearing health care as we know it. My own research investigates the impact hearing loss has on people's mental well-being. Many people share Beethoven's despair when they realise that their hearing can't be restored. Hope is an essential element for good mental health.

Other members of the deaf community see themselves as a cultural minority, rather than as a disabled group to be 'cured'. My and other scientists' research aims to help those who feel disadvantaged by deafness and want to be able to hear.

Islam and I come from interracial parents, so we look very different. I have white, freckled skin, and his is olive (he gets perfect suntans, and I turn into a tomato). I have blue eyes, and his are hazelnut. I have normal hearing, whilst he has severe hearing loss. He and I have shared the many chapters of our lives, and when things became difficult as his hearing declined, what helped us cope was being able to make sense of it all together. Communication, self-expression, hearing and being heard (even through sign language) are basic human needs. I hope that when I voice support to my brother in the future, that he'll be able to hear it, receive it and not feel alone.

When Beethoven lost his hearing, he secluded himself from society — but one thing that gave him strength was the hope that his hearing could be regained one day. But each medical remedy he attempted failed. In 1802, he wrote: "But, think that for six years now I have been hopelessly afflicted, made worse by senseless physicians, from year to year deceived with hopes of improvement, finally compelled to face the prospect of a lasting malady."

Beethoven's dream of regaining his hearing did not come true for him, but through the scientific advance of regeneration of hair cells, it could become a reality 217 years after his June walk. On his deathbed, it is said that Beethoven's last words were "I shall hear in heaven!" Luckily for us, those facing hearing difficulties could soon be able to hear on Earth.

Article by Yasmin Ali, winner of the Young Scientist Essay Competition 2019, writing for Nature.

[https://www.nature.com/articles/d41586-019-03358-x?fbclid=IwAR3DewMbDZfbyauKTMiQducnLkgGSQu6f3QAES40lltKg3\\_k0PqVqugDmJQ](https://www.nature.com/articles/d41586-019-03358-x?fbclid=IwAR3DewMbDZfbyauKTMiQducnLkgGSQu6f3QAES40lltKg3_k0PqVqugDmJQ)



Dear members and friends,

I wanted to give you a report on how Deafness Forum is operating in this current health emergency.

We will keep our communication channels open. But we can't anticipate the effect of increased demand on Australia's NBN.

Our IT provider has made arrangements to fix any bugs that might occur.

Our accounting firm has put measures in place to pay bills so that our creditors are not disadvantaged.

We have contacted our funders.

We ask that our volunteers and representatives on various government organisations and community groups follow the directions of those organisations and put their individual health and wellbeing first.

We will reduce or avoid face to face meetings and travel where possible. We have one staff member (yours truly) - without wishing to appear precious it's important that I work from home in Canberra to avoid disruption to our advocacy work. I know that you will let me know if I drop the ball at any time. You can email me at [steve.williamso@deafnessforum.org.au](mailto:steve.williamso@deafnessforum.org.au)

Our board members are sensible and experienced people practiced in overseeing the organisation from a distance via regular reports and board groups which focus on special areas such as finance & audit.

This week, the board introduced an Epidemic-Pandemic policy and procedure that will guide our operation in the months ahead. This new policy comes from a template created by the Institute of Company Directors Australia and was made available at no charge to not for profit organisations. If your organisation wants to create its own policy and procedure you can download the free template at <https://www.deafnessforum.org.au/epidemic-pandemic-policy-and-procedure-template/>

These are, I hope reasonable and necessary arrangements for the organisation.

But mainly, our thoughts are with you and your family.

Best wishes

Steve Williamson

CEO

Deafness Forum of Australia



# ROYAL COMMISSION

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has suspended public hearings due to concerns about the spread of COVID-19 coronavirus.

The Commission has postponed the following hearings:

- Education scheduled for next week in Brisbane
- Justice scheduled for April in Brisbane
- First Nations People with disability scheduled for May in Alice Springs

Community forums to be held in Tasmania this week were suspended.

Face to face private sessions have been suspended for the time being.

In this captioned Auslan video you can learn how to use the Disability Royal Commission website.



The video explains the many ways you can choose to engage with the Royal Commission to share your experience, to find support or legal assistance and much more.

[https://disability.royalcommission.gov.au/publications/welcome-royal-commission-website?fbclid=IwAR1gp1Ad\\_puvOJXzLcOnBAdd-zVRi5HOOdDI2C0dct9Iy-dS7gygNfzw\\_UA](https://disability.royalcommission.gov.au/publications/welcome-royal-commission-website?fbclid=IwAR1gp1Ad_puvOJXzLcOnBAdd-zVRi5HOOdDI2C0dct9Iy-dS7gygNfzw_UA)



## Deferred: Libby Harricks Memorial Oration 2020



Deafness Forum of Australia and Audiology Australia present the annual Libby Harricks Memorial Oration.

The Oration series raises awareness of issues of hearing health, deafness and ear and balance disorders.

This year's Oration was to be a key-note address during the 2020 Audiology Australia conference in Perth in May. But due to the current health emergency, organisers of the conference have deferred it to a yet to be decided date later in the year.

We will keep you posted on developments.



The 2020 Oration is to be presented (date to be fixed) by Clinical Professor Harvey Coates AO DM MS FRCS(C). His topic is 'Indigenous Ear and Hearing Health: Tackling the silent epidemic'.

Professor Coates is a paediatric otolaryngologist at the University of Western Australia, and retired from PMH for Children after 38 years' service. His Otolaryngology training was at Mayo Clinic and he has recently been awarded the DM degree from UWA for his thesis on 'Translational research in otitis media in Western Australian children'.

Professor Coates has received many National, Society and Community awards including Officer of the Order of Australia, the inaugural Royal Australasian College of Surgeons ATSI Ear Health medal and the Fiona Stanley Medal. He has been a keen participant at the WHO over the last three years and was involved in Commonwealth Minister Ken Wyatt's Roadmap for Ear and Hearing Health committee.

# The woman finding new homes for deaf doggies

By Tami Head, News Corp Australia



Sonja Coombes founded rescue organisation Hear No Evil Australian Deaf Dog Rescue in 2014 to help give deaf dogs the second chance they deserve.

"I was working with another rescue groups fostering deaf dogs but found that they just kept getting overlooked," she recalls. "The cute puppy who wasn't deaf would get taken, but the dogs with a hearing impairment would get left.

"It became really obvious that these guys needed more attention." And thus Hear No Evil was born.

Originating in Townsville, there are now volunteers all across Australia who act as foster parents of hearing-impaired dogs, providing training and care until they are matched with an adoptive family. But quite often, the foster carers end up being the ones who keep the dog, Coombes has found.

"Effectively, it's what we call a foster fail," she said. "My vision is to create a strong, compassionate and respected rescue that not only saves and rescues deaf dogs but also one that helps educate the community that a deaf dog is first and foremost just a dog and deserves a second chance to find a safe and loving home."

As for her advice for those looking towards adoption, Coombes said they're looking for people who aren't willing to give up at the first hurdle. They must understand or be willing to learn what's going on for the dog," she said.

"The bonus is people who will spoil the crap out of them. We want them to live their best life."

From The Advertiser SA, <https://www.adelaidenow.com.au/lifestyle/pets-and-wildlife/meet-the-woman-finding-new-homes-for-deaf-dogs/news-story/fb8698830877b4e32929342c793588ef>



## Hearing Australia Hear&Now 2020 Challenge

According to research commissioned by Hearing Australia (formerly Australian Hearing), nearly 60 per cent of people interviewed say their partner or parent doesn't believe they have a hearing problem or they think they're coping fine – despite knowing their hearing isn't what it used to.

For the over 50s, almost 75 per cent of those who have a family member who hasn't had a hearing check, say it's likely due to them thinking they don't have a problem.

The research findings also indicate that the most common emotion felt by those who have a family member with hearing loss was frustration (68 per cent) – and the most affected are women and those aged over 50.

To make getting hearing help easier, Hearing Australia is calling on all Australians to take part in the Hear&Now 2020 Challenge by jumping on to [hearing.com.au](https://hearing.com.au) to do a 10-minute hearing check.



## Coronavirus information for people in the National Disability Insurance Scheme

The NDIS said that it is taking necessary steps to prepare and support participants and providers.

There is *Easy Read* information, answers to frequently asked questions and the latest information about the NDIS' response to the coronavirus (COVID-19) at

[https://www.ndis.gov.au/understanding/ndis-and-other-government-services/ndis-and-disaster-response?fbclid=IwAR3ZXdCIYMTHUx5qthE3VE9iCJl3lL9UIwl1afqjcx\\_eqm5fqObQInXSMgU](https://www.ndis.gov.au/understanding/ndis-and-other-government-services/ndis-and-disaster-response?fbclid=IwAR3ZXdCIYMTHUx5qthE3VE9iCJl3lL9UIwl1afqjcx_eqm5fqObQInXSMgU)



## World Hearing Day & Hearing Awareness Week, March 2020

In Perth, Deafness Forum directors Raelene Walker and Jeff Johnson dropped by to see Martin Pritchard (at left), a Labor member of the Western Australian Legislative Council.

Rae, Jeff and Martin are working together to create a new Friends of Deaf and Hearing Health group in the WA Parliament.

Martin, a former union official, now politician and advocate for vulnerable members of the community has been a patron, advocate and supporter of Shenton College Deaf Education Center for many years.

David Brady, chair of Deafness Forum was in Sydney for a NSW Parliamentary Friends of Hearing Health and Deafness breakfast event.

His interpreter was Sean Sweeney became an international media celebrity for his signing of NSW bushfires emergency announcements.

During the event NSW parliamentarians learned the results of their hearing tests conducted a week earlier by Macquarie University.



Later the same day, David was with Tony Coles from Audiology Australia to launch World Hearing Day in the Federal Parliament in Canberra.

World Hearing Day is held on 3 March each year to raise awareness on how to prevent deafness and hearing loss and to promote ear and hearing care across the world.

World Hearing Day is part of Hearing Awareness Week in Australia.

## Launch of World Hearing Day in the Federal Parliament, 3 March 2020



The Government minister responsible for Hearing, Mark Coulton with Jane MacDonald from Hearing Business Alliance; Opposition Health Spokesperson Chris Bowen; Communications Minister Paul Fletcher with Deafness Forum's Steve Williamson.



Trent Zimmerman was the chair of the Parliamentary Hearing Health & Wellbeing inquiry in 2017; Chris Bowen and former Prime Minister Bill Shorten; Jane MacDonald with Better Hearing Australia national president Andrew Bush.

**Know someone who might like to get their own One in Six?**

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

We acknowledge the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay respect to them and their cultures, and to elders past, present and future. We acknowledge the challenge of overcoming high levels of ear health issues among First Nation people and its role in Closing the Gap. We acknowledge the risk to indigenous sign languages and the importance of Auslan.

People with disability have and continue to be subjected to isolation, exploitation, violence and abuse in institutions. We thank the Australian Parliament for its bipartisan support of a Royal Commission into the evil committed on people with disability.

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