# CICADA CHORUS SHARE | LISTEN | CONNECT WINTER 2023

## **FUSING BIOLOGY** With the Bionic Ear

### **GRAEME CLARK**

History made from humble beginnings

## ELLA

A little girl's view of hearing

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## PRESIDENTS DESK

Welcome to all of our new members, And also to our new group now meeting in Townsville. Thank you to John Foreman and his wife Coral for pioneering CICADA in North Queensland.

Throughout May John and I visited Cairns, Townsville, Mackay, and Rockhampton

promoting CICADA Queensland but also raising awareness for cochlear implants and hearing loss while exhibiting at Regional Disability Expo's. By the end of this year CICADA Queensland will have exhibited at no less than 9 expo's throughout Queensland.

It is important to note that typically I feel we learn more from those who visit us at these events than we give out. Every MeetUp or Expo that I have attended this year has always taught me something new, but also shown me areas where we need to grow and assist our members. We may have a Hearing Loss in common, yet so many of our peers have needs and journeys that differ dramatically and we all have unique situations and stories to share.

The median age of CI recipients in Queensland is now below 60 and we have members who recently were implanted and are in their early 20's. Recently I was told that the median age of Candidates waiting for surgery was under 55 (in Queensland).

With that knowledge it is important to know we are growing but also our median age is becoming younger. We need to embrace each other and learn more to share ~ listen and connect. We encourage you to get together, be social and willing to comment and ask questions on social media. Do not feel like you have to wait till the next MeetUp to ask a question - we are a community of people who are all over Australia and Queensland, who can, and should, assist each other.

Being social in a public environment is a big part of rehabilitation and should be encouraged, so get out there, ask on facebook who wants to meet for a coffee, connect with others and make new friends. That is the backbone of who we are.

Thank you to our coordinators around the state, who truly put in so many hours behind the scenes to ensure support is given and events take place. We are truly grateful.

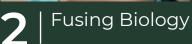
John Ross, President



John Foreman at a Regional Disability Expo.

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# FUSING BIOLOGY WITH THE BIONIC EAR

This article is provided with the kind permission of the author Heidi Vella. Published Friday, July 7, 2023.

Researchers are trying to improve the way people with cochlear implants perceive speech and music in noisy surroundings.

If Beethoven, who died in the early 1800s, had gone deaf today, his experience would have been very different.

That is thanks to the cochlear implant. Developed in the 1960s, it is the first ever bionic device created to restore a sensory organ and has now been fitted in over a million people.

Although not perfect, almost every recipient will eventually understand speech, even in modest background noise.

Yet, beside incremental improvements to the implant's algorithms and coding systems over 40 years of operation, the underlying technology has largely remained unchanged, even though the number of research publications on the topic have tripled per decade in the last 30 years.

This could soon change. New research is seeking to combine gene therapy with improvements in the mechanical engineering of the cochlear implant to improve hearing outcomes for patients.

This endeavour is ever more important, given it's expected that one in every 10 people will have disabling hearing loss by 2050, and because researchers are starting to find evidence of a link between dementia and this sensory loss.

The cochlea is a small, hollow, snail-shaped structure in the inner ear that connects to the auditory nerve. Three-and-a-half-thousand acoustic hair cells in the inner and outer cochlea convert vibration of sound into an electrical signal into the brain.

These cells are like 'keys on a piano' and range from low to high frequency, explains Dr Robert Gay, director of pharmaceutical approaches at Cochlear, a Sydney-based manufacturer of the device.

For many people with profound hearing loss, these hair cells are damaged, lost or mutated, but a residual population may still exist that can be stimulated.

The Cochlear Implant, which is surgically implanted into the cochlea, contains 22 very small electrodes – bionic replacements for the defunct hair cells – at the end of a very thin tip that is around 400 micrometres wide.

The external device acts like a hearing aid, taking in sound and speech, where a processor converts the sound waves into a digital code that is then sent to the transmitter coil and transmitted across the skin into the electrodes. The electrodes stimulate the auditory nerve, which then transmits the sound to the brain.

"The plasticity of the brain embraces the signals from the artificial 'piano keys' and learns to interpret them as if they were coming from the ones a person was born with," explains Gay.

Though undoubtedly a medical marvel, the sound output from the cochlear implant is far from pitch perfect. People who previously had natural hearing say sound is robotic or electronic, making music enjoyment difficult, and its software stack cannot very well process for tonal languages, such as Cantonese or Thai. For a small number of eligible people, it doesn't work at all.

The scope for addressing these limitations through mechanical engineering is now limited, according to experts, which is why researchers have turned to pharmaceutical and biological interventions.

One such study is a first-in-human clinical trial, conducted by four Australian universities, to use gene augmentation therapy to improve hearing outcomes in cochlear implant patients.

### "We know we have successfully reengineered the cochlear implant array to establish a new, super-efficient gene delivery technology."

The trial, involving 15 implant recipients, hopes to address the 'neural gap' challenge of cochlear implants that affects hearing dynamics and pitch perception. This is, put simply, the gap between the electrode array and the wasted-away auditory neurons. The gap makes the selective recruitment of discrete subpopulations of neurons normally associated with particular sound frequencies (tonotopy) challenging.

The Cochlear Implant Neurotrophin Gene Therapy (CINGT) clinical trial hopes to bridge the gap by delivering small DNA molecules (neurotrophic factors BDNF and NT3) that have previously been shown in animal studies to stimulate rapid directed regrowth of neurons towards the implant electrode array.

It's hoped the treatment can bring the nerve fibres



closer to the cochlear implant electrodes for much more local recruitment of the neurites. This could more authentically recreate the tonotopic map [the spatial separation of frequencies within the inner ear] to improve pitch perception.

"This could be improved even further in 'nextgeneration' cochlear implants where closer nerve proximity would make increased electrode density beneficial," explains Professor Gary Housley, who holds the chair of physiology at the University of New South Wales and is leading the trial.

Notably, delivery of the DNA into the targeted area of the ear is done by a patented method, called bionic array electric gene electrotransfer (BaDGE), developed at UNSW.

The cochlear array has been reengineered to put a superfine lumen through the centre from which DNA can be pumped.

The process is a technological breakthrough and nullifies the need to use a technique called electrotransfer, which requires high currents that can damage tissue, says Housley.

"We adapted the electrode array to create an electric lens, an asymmetrical compression of the electric field, which is very efficient at making DNA stick to cells without damaging tissue. The DNA solution is inert except within the focus on the electric field."

Housley and his team are confident they have proved the process doesn't cause harm to patients or make hearing outcomes worse, but they need to complete data analysis to determine whether better hearing outcomes have been achieved. The full study results are expected later this year.

"We know we have successfully reengineered the cochlear implant array to establish a new, superefficient gene delivery technology," he says, "In the future, if we can repair the ear with therapeutics, the array in the cochlear implant may become a delivery instrument, with patients requiring it only temporarily – but that's looking decades into the future."

Cochlear is also running a clinical trial that seeks to protect auditory neurons from trauma – such as when an implant is inserted – with a cochlear implant that releases an antiinflammatory drug therapy directly to the cochlea that could be neuro-protective and potentially improve hearing outcomes.

Another team of researchers at the University Medical Centre Göttingen in Germany are hoping to start clinical trials in 2027 to prove the efficacy of a cochlear implant they have developed that uses optogenetic gene therapy and an optical stimulator instead of conventional electrode arrays.

Tobias Moser, professor of auditory neuroscience at the Institute for Auditory Neuroscience and InnerEarLab at the university, who is heading the multi-million-euro research project, believes it could be the 'game-changing' moment the cochlear implant has been missing all these years.

The technology aims to address the poor quality of sound encoding of the implant by using light, instead of electrical current, to focus and stimulate the auditory neurons more efficiently. Currently, the large lateral spread of electrical current from each electrode means too many auditory neurons are stimulated at the same time, which is why a user might find it hard to converse in a busy, noisy environment.

The research, which started in 2007, is based on an optogenetics method that emerged around the millennium and has been shown to work in rodents. It was discovered that a genetic trigger – in this case f-Chrimson, which is delivered to the neurons via a harmless viral vector containing the DNA information – can make auditory neurons lightsensitive.

This creates a light-activated ion channel that allows

ions to cross the membrane and charge the auditory neuron, firing an action potential that travels to the brain and is identified as sound.

According to the researchers,the technique could allow future cochlear implants to transfer sound stimuli via up to 30 independent stimulation channels, using microscale light sources such as laser-coupled waveguides in the cochlear implant. This could provide significant improvement in pitch discrimination and volume, potentially much closer to those of a normal hearing person, they say.

The new cochlear implant would use hermetically sealed laser diode arrays to emit light, which is then focused onto polymer waveguides, like optical fibres, replacing the electrical input. Initial investigations suggest the device could be mass-manufactured and worn for up to 20 years.

"The idea of using optical stimulation to overcome the bottleneck of poor spectral selectivity could be transforming. People could have much more information available to their brains," says Moser. "The cochlear implant is nothing other than a brain link and we're essentially working on making this interface more powerful."

To achieve clinical trials by 2027, the team need to develop the chip that drives the laser diodes and secure venture capital funding, among other things. Other challenges include addressing safety concerns, and some evidence of auditory neuro losses over time. Others are also looking at developing light-based cochlear implants, including researchers at The University of Melbourne.

Gene therapy treatments for cochlear implant users are 5-20 years away, depending on who is being asked. But, besides developing the technology, another barrier to adoption could be the price: a gene-therapy treatment currently available to restore genetic-related sight loss costs a considerable \$800,000.

Nevertheless, Cochlear's Gay believes "niche areas" of hearing loss can be cured with gene therapy. In 30 years' time, he expects the cochlear device could have advanced to the point it will be concealed within a patient's skull, it will contain more than 22 electrodes, and possibly be delivering drugs and reporting back on infections.

Raymond L Goldsworthy, an associate professor of research otolaryngology at Keck School of Medicine of University of Southern California and a cochlear implant recipient of 30 years, is equally optimistic.

"In 20-30 years', time I think hearing loss could be restored close to normal," he says. "I used to think it was the cochlear implant versus neuro regeneration, but both are making great progress and it'll probably be a hybrid approach, with the implant still used but neural regeneration bridging the gap."

To continue reading about advances in hearing engineering go to https://cicadaqld.org/featuredarticles/f/fusing-biology-with-the-bionic-ear

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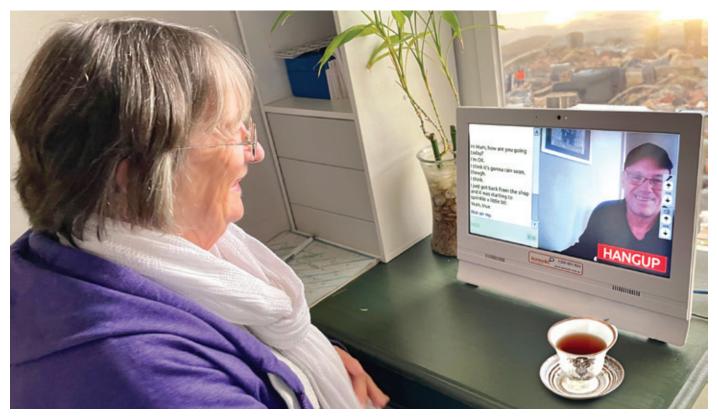
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# HOW WE'RE CONNECTING AUSTRALIA'S HARD-OF-HEARING COMMUNITY



After living with hearing loss for five decades, Penny Phillips has tested all sorts of accessible tech – from a Captel phone that endured "endless delays", to an "extremely slow" teletypewriter. But it was ultimately a captioning phone designed in Melbourne that reconnected her with the "joy" of speaking face to face.

"Before I got my Konnekt phone, I hadn't used my voice on the phone for over 40 years," says Penny, 72, who as the secretary of Cicada Queensland is an active advocate for people with hearing loss. "It used to be email, texts, or Facebook Messenger. But now I've got my voice back!"

Originally developed in 2013, it wasn't until 2020 that its diverse uses were recognised by Telstra and the Department of Communications.

The pilot program led to a series of broadbandenabled enhancements, and ultimately to a program providing free devices to 170 hard-ofhearing seniors around Australia.

### **Solving Multiple Needs**

Konnekt's simplicity makes it a practical solution for anyone with hearing or vision loss, dementia,

arthritis, or other mobility challenges that confront old age. "You just press your contact's name and if they're available they'll pop up straight away with captions that always work well if people speak clearly," says Penny. "It's been wonderfully uplifting having normal conversations with my sons – instead of relying on slow text messages."

Konnekt calls it "the world's simplest phone" – and it's hard not to agree. Making a call involves one touch of the large named call buttons on the 15inch screen, or entering a regular phone number. The powerful speaker bar provides clear sound, and captions pop up while you're talking – available up to 7cm tall in 40 different languages. The phone also supports free Skype calls, Bluetooth for headphones and hearing aids.

This world-class innovation is a great example of how the power of broadband communications can improve outcomes for the isolated and elderly. More information on the Konnekt phone is available at the Konnekt website.

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# GRAEME CLARKE

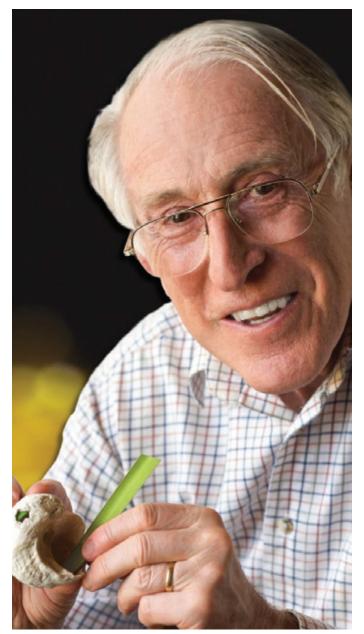
by Rob Frith

It seems to be that what you are and who you become is determined almost entirely by the environment you are raised in. Your basic genetics may give guidance or direction, but it is your experiences that mainly shape you into the person you become.

And so it was, it would seem, for Graeme Clark, the father of the cochlear implant. Graeme Clark's father, Colin, was a pharmacist and clearly endowed with high intelligence, but slowly became deaf. Indeed, so common to all who have varying levels of deafness, even with aids, background noise is debilitating and in those early days, hearing aids were of little to no assistance and Colin truly battled. The impact of his father's plight was so influential on Graeme that from a very early age, he told his teacher when he grows up, he wants to "fix ears". Graeme's single-mindedness drove him to do the seemingly impossible. A defining moment for him was to read a medical article during one of his lunch breaks as a surgeon, sitting in the park with his sandwiches. There he read the results of research from America, where it was reported that electrical stimulation of the auditory nerve caused a hearing response. That was enough for Graeme to believe it was possible and set him off on a long course of action to acquire the skills needed to do the impossible. It's amazing to learn of the inspiring support from his wife and family in making the sacrifices necessary. For many years Graeme accepted a very humble existence, and some would say he was poor. Turning his back on a lucrative lifestyle as a surgeon to obtain a PhD investigating the current status of research into electrical stimulation of the auditory nerve. During that time, they could not even afford to upgrade their car when it finally broke down irreparably. Graeme stoically stated that public transport gave him time to think about his research. Graeme always maintained a positive outlook.

What carried him through was his strong Christian faith. He prayed about every critical decision he had to make, and his faith never wavered. Arguably it was that single element that carried him to his final achievement.

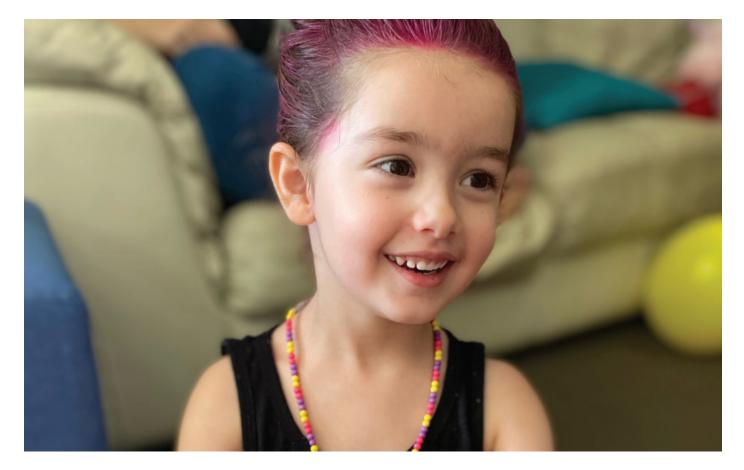
Things started to fall into place when he gained the inaugural seat as Professor of Otolaryngology in Melbourne. Building his department from the ground up, he eventually achieved his dream. To get there, he battled against the current wisdom that said a cochlear implant is not possible. He



fought against incredible odds to have the research stay in Australia and eventually commercialised in Australia. His cochlear Implant was the first successful implant in the world. It was interesting to learn that in his efforts to have the commercialisation stay in Australia, he was dependent on Australian Government Grant money. At one stage the grants may have been refused and he was asked to defend why he should be supported (remember there was an oppressive "it can't be built in Australia" thinking). He was able to demonstrate that he was way ahead of the nearest competitor who at the time was in America, listing all the features that his invention processed which were streets ahead of his nearest rival. He obtained his grant and history was made. Graeme Clark's cochlear implant was changing lives.

I think we should be proud that Australia has a true champion, an intellectual giant. Graeme Clark remains so humble he has refused continual calls to rename research centres after himself. Graeme is retired but that is only a term. He remains as active as ever and now at 88, age refuses to limit him.

\*This article is a brief summary from the book Graeme Clark by author Mark Worthing.



# ELLA GOES WILD FOR ANIMALS AND THEIR SOUNDS

From the roar of a lion to the squeak of a mouse, five-year-old Ella already has her sights set on a career working with creatures great and small.

"Ella loves animals – from turning our house into a zoo or animal hospital, to watching *Bluey*, to getting out her glue and colouring supplies to turn empty boxes into decorated cubbies for her toys," said Ella's mum, Stephanie.

"Ever since being fitted with her first hearing aid as a baby and now with her cochlear implant, Ella has come along in leaps and bounds."

"She says she's going to work at Australia Zoo in the animal hospital when she grows up."

Ella was born with mild hearing loss in her right ear which later developed into a profound loss at 18 months old, due to an inner ear condition known as large vestibular aqueduct syndrome. After receiving a cochlear implant at two years of age, Ella began attending Hear and Say for specialised speech therapy and audiology appointments. Stephanie said their family were continually blown away by their daughter's ongoing progress, and felt grateful for Hear and Say's guidance and support through a sometimes-confusing process of ensuring Ella could reach her full potential.

"Hear and Say came highly recommended to us by our speech therapist in the cochlear implant program at Queensland Children's Hospital," Stephanie recalled.

"We now see Hear and Say for weekly speech therapy, together with regular audiology and occupational therapy. The hearing in Ella's left ear also now has a mild loss, which is expected to worsen over time but for the time being is being closely monitored."

"Ever since being fitted with her first hearing aid as a baby and now with her cochlear implant, Ella has come along in leaps and bounds. More recently we've also noticed a big improvement in her confidence – we are so proud of her!

"Hear and Say always feels like a safe place for Ella, and it makes such a difference that we can do everything in one place so it's not so overwhelming for her. It's been amazing support through our hearing journey."

Reprinted with kind permission from Ella's parents, and Hear and Say, a specialist provider of audiology and speech pathology services in Queensland.



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^ Compared to previous generation Nucleus 7 and Nucleus 6 Sound Processors. ~ Comparison made using a Compact Battery Module with the Nucleus 8 Sound Processor and the Nucleus 6 (CP910) Sound Processor. # Comparison made using the Compact Battery Module for Nucleus 8 Sound Processor and the Compact Rechargeable Battery for Nucleus 7 Sound Processor. ¥ When the technology becomes available for the Cochlear Nucleus 8 Sound Processor, a firmware update to your sound processor will allow you to connect to Bluetooth LE Audio compatible devices. † ForwardFocus is a clinician-enabled feature that can be user-controlled or automated. \*\* Compared to Nucleus 7 Sound Processor with ForwardFocus on. \* The Cochlear Nucleus 8 Sound Processor is compatible with Apple and Android devices. The Cochlear Nucleus Smart App is available on App Store and Google Play. For compatibility information visit www.cochlear.com/compatibility .% For information regarding the sound processors, implants, operating systems and devices that are compatible with Cochlear's Remote Care services, visit www.cochlear.com/compatibility.

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Please seek advice from your health professional about treatments for hearing loss. Outcomes may vary, and your health professional will advise you about the factors which could affect your outcome. Always follow the directions for use. Not all products are available in all countries. Please contact your local Cochlear representative for product information. In Australia, Cochlear Nucleus implant systems are intended for treatment of moderately severe to profound hearing loss. For Cochlear Nucleus systems: This product is not available for purchase by the general public. For information on funding and reimbursement please contact your healthcare professional.

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# இ) EAR TO THE GROUND...



### FRASER COAST

CICADA QLD Fraser Coast Support group has had a change of venue, day and time. We now meet at the Hervey Bay Library. However, the Library will be undergoing roof and air conditioning

repairs from the 16th June and will be closed for 4 months. Their staff are endeavoring to find a suitable venue for the various groups who use the CREATIVE Room. Hopefully we will still be able to meet on the first Tuesday of the month from 1pm to 3 pm.

At the May meet up we had a very interesting presentation by Hearing Australia. Carla Keleher, their Community Hearing Advisor introduced Audiologist Bev Lewis. Bev's presentation on The Ear and How It Works, Types and Causes of Hearing Loss and Deafness, was very interesting with members asking many questions. Hearing Australia generously donated a TV Streamer for our lucky door prize. Bill and Esther Rudd from Bundaberg were the lucky winners. We all went home with a bag of goodies.

We are looking forward to the Regional Disability Expo to be held at the Maryborough Showgrounds on 18th August. Our President, John Ross, has manned a CICADA QLD Information Stall so far at 5 Expos. The total count will be 8 Expos. That's dedication! I have no doubt John's report will highlight the need for our Support Groups.



### TOWNSVILLE

The Townsville support group meets on the third Thursday of the month at the Townsville RSL from 10 to 12.

We have members and visitors with cochlear implants, hearing aids and those who are navigating

the hurdles to be implanted.

We launched in February this year with a rehabilitation seminar from MED-EL. Informal and informative chats over a brew have been the style of our MeetUps since then and some stay on for lunch.

Another presentation, the listening rehabilitation resource, HearingSuccess, will be presented by Advanced Bionics in August.

We will continue to support those people affected by hearing loss in North Queensland.



Penny Phillips

### SUNSHINE COAST

This year has seen a huge growth on the Sunny Coast, as more and more people access a Cochlear Implant.

At our last MeetUp we had 32 people attending which was A...mazing - considering we started with just 4 members and now we have over 40 members!

The group is very supportive of each other and in recent months we have enjoyed presentations from Tony Whelan from Better Hearing and Gillian Bartholomew, a Counsellor for the Deaf and people with a hearing loss. Both were very much appreciated.

Our cuppa and chat mornings are always fun as we get to know each other and listen, share and connect with our own personal stories. We learn something new all the time about managing our 'magic ears'!

### BRISBANE

A new venue for our popular Sunday Meetups in Brisbane. Come along to Chermside Library on Sunday September 10th and check out our new place for a cuppa and a chat.

375 Hamilton Road Chermside commencing at 10.00, we have the room till 2 pm so you don't have to rush to join us.

Contact Penny if you want any further details. Look forward to seeing you there.

### WESTERN AUSTRALIA

Other appointments along with the Winter weather has affected attendance at meetings. Since the last Newsletter we have had a few activities.

A presentation from Lions Hearing Dogs highlighted the wonderful work and support the dogs of various breeds provide.

Our social outing to a favourite spot for a fish lunch at the Mandurah Foreshore is always enjoyable and tasty!

In June we had a most interesting presentation from Dayse Tavora-Vieira head of audiology at Fiona Stanley Hospital who updated us on the world-standard research being done here on single-sided-deafness. It was also an opportunity to raise awareness of the services funded in Audiology under the public health system.

Our July AGM brought one or two changes to share some of the secretarial duties and which should work quite well. - Jane

## THE AMBIENT MENU: A BREAKTHROUGH SOLUTION FOR DINING COMFORT FOR THE HEARING IMPAIRED IN QUEENSLAND

Are you tired of straining to hear your companions at restaurants due to excessive background noise? The Ambient Menu, is here to revolutionize your dining experiences and guide you to conversationfriendly eateries.

Created by Laura Drexler, an Audiologist and Committee member of CICADA QLD. She understands the frustrations faced by her patients in finding accessible restaurants where they can enjoy both good food and meaningful conversations with their guests.

The goal of the Ambient Menu is simple: to create a network of quieter eateries that enable diners to indulge in relaxed conversations without straining to hear. Diners can now leave reviews based on ambient noise levels, sharing their experiences and helping others in the hearing loss community make informed choices.

The Ambient Menu goes a step further by collaborating with acoustic specialists who provide valuable insights on the best tables to sit at and the most suitable times to visit these eateries. This unique feature ensures that every aspect of your dining experience is tailored for your comfort.

There is even an acoustic-based accreditation system

for eateries. The Ambient Menu assesses restaurants against its 'conversation-friendly' criteria, thereby setting new standards in the industry.

With nearly 200 eateries already reviewed for their ambience in Queensland, this initiative is making waves in transforming the dining landscape for the hearing impaired. Imagine a future where diners can effortlessly enjoy every meal without the burden of background noise.

Join the 'Easy on the Ears Eateries QLD' Facebook group today, a collaboration between CIADA and the Ambient Menu, and become part of this remarkable journey. Don't miss out on any updates or the opportunity to explore new hearing-friendly dining destinations across the region.

Let's together take the 'din' out of dinner and embark on a path of enjoyable, immersive, and conversation-filled dining experiences. The Ambient Menu is more than a website; it's a game-changer for the hard of hearing community in Queensland. So, join us today and savour the joy of dining without compromise!

(Note, currently available on the Sunshine Coast, soon to be launched in the Gold Coast, followed by Brisbane then the rest of the state).

# Frustrated by Noisy Restaurants?

Then use the guide based on noise level / ambience.

Search: For an eatery based on noise level.



**Review:** Eateries based on ambience, food + service.



Lively

**Reward:** 25 reviews = \$50 Restaurant Voucher.



Ambient Menu ambientmenu.com.au



# A POSITIVE JOURNEY

Kylie was the first girl to be introduced to the Shepherd Center when it first started up in NSW in 1970 and she is so thankful for their help and support in those early days.

The Shepherd Center is a notfor-profit organisation providing specialist early intervention programs for children with hearing loss and their families. Their mentoring program, Hear for You, supports school-aged children and teenagers. Based in NSW and the ACT, they also offer online telehealth for families across Australia.

#### Kylie's story so far:

"I have been deaf since birth. Hearing tests weren't done on babies back then so it wasn't until I was about 18 months old my parents noticed something was not quite right.

I was found to have a severe to profound hearing loss and then fitted with two hearing aids. The deafness may be hereditary as my paternal grandparents were deaf but we are not too sure to this day.

My parents wanted me to learn to speak so lattended The Shepherd Centre in Sydney when it first opened in 1970. There were just five of us, four boys and me.

We had speech therapy daily as well as integrating with hearing children.

I mainstreamed in public schools and my lip-reading skills got me through these schooling years. Post high school, I went on to have several jobs, married and had three children, all are hearing.

I was very hesitant to have a cochlear implant having heard for 50 plus years with hearing aids. I did not want the sounds to be different to what I could hear with an aid.

After a long time of thought and lots of research, I thought I'd go for it. I underwent surgery in 2021



and was switched on 10 days later.

I heard nothing but beeps at first and was thinking oh no what have I done? Gradually my brain got working and sounds and words started to click. It has been quite a journey and I am still learning every day.

The clarity is amazing and I am now able to speak to the family on the phone.

My goal is to be able to speak to others on the phone such as for making appointments, queries etc. which I had never done before. I have gained so much and hope to continue to do so."

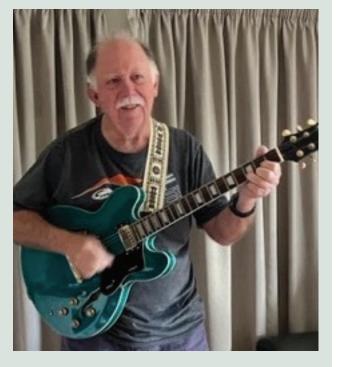
Kylie is now a welcome member of the Brisbane CICADA QLD group.

# CALL OUT FOR

Are you a cochlear implant recipient who loves to jam? Been in a band previously and would love to make music again? CICADA Queensland member Lindsay Creighton from Mackay would love to hear from you!

Lindsay plays guitar and has suggested forming a group, to practice and share musical knowledge and skills, have fun and maybe even perform at events! All instruments welcome - vocalists too! Potential band names: "The Implants' or 'The Implanted'! Open to all suggestions!

If this sounds like you, get in touch with us at connect@cicadaqld.org





# Personalised support on your journey to better hearing.

### Connect with the MED-EL Engagement Team

- Are you considering new hearing technology?
- Do you have questions about implant technology, or funding options?
- Curious about the MED-EL Difference?

We've been looking after Australians for almost 20 years, and can provide you or your loved ones with personalised information, resources and support to help you make an informed choice.





hearinghelp@medel.com.au



# Rediscover your favourite show

With sound tailored to your hearing.





Scan to buy or visit audeara.com



HAVE YOUR SAY...

# A PERSPECTIVE ON HEARING LOSS

#### by Rick Thornton

"Speak up lad! Stop mumbling! Silly woman whispers all the time, needs her voice trained. No, I did not ignore you at the shops, I was distracted." Classic signs of hearing loss maybe?

Sometimes people simply refuse to accept that they have a problem (or ARE the problem) for any number of reasons. They rationalize their situation or try to blame others. Additionally, they will try to avoid doing something about it or not use the help available. Like the old joke about the three types of hearing aids - "in the ear", "behind the ear" and "in the top drawer". The last ones don't work and never will!

Further, sometimes when I ask have you had your hearing tested I am informed "I've got hearing aids but don't use them" or "they are uncomfortable" or "I don't like the sound". Vanity (they make me look old), fear of appearing weak or needing help, the list is endless.

I am reminded of the first time and the last time I got help. First time (after getting ambushed by the base doctor who said I needed hearing aids to stay in the service) I was super keen to get the smallest in the ear ones so no one would see them. The Audiologist laughed and said you pay hundreds of dollars for a stereo that you show off to your friends and are afraid to show them thousands of dollars in hearing aids! The last time was when I got my first CI and complained that they needed to be turned down, it was so noisy. The Audiologist laughed and said NO, this is the world - it is a noisy place! It is and I now hear better than my peers!

Hearing loss can cause you more than sound loss. Social contacts lessen, people avoid you as you are "difficult", you avoid them out of embarrassment, social isolation can happen, relationships can suffer, long term loss can increase the risk of dementia, depression. You are increasingly vulnerable (Didn't you hear that fire alarm or that car?) Another list that goes on and on. So swallow your pride and get some help!

First stop is a good audiologist to see how bad it is and an ENT doctor to see what caused it. Could be industrial deafness or a disease or worse. Find out! The Audiologist/ENT will recommend a way to improve the situation with hearing aids or perhaps a BAHA or Cl. Second step is to accept the hearing loss and that your hearing will likely not be the same again. The big thing is that you will be able to hear better and enjoy life more fully again. So start wearing your hearing aids and practice or get tested.

Protect what's left as well. I spend a lot of time in a workshop with high intensity noise and I can't tell you how often I have to repeatedly tell somebody to put on hearing protection! I have to yell in their hearing aids (that are amplifying the noise and damaging their ears further!)

Don't hide it. TELL people you have the issue and ask for accomodations (Face me, speak clearly, stand in the light, etc.) Help yourself by helping them help you. Use assistive listening devices to help in difficult situations (Audiologists can help with that too).

Please don't continue to ignore what can be a serious life issue. Failure to deal with it can lead to either deafness, surgery or other serious situations. Not to mention missing out on a lot of life's joys.

Be like Cicada QLD- Share your burden, Listen to professional help and Connect with life more fully again.

If you have a story to share and would like to feature in a future edition of CICADA CHORUS, please send your submissions to https://cicadaqld.org/submityour-story





Above: Tristan Allsopp. Right: Some attendees at the presentation.

# UNRAVELLING THE MYSTERIES OF COCHLEAR IMPLANT SURGERY IN TOOWOOMBA

by Rob Frith

Dressed in his blue surgeon garb, Dr Tristan Allsopp led the 23 attendees on a journey from commitment to a cochlear implant, the surgery and finally onto recovery. There was no "clock watching" and the audience listened attentively for 60 minutes before Dr Allsopp glanced towards me, and uttered, "When do you want me to finish up?" We emerged from our almost spell-bound state and a few questions later, the presentation was called to a close, thanking Dr Allsopp for his generous offer of time. I believe everyone present received useful information.

Tristan did not "sugar coat" the risks and pointed out that there is a window of 2mm between two critical nerves, which the surgeon must drill between to reach the round window through which the electrode array is passed into the cochlear. One nerve controls the facial muscles and the other taste. Damage to the facial nerves is unacceptable and monitoring electrodes are arranged on certain muscles of the face to indicate if the surgery is placing the facial nerve at risk. If a nerve must be damaged, it will be the taste nerve. I spoke to several recipients after the presentation and damaging the taste sensation nerve does happen. One noted that only one side of their tongue could experience no taste.

The audience was mixed, with several audiologists, and special needs teachers present plus potential recipients as well as existing implantees all curious to learn about the details. We now have a better understanding of the surgery, the lead up, the risks and the recovery.

CICADA Queensland gives thanks to Dr Allsopp, an ENT surgeon based in Toowoomba.



### FROM SINGLE-SIDED DEAFNESS TO STEREO HEARING: KYLIE'S STORY

My name is Kylie and I live in Perth, WA. I'm a mother of two, an occupational therapist, and a singer. Despite my hearing loss, music is my number one hobby. In my free time, I love to play the piano, crochet, do yoga, and play tennis.

My hearing loss was sudden. I woke up deaf in one ear, but didn't notice immediately as I was also nauseous and dizzy, and I felt very unwell in general. All these symptoms were caused by an inner ear infection, which caused damage to my cochlea (*not typical for this type of infection*). I then found out that my hearing loss would be permanent... ....It was a real shock to be diagnosed with single-sided deafness (unilateral hearing loss) at the age of 38.



When I'm performing, my hearing with a cochlear implant is 98% of my natural hearing. When I'm at work or at home,

### my CI hearing is indistinguishable from my natural hearing.

I tried to live around my hearing loss in the months following, constantly hoping for improvement that would never come. When and ENT recommended that I get a cochlear implant, I took some time to do some research. This was when I discovered the Hearpeers forum. I was able to speak to cochlear implant users online who shared their personal experiences with me, which was a very helpful part of my research and ultimately aided my decision to get a cochlear implant. When I lost my hearing, my biggest fear was that I wouldn't be able to sing and make music again. This was my biggest motivation in pursuing a solution through technology.... I could not imagine my life without music!

With my cochlear implant, I'm much more flexible in daily life now. I don't have to adapt just because of my hearing loss; I can easily communicate at work, and meeting friends and family has become much easier. My CI helps me live a more relaxed life.

### Read more about Kylie's story on the MED-EL Blog - blog.medel.com



### Want to Ask Kylie a Question?

Hearpeers is the place where you can connect with others who have hearing loss, share experiences, and learn more about hearing solutions.

### Connect with Kylie today!

MED<sup>©</sup>FI

"I'm a Hearpeers mentor because I want to help others with hearing loss get the answers & the reassurance they need. If you are looking for support for yourself or someone you might know, just scan the QR code to connect with me".

### hearLIFE



### WHO WE ARE

CICADA Queensland is a completely independent, not-forprofit organisation staffed by volunteers.

We support people from all walks of life who have been affected by hearing loss, including current and prospective cochlear implant recipients and hearing aid users. Whether you identify as Deaf or Hard of Hearing, use Auslan or spoken language as your primary method of communication, or simply need some support for yourself, family or friends, CICADA Queensland is here to help you navigate this journey!

### **VISION STATEMENT**

To ensure all Queenslanders, of all ages affected by hearing loss or considering or using Cochlear implants, and their families are supported and informed.

### **MISSION STATEMENT**

To provide education, rehabilitation support and opportunities for social engagement in a community to all people with hearing loss or those considering or using cochlear implants, including their friends and family.



### Would you like to host a CICADA Qld group in your local area?

Can you spare a few hours a month to hold a regular MeetUp? We are looking for friendly, outgoing people with a passion for supporting people with

hearing loss, cochlear implant users and prospective cochlear implant recipients.

Good with technology? We need volunteers to assist with social media, graphic design, digital content and technical assistance. Are you a business with a venue or room suitable for our MeetUps? If any of the above apply, please contact us.

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